Handbook for Laryngectomy Patients

The National Association of
Laryngectomee Clubs

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Compiled and issued by:

THE NATIONAL ASSOCIATION OF LARYNGECTOMEE CLUBS

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Introduction

This book has been designed for the use of 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 the Head and Neck Multi-disciplinary Team at the Radcliffe Infirmary, Oxford, who contributed to updating this publication.

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, ear-ache, difficulty with swallowing and breathing, the breathing also may become noisy (called stridor).

Very occasionally the cancer in the larynx (more commonly known as the voice box) 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 made on the basis of an examination of the voice box. This is often done with a nasendoscope – which is a narrow 'camera' for looking into the throat. These fibre-optic endoscopes are very small in diameter and can be slid 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 prescribed 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.

Special scans will be ordered of the voice box, and these can be taken in progressive views showing the voice box in detail from the front to back and top to bottom, MRIs or ultrasound, sometimes with a needle-biopsy of the suspect area in the throat.

A chest X-ray or CT scan of chest is always done, since most people with laryngeal cancer have been smokers at one time or another.

Blood tests are usually arranged.

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 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). This is called a microlaryngoscopy.

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 an 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, and an overnight stay in hospital is usual.

When you are admitted to hospital you will usually be seen again by the surgeon just prior to the procedure, and there will be an opportunity for further questions and your consent taken. 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 (laryngoscopy 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 as mentioned above after a night's stay 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, doctors will be very frank with their patients about the diagnosis, the likely treatment, and the chances of a probable cure.

Radiotherapy

Some patients with cancer of the larynx are treated with radiotherapy, and some may be treated by surgery followed by a course of radiotherapy.

Following a course of radiotherapy treatment, all patients are kept under close observation by their surgeon, oncologist and healthcare team. In some cases, the cancer will never go away although it will 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 disease, before the symptoms reoccur, and it is clear to the surgeon that the growth has come back. Some patients have many more years of remission. Each person is different.

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 (a laryngectomy stoma). 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, already 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.

Many hospitals might bring you in to a pre-admission clinic where routine tests for fitness for operation will be carried out such as ECG, chest x-ray and blood screening, otherwise some 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 meet members of the team who will be responsible for your care.

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

2

The operation

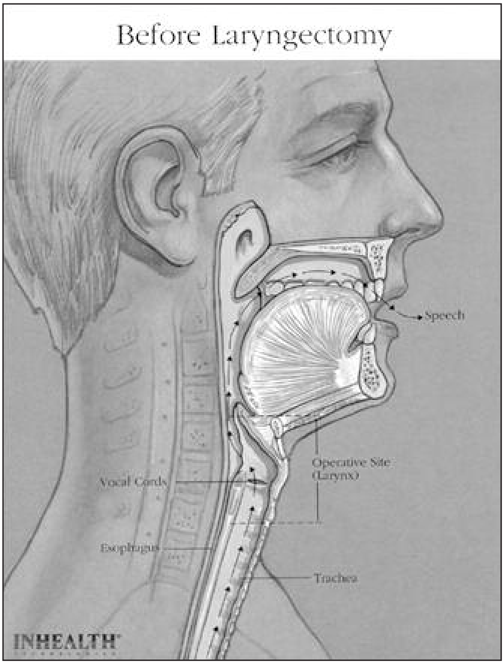

Fig.1

The larynx

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

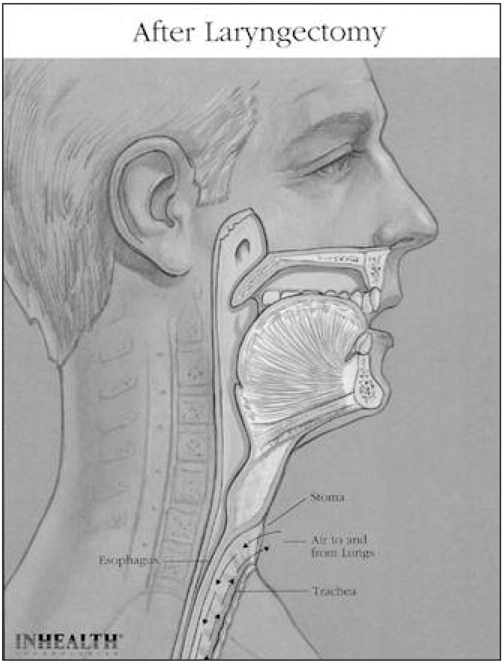

Fig. 2

It does mean that a permanent hole remains in the neck, called a stoma which is easy to breathe through. It may be necessary to wear a tube through the opening for a while, until the stoma has become stable in size, up to 6 months. Not all patients have to wear tubes.

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. This will have been explained to you prior to the operation.

3

After the operation

When you have recovered from the anaesthetic, the nurse who will be looking after you will collect you from theatre and return you to the high dependency ward or the intensive care unit. You will be aware of various tubes, bandages and drains attached to you. Neither you nor your relatives should be frightened by these or the equipment. 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 fluid or blood. This will keep you hydrated, prevent anaemia from blood loss and also enable any drugs you may need to be given to you in the first few days after your surgery.

Urinary Catheter: This will be inserted in theatre and will only be in place for 24 hours to measure urine output.

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 via your nose into your stomach or through a small hole at the back of your stoma into your food passage (oesophagus). Sometimes a little tube called a 'peg' is put in your stomach through your abdomen, and your feeds can also be given through this.

You will be fed through one of these tubes, with a formulated feed, until the tissues inside the throat are healed and there are no signs of leakage through the wound. This normally takes about ten days and is confirmed by a radio fluorescent swallow test which is done by the speech & language therapist. The tube will then be removed and you should be able to eat and drink as advised by the speech & language therapist – the dietitian will guide you from a soft, liquid diet, moving over a period of time to a more solid diet.

Neck Dressings

From the neck there are two drainage tubes running into bottles. These help to drain excess blood and serum from the operation site and will be removed after 2-5 days. The stitches in your neck will be removed about 7-10 days after your operation. Your face and neck will be very swollen on both sides (like a child with mumps) but this does subside with time – it can take two to three weeks, or sometimes a little longer.

Your Stoma

Immediately after the operation, you may have a tracheostomy tube or button in the stoma. The tube may be held in place by tapes tied at each side of the neck or stitched in. 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 team will decide if you need to wear a tube or stoma button and for how long.

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

Suction

For a few months after the operation, your lungs will be producing more mucus that normal. You will soon 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 by a nurse and you will hear a ‘hissing’ sound as the mucus is sucked out. The nurse may teach you to do this yourself, if you wish. The physiotherapist will also help you to learn to cough up your secretions and keep your chest clear. They will also teach you deep breathing exercises.

Communication

Immediately after surgery the nurse will ensure that you have a call button and pen and paper at all times. It is good to remember to take in your own paper and pens, some hospitals provide ‘magic-boards’ for patients to write on. The speech & language therapist will be 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 walk 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. It is good for you all to write down what you want to ask and have it ready when you see the doctors or nurses not to forget something important. As you gradually recover you will be shown about caring for your stoma in preparation for your discharge home. The hospital team may refer you to your district nurse to give guidance in your first few weeks at home.

Speech & language therapy

Communication is a very basic human 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 both for laryngectomee and his/her family, and for the team looking after him/her, 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 & language therapist before your operation. It is easier then for you to get to know each other. As well as simply introducing him/herself, they will be able to explain the various ways in which you will be able to communicate during the next few months, and the plans for helping you to develop your new voice. They will also answer any other questions you may have. If you wish, it may also be possible for the team 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 team 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, teeth and palate (articulators) to shape the sound into words.

Before a laryngectomy

the source of air is the lungs

the vibrating source is 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 – see below – 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

From figure 2 in chapter 2, it will be seen that the air from the lungs goes directly to the stoma and cannot make its way to the mouth at all.

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 easily and quickly. Others are unable to use this type of speech.

Surgical voice restoration

Most patients are being offered voice valves – prostheses. The decision as to whether this is 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 e.g. Provox or 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.

All mucus has to be removed manually from the stoma, by coughing, removing crust or keeping the valve prosthesis clean with a little brush.

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 to 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 the advice of a speech and language therapist and a chance to try various models.

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, your speech & language therapist and the team.

It is for your speech & language therapist to explain and instruct you in the various ways to communicate again.

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 & language therapy near 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, but mucus must be removed from speech valve or no speech will be possible.

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

1. Always remember to wash your hands before and after cleaning.
2. Warm water can be used with a 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 you 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

Your 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, tissues, mirror, 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.

Humidification of your stoma

Before the operation, the air that reached your lungs passed through your nose and mouth, where the air is warmed, moistened and filtered. After your operation, the air that enters your stoma is dry. It is therefore important to humidify the air that you breathe 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:

1. **Always** wear a cover over your stoma. It acts as a filter to prevent anything entering your stoma, it also warms air you breathe in. There are housings available, for when the skin is healed, from various manufacturers. These enable you to wear heat moisturisers, which also give the power of speech with a speech valve.

Different stoma filters are available and your speech & language therapist will advise which is best for you. All equipment is available on prescription from your doctor (G.P).

2. 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.

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 or specialist nurse.

All people involved in your care should have knowledge of laryngectomy and again you should be able to call on the services of your district nurse. The hospital or your G.P. can arrange a visit from her/him.

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 moment's notice to help.

You may experience a 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. Your specialist nurses are available to listen and offer support. As you learn to come to terms with cleaning your stoma and the change in your speech, these negative feelings will lesson and, after a few months, you will adjust completely, although mourning for your voice is completely normal.

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 your may feel is a trivial problem, deal with it then – don't 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 unit and ask advice, or call your district nurse.

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 or may not return. If you eat slowly and particularly if your sense of smell and appetite is diminished, smaller high calorie meals & snacks taken more frequently may be a good idea. Do look after yourself, though, don't miss meals. It is important to stay well-nourished. Initially you may need to eat softer consistency foods, but you should be able to progress to a normal diet. Seek advice from dietitian if needed. Regurgitation is always a problem after laryngectomy; that is why small meals are helpful. Try not to do much physical bending for a couple of hours after eating. Talk to the dietitian if this becomes too much of a problem.

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.

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 needs 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 usually 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 possibly 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 do 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 at 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 that listening to orders given. It can be a great confidence building to go into a pub and order a round of drinks for your friends.

There is no reason why a laryngectomee should not travel, although it is advisable to check with your surgeon first 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 to 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 that actually hearing what is being said to them, it is therefore certainly worth trying communicating without any aids but if you do have difficulties in being heard, there are speech amplifiers available – small hand held (for one to one conversation); larger types with their own microphone (for speaking to groups of people); and some specifically for use with a telephone.

Artificial larynxes are often useful if surgical voice restoration has failed/not appropriate, 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.

If you decide to take early retirement or it is not possible for you to return to your former employment you may be re-deployed to a job which is more suitable for you.

Sexual relationships

It is very common for people who are 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. People are loved for their total worth not for the appearance of their neck. If you were considered attractive and loveable 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 hospital. There are however some practical tips that may be of help to you.

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, time will help.

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.

7

NALC

(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 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 multi-disciplinary (for professionals) – some for patients, their relatives and friends – several have been specifically for nurses and others for district speech & language therapists.

Laryngectomee clubs

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

Now we have clubs in all parts of the British Isles, with several more due 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 to NALC at any time.

Most of the clubs hold monthly meetings and organise a variety of social events, including visits to 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 club's and Association's 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.

In the case of an emergency it is 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/DVD) clearly showing emergency resuscitation being performed on a laryngectomy patient. It is exactly the same as for any other patient except the breaths are given over the NECK and not the mouth.

The Association produces a range of literature, and videos/DVDs 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. It also produces a booklet on Disability Living Allowance and how to claim.

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 problem solving and help service and it is open to any patients, 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.

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Resources

LITERATURE AVAILABLE FROM NALC

NALC PUBLICATIONS

Information Pamphlet	Gives details of entitlements from the NHS and DHS.
'Living with a Laryngectomee' Packs	Pack of four leaflets: first reactions, adjusting, healing problems, mood changes.
Living with a Pharyngo-Laryngo-Oesophagectomy	Pack of four leaflets: the operation, eating and drinking, communication and returning to a full and active life.
NALC Handbook	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 Pamphlet	General information about the Association including aims and objectives.
NALC Poster (A4)	Includes NALC's logo and gives a brief outline of the work of the Association. Useful for hospital waiting areas and exhibitions.
N.A.T.O Alphabet	Small pocket card for use when spelling words over the telephone.

Professional Care Pack	A pack with three leaflets covering ENT Nursing, Speech Therapy and Social Work.
Resuscitation Pamphlet	Illustrated pamphlet describing the method of giving mouth to neck resuscitation: also includes resuscitation for tracheostomy patients.
Stoma Care	Pamphlet guide to looking after the stoma.

DVDS

LIFE 2	Laryngectomy Information for First aid and Emergency treatment. 30 minute DVD showing how to give mouth to neck resuscitation.
Nursing and Laryngectomee Care	An introduction to the needs of the laryngectomee after leaving hospital. DVD aimed at nurses working in the community.
Talking it Through	A pre- and post-operative DVD for laryngectomees, family and friends.

EMERGENCY IDENTIFICATION

The following items give information about the patient and their 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	Available from NALC.
Emergency Car Sticker	Available from NALC.
SOS Talisman	Talman Ltd, 21 Grays Corner, Ley Street, Ilford, Essex IG2 7RG. Tel: 020 8554 5579 www.sostalisman.co.uk

Medic Alert
MedicAlert Foundation, Freepost, 1 Bridge Wharf, 156 Caledonian Road, London N1 9UU. Tel: 0800 581 420
www.medicalert.org.uk

USEFUL ADDRESSES

NALC
Lower Ground Floor, 152 Buckingham Palace Road,
London SW1W 9TR
Tel: 020 7730 8585
www.laryngectomy.org.uk

Macmillan Cancer Support
89 Albert Embankment, London SE1 7UQ
Tel: 020 7840 7840
Freephone: 0800 500 800
www.macmillan.org.uk

Relate
Formerly The Marriage Guidance Council
Local addresses and telephone numbers can be found in local telephone directories or directory enquires or web site: www.relate.org.uk

Carers UK
20 Great Dover Street, London SE1 4LX
Tel: 0808 808 7777 www.carersuk.org.uk

The College of Speech & Language Therapists
2 White Hart Yard, London SE1 1NX
Tel: 020 7378 1200 www.rcslt.org

Benefit Enquiry Line
0800 882 200, Textphone **0800 243 355**
Monday-Friday 8.30am-6.30pm, Saturday 9.00am-1.00pm (in Northern Ireland **0800 220 674**) gives advice on benefits for disabled people, their carers and representatives

NHS Direct
Tel: 0845 4647
www.nhsdirect.nhs.uk

The Information Standard

Certified member

This organisation has been certified as a producer of reliable health and social care information.

www.theinformationstandard.org

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