YOU CAN SAY THAT AGAIN

admin's note: This webpage has been prepared using a file (YOU CAN SAY THAT AGAIN.pub 01/08/2009) located on a memory stick associated with Colin Bolton's laptop. It was apparently not the final version used to print the Fourth Edition hardcopy but is being revised and updated. This webpage is under construction. The page is being written and tested using Google's Chrome Browser and some diagrams are Scalable Vector Graphics (SVG). It also works with FireFox and Safari and with Internet Explorer 9 or later. Internet Explorer 8 or earlier will not display the .svg diagrams.

During revision, new or modified texts will be (mostly) highlighted in brown. It is setup as a single webpage to assist with the browser's scrolling and 'find in page' command.

The webpage is intended to be responsive to window width so that it can be comfortably read on a computer, tablet or smart phone. It is setup to initially display in a format for an A5 booklet but, if displaying as a webpage, the top-right menu window can be used to free the TextWidth and the user may adjust the window width to make the reading of a text line comfortable.

The intent is to develop the content as an interactive webpage and then add pagination and layout for printing of a hardcopy booklet to cater for the 'digital divide' (some 3.5 million Australians do not have access to the internet).

FOR SUGGESTIONS, COMMENTS, CRITICISMS re this booklet: please email admin@stilltalking.org
You Can Say That Again

This "You Can Say That Again" webpage and booklet is intended to be an easily readable reference, guide and helpline for people who are about to have, or have had, a laryngectomy (the surgical removal of the larynx (voice box)). The purpose is to assist them, their families, friends and carers towards a positive rehabilitation and future and to give confidence that they will speak again.

The Laryngectomee Association of NSW (LANSW) published the First Edition in March 1989. It has been a successful publication and lasting legacy left to our Association, or for that matter, to all Laryngectomees, by the original author, Alan Dear. This is now the Fifth Edition.

The Laryngectomee Association of NSW LANSW retains ownership and publishing rights. The Cancer Council of NSW will contribute to the printing costs, store excess stock, distribute the booklets to other Cancer Council Helplines and acknowledge it in its Head and Neck booklet PDF online with link through to the Association's stilltalking.org website.

In addition to the original author, Alan Dear, LANSW would like to acknowledge the contributions of Colin BOLTON (1934-2009) Secretary/Editor of the monthly Newsletter "Still Talking" to September 2009 for his enormous and tireless effort towards the revision and compilation for the Fourth Edition. Clare McGregor for proofreading. Margaret Patterson (Royal North Shore Hospital Speech Pathologist) for her ongoing revision and updating of the text in association with other Speech Pathologists.

Brian Gardner (1938-2015) President 1998-2015. His wife Carol has been a stalwart Treasurer, Secretary and Welfare Officer of the Association. They have been active Accredited Hospital Visitors promoting the booklet to many facing the operation.

The Publishing Manager Alyssa White and Project Co-ordinator Kim Pearce from The Cancer Council NSW for their understanding and assistance with earlier editions.

About The Original Author: Alan Dear OAM (1941-1996) was a senior journalist with the Australian Financial Review who, he said, "got his laryngectomy for his 40th birthday in 1981." He worked as a journalist in Australia and Britain before becoming a public relations consultant to a variety of large Australian and multi-national groups. After his operation, he returned to newspapers and became actively involved with the Lost Chord Club of NSW as a counsellor to people about to undergo a laryngectomy, and their families. He said "You Can Say That Again" was a combination of his own observations and experiences as a Laryngectomee and those of his family, wife Lesley, and daughters Kate and Alison - and of his parents, his brothers and sisters. He also drew on the experiences of fellow Laryngectomees and their families and their feelings before and after surgery. "Anyone about to have a laryngectomy is going to have a lot of worries and unanswered questions," he said, "and I hope this book helps them face the operation with the confidence that they will speak again."

Alan died of a non-related cancer on 5th March 1996.
**LARYNGECTOMY**
Surgical removal of the larynx (voice box).

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1. INTRODUCTION

Of all our faculties, the power of speech is perhaps the one we take most for granted. It allows us to communicate, express our emotions and convey our needs to others. It is only when we are deprived of the power of normal speech that we realise our loss. You are about to lose - temporarily - the power of speech. The operation you are about to have - a laryngectomy or removal of your larynx (your voice box) - means you will have to learn to speak again, and make some adjustments which at first may seem difficult.

This booklet has been written by people who have lost their voice boxes - Laryngectomees - for Laryngectomees and their families and friends. It aims to answer most of the questions Laryngectomees and their families and friends will have before surgery and after. Together with the many health care professionals (including doctors, surgeons, radiotherapists, nursing staff, speech pathologists, physiotherapists, and social workers) with whom you will be closely involved in the weeks to come, "You Can Say That Again" demonstrates that a return to normal life is not only possible, but most likely. It shows that loss of speech need be only temporary and that the adjustments you will have to make, while challenging, can be made. During the weeks ahead you will be helped by a caring and willing band of people ranging from your surgeon, through social workers, speech pathologists and other Laryngectomees, to your family and friends.

This booklet explains simply and directly what you and your family and friends might expect and how to adjust to your new condition. Differences in treatment may vary slightly from place to place, but to keep this booklet to a manageable length, we have given an overall view rather than a lot of detail. It is divided into chapters which deal with the operation before and after, but you will probably have many more questions than the book could hope to answer in such a limited space. We suggest that you make a note of these questions and ask your health advisers for frank and understandable answers. Keep asking until you are sure you understand, and do not think any question is trivial. There are no unimportant questions when it comes to your future. It may help to have a trusted companion attend appointments with you. It is likely to be a stressful time and that can make it difficult to remember what questions to ask and what exactly had been said when you try to reconsider the advice given.

2. THE DIAGNOSIS

You are probably familiar with the phrase "Cancer is a word, not a sentence" and although you are naturally anxious about your illness, you should know that the cure rate of laryngeal cancer or cancer of the voice box - is one of the highest, if the problem is detected early enough.

These days the diagnosis and management of throat cancer is multidisciplinary. Your GP referred you to an ear nose and throat specialist (Otolaryngologist) who examined you, ordered imaging studies and may also have biopsied your cancer in order to make a formal diagnosis. You may then have attended a Head and Neck clinic where a team decision was made about possible treatment options. Before having this surgery you may have had some surgical procedure, radiotherapy and chemotherapy.

There are more than 2,000 Laryngectomees in Australia. About 555 new cases of laryngeal cancer are diagnosed each year. Only 13% to 25% of these will have surgery. The rest are treated with radiation and chemotherapy. Cancer of the larynx affects about seven times as many men as women, most of it occurring between the ages of 40 and 69 years with less than 1 per cent under the age of 30 years.

For information about diagnosis, treatments and head and neck cancer generally, please read: Cancer Council booklets "Understanding Head and Neck Cancers" (NSW) or "Cancers of the Mouth, Nose and Throat" (Victoria).
Cancer Institute factSheet_mouthcancer.pdf
Phone Cancer Council Helpline 13 11 20 to receive your copy.

The combined effects of excessive drinking and smoking are risk factors in the cause of the disease. Other factors - such as industrial exposure, heredity, and viruses may also play a role. Once cancer (or carcinoma) of the larynx has been diagnosed, treatment is based on exactly where the disease is and what state it has reached. Early cancers are generally treated with radiotherapy or combined radiotherapy and chemotherapy. Some advanced cancers are also treated using these tools, depending on the multidisciplinary team's assessment of successful treatment and on patient choice.

Cancers on the vocal cords produce earlier symptoms than at other sites, and this usually allows earlier diagnosis and treatment without having to resort to major surgery. Your specialist will tell you in detail what is involved and the choice open to you. It is up to you to make the final decision.
2. THE DIAGNOSIS

RADIOTHERAPY  If the doctor recommends radiotherapy, it will involve you making daily visits to a clinic or a major hospital as close as possible to where you live. The treatment itself is completely painless and only requires you to lie still in a special room while radiotherapists treat the cancerous tissue with radiation. There may be side effects from the treatments. These vary and may include a change in the sense of taste, tender skin near the area being treated, difficulty in swallowing and tiredness. However once again, the treatment itself is painless. Your surgeon and other specialists may also suggest radiotherapy as a follow-up if they feel it might help your treatment.

CHEMOTHERAPY  Chemotherapy is the use of drugs in the treatment of cancer. There are a number of drugs which may be used. Some are given by injection into a vein (intravenous drip) over hours or days. This involves either a visit to the out-patient department or admission for a few days. It is often given at the same time as radiotherapy to increase the effectiveness of treatment. The treatment is usually reviewed after a few cycles and only continued if there is evidence of benefit. There are various side-effects including low white blood cell counts, nausea, hair loss and tiredness. Many of these can be controlled by various medications. Your medical oncologist (a type of cancer specialist) and nurse will give you specific details about the proposed treatment.

SURGERY  If your doctor has recommended surgery, it is his or her judgement, based on the cancer’s location and stage of development, that surgery is the best way to treat your cancer. What the operation involves is described in the following chapter: The Operation. (page 4)

SUMMING UP  Radiotherapy is usually the chosen treatment for early cancer of the larynx as it is usually the most effective in getting rid of the cancer cells at the site of the disease. Where surgery is necessary some doctors may suggest a course of radiotherapy before the operation to reduce the size of the tumour. Radiotherapy may also be prescribed after surgery to reduce any possibility of secondary growths. A dental assessment before treatment is recommended.

3. THE OPERATION

BEFORE SURGERY  Before the operation you will have to have a number of tests, most of which are routine and are standard hospital procedure. These will include a chest x-ray, lung function and blood tests, an electrocardiogram of your heart and a urine test.

The physiotherapist may also check to see if there are any other conditions that might need attention, such as congestion on your lungs. If there is, the physiotherapist will help you to clear it with exercises. It is most important that your lungs be as clear as possible to help you breathe easily after the operation. The day before surgery your anaesthetist will visit you to explain their role and to check your condition, ask if you are on regular medication and other factors.

The night before surgery you may have your upper chest and neck shaved. Usually you are not allowed to eat or drink anything for six to eight hours before surgery. Before going to the operating theatre you will receive some medicine which will make you drowsy and make your mouth dry.

Foodpipe(oesophagus) & Windpipe(trachea) in a person with a Larynx
3. THE OPERATION

THE OPERATION You will be surprised to learn that although you will experience some pain after surgery, it will probably only be on the level of a sore throat. The doctor will give you a pain killer if you need it. In a total laryngectomy, such as you are about to have, your voice box or larynx and the tissue around it will be removed. When your larynx is removed, you also lose the natural ability to stop food and liquid entering your lungs. Therefore, to make your breathing safe, your surgeon moves the opening of your windpipe (trachea) to the front, near the base of your neck.

The surgeon also makes an opening in your neck at the point where your neck forms a V. The edges are stitched to the trachea, forming a hole - called a tracheostoma or stoma. You will now breathe through this instead of your mouth and nose. You will also cough or as some people call it, huffing - since your airway is no longer connected to your mouth or nose.

In a partial (subtotal) laryngectomy you may have a temporary tracheostomy. The temporary tracheostomy will help your breathing. Swallowing can be difficult for some time after partial laryngectomy surgery but this will depend on the exact kind of surgery. Some people may have operations just on their vocal folds, they are less likely to have major swallowing problems but will have a rough and breathy voice.

The operation may also involve radical neck dissection which could mean removing your lymph glands, your thyroid gland and extra neck tissue. This may make your neck smaller and restrict your arm and shoulder movements. AFTER THE OPERATION When you leave surgery you will be taken to a recovery room. You might then go to the hospital’s intensive care unit - a routine measure - where staff will closely check your condition before you return to your ward. Your doctor will tell you not to swallow for a few days, to avoid damaging the extensive stitching (or stapling) in your throat and neck and to give the surgery time to heal. You will be able to remove excess saliva with a suction tube or by spitting into a container.

When you wake up you will notice some tubes leading to and from your body. These will include a drip in your arm so you can receive fluids and medication. Drain tubes will run from your upper chest into special vacuum bottles. In addition, a tube will pass into your nose (naso-gastric tube) or the base of your trachea (tracheo-gastric tube) if a tracheo-oesophageal puncture has been made for a voice prosthesis. The surgeon inserted this tube during surgery and it goes down your throat and into your stomach. It allows you to take food straight into your stomach without swallowing and you will have your first meal two to four days after the operation.

You will also probably be catheterised to enable you to pass urine. These measures are necessary not only because of your operation, but also because of temporary changes in your body as a result of the anaesthetic. These wear off in a few days. You will be encouraged to resume normal personal functions - such as going to the toilet and washing yourself - as soon as possible. The doctor and nurses will also teach you how to look after your stoma. Soon after the operation you will be ready to move around and the hospital staff will help you become mobile again.

ON THE ROAD TO RECOVERY The hospital staff you saw before the operation - the physiotherapist, the speech pathologist and the social worker - will also come to see you. The physiotherapist may suggest some simple exercises to help you breathe more easily and maintain muscle tone. They might also suggest some extra exercises if you have had more radical surgery. Because you can no longer cough in the normal way to clear your chest, you will need help for the first few days after the operation. This may involve using a suction tube which passes into your stoma and down to the lungs. This is uncomfortable but necessary to help your breathing if your chest is congested. The nursing or physiotherapy staff will carry this out. Your physiotherapist will also teach you how to clear your chest after the need for suctioning has passed. Eventually you will clear your own secretions by coughing or huffing into a tissue using a mirror to guide you at first. It is important that you do this whenever you feel like coughing. Do not try to stop it as it is important to prevent chest infections.

The speech pathologist will talk to you about getting your speech back, but you should not try any exercises before your speech pathologist or doctor agrees. The next major event comes when your naso-gastric or tracheo-gastric tube is removed, usually about ten days after the operation. Before it is taken out you may have your neck x-rayed to ensure your throat has fully healed. Once the tube is gone you will be able to eat your first solid meal since the operation. It will be very soft to make it easier for you to swallow. During your stay in hospital the nursing staff will show you how to care for your stoma or your tracheostomy tube if one is used. Chapter 8 The Stoma (page 22) gives you more information. If your tracheostomy is temporary you will be progressed through a series of steps to ensure that you will be safe to have it removed.

Swallowing problems can occur after both a laryngectomy and a partial (subtotal) laryngectomy but are generally less of a problem when a full laryngectomy operation has not been carried out. A total Laryngectomy may have a problem with lumpy or dry foods which become stuck in the back of the throat. For this reason you will start with fluids and smooth moist foods.
3. THE OPERATION

When someone has a partial (subtotal) laryngectomy there can be problems with drinks or saliva going through the windpipe to the lungs. This can easily cause a chest infection. Both the speech pathologist and doctor will help you with this problem. You may have tests which involve swallowing with a nasendoscope (camera on a tube down your throat via a nostril) or an x-ray or modified barium swallow study. You may need to follow a special diet and do special exercises.

DON'T BE AFRAID TO ASK QUESTIONS  This is also a good time to ask as many questions as you can about your new life as a Laryngectomee. You probably will never have as many qualified medical people within easy reach ever again. Keep a notepad, magic slate or your tablet or smart phone handy so you can write down the questions as they occur to you. Family and friends also should be encouraged to ask questions so you all understand what lies ahead.

*** some tips on going home may be useful and reassuring! ***
After.. Before leaving hospital
eg removal of stitches or staples

4. HOW OTHERS CAN HELP YOU

By now you've probably had a visit from another Laryngectomee - someone who has had the same operation as you and who is now living normally, perhaps back at work, or enjoying retirement and relaxing. He or she is probably a member of one of the Laryngectomee Association, Lost Chord Clubs or New Voice Associations which have been set up around the world.

Members of these groups visit people who are about to become Laryngectomees to talk to them and their families about what to expect. The visits are usually organised by the hospital staff. Most new Laryngectomees are encouraged by these visits because they show that a normal life after a laryngectomy is what most people can expect. Your visitor also clearly shows you that speech does return.

The visiting Laryngectomee is just one of many people who are available to advise you and your family at this time. Your doctor, your surgeon, the nursing staff, physiotherapist, speech pathologist, social worker and other health care professionals are there to help you. You will also find that your family, friends and workmates are also anxious to see you fit again. The physiotherapist will give you exercises to get you moving again and help you if you have breathing difficulties. The social worker, will tell you about the practical assistance you are entitled to, and answer any issues that bother you and your family during this difficult time.

Remember that you are not alone - there are many others who have had the same operation who have returned to normal life and there are many professionals to help you with any problems and doubts that occur. You should ask these visitors about life as a Laryngectomee. Write down your questions as you think of them so you don't forget any. Your family and friends also should ask questions as they too will have to get used to changes as well. Eventually you'll find that you have adjusted to make up for the minor and major differences that result from having a laryngectomy.
5. GETTING YOUR VOICE BACK

While a laryngectomy operation means that you will lose your voice box, there are now many ways you can speak again. There continues to be advances in surgery and post operative rehabilitation which mean that it is rare to be voiceless for long. Getting your voice back is a joint effort between you and your Speech Pathologist. He or she has been trained and has experience in helping Laryngectomees regain the power of speech.

Your Speech Pathologist will help you decide and advise you on the best method of getting your voice back. Even though you have lost your larynx, this will not stop you speaking again, in fact your larynx is just one part of the complex system you use to speak.

Before surgery you made a voice in your larynx. Your lips, teeth, tongue and mouth converted the sound to speech. Without a larynx you will have to learn a new way to make a voice to speak. There are three basic ways of doing this:

- with an artificial larynx (or speech aid),
- using oesophageal speech, or
- with a voice prosthesis.

Any of these methods will give you a new voice - one that you can produce with minimum effort and that anyone can understand either face-to-face or on the telephone.

**TRACHEOESOPHAGEAL AND OESOPHAGEAL VOICE**

Oesophageal voice is produced in one of two ways - the most common requires a hole which connects the trachea or windpipe with the oesophagus or foodpipe. This allows you to push air from your lungs into your oesophagus. This air vibrates the upper food tube to make 'voice' and is referred to as tracheo-oesophageal voice (track-eeoh-oss-off-uh-jeel voice) using a voice prosthesis.

Oesophageal voice (oss-off-uh-jeel voice) is produced by charging or pushing air trapped in the mouth into your upper oesophagus or food tube. This method of speaking is less common today as tracheo-oesophageal voice has become easier. Both methods make a sound like a soft burp which a Laryngectomee learns to lengthen and control to produce an almost natural voice.

While you are working on your voice, your Speech Pathologist will probably suggest that you use a speech aid to allow you to talk. As achieving oesophageal voice takes considerable practice, today most people prefer to use the voice prosthesis rather than oesophageal voice as it is faster to learn and generally requires less effort to talk.
SPEECH AIDS  Laryngectomees have a number of speech aids available. These vibrate to produce a sound inside your throat which your teeth, lips and tongue then convert to speech. These may be the only option available to you if you have had extensive surgery and it can be a very effective and acceptable form of speech when used well.

There are two main types:

The neck aids: These are about the size of a small torch and run on a battery. Typical ones include the Servox and Nu-Vois; the Blom-Singer is somewhat less expensive. You hold the aid against your neck and press a button to make a tone or voice inside your mouth. The pitch and volume can be changed.

The in-the-mouth; or intra oral: Sound travels along a small tube which you put in your mouth. You can hold a tone generator and press a button to make a sound. The most common is the Cooper-Rand which is battery operated.

In addition there are pneumatic devices driven by air from the stoma using a diaphragm or reed to provide the tone vibration through a tube to the mouth.

Each voice prosthesis has its own instructions which come with it. Your Speech Pathologist or surgeon give you any information you need. Your Speech Pathologist will help you learn to use and look after the voice prosthesis. There are many different models of voice prosthesis available in Australia including removable 'duckbills' and 'low pressure' voice prostheses and Indwelling or non removable types. Blom-Singer, Provox or Bivona are common brands. The Removable voice prosthesis is taken out every two to seven days for cleaning while the Indwelling type is only removed by a health professional when it leaks or no longer works.

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TRACHEOESOPHAGEAL VOICE PROSTHESIS (TOP (or TEP (US))) Your surgeon may have made a hole or fistula connecting your trachea to your oesophagus. Your Speech Pathologist or surgeon will insert a voice prosthesis in the fistula. This allows air from your lungs to pass into your oesophagus where it makes sound by vibrating the soft tissue in your throat.
5. GETTING YOUR VOICE BACK

When using an artificial larynx, it will occupy one hand. This will make note taking, particularly during telephone conversations, a bit of a problem.

A woman Laryngectomee will produce a deeper voice than normal which may embarrass her at first, but with practice a feminine voice can be achieved.

You may find that your listener feels embarrassed or concerned by what he or she considers is an unnatural method of speaking, or that you are under some sort of stress. Don't be afraid to ask them to have patience with your new voice. Sometimes it helps if you explain to them how your new voice works. Children tend to react is one of two ways; most will be intrigued with your difference but some may be initially put off by the difference and take time to accept you.

You should resist writing things for listeners who will not hear - as opposed to those who cannot hear. Naturally if your listener is hard of hearing and your voice is very soft, it will make conversation much easier if you do write some things down or use an amplifier. Remember to try the amplifier before you buy. Your Speech Pathologist can help you with this. The more practice you get in speaking - and the more your listeners listen to you - the sooner both of you will find the new voice just as natural as the old. Remember: no matter what method you use, your listener must be able to understand you, what the problem is and to help you solve it. If you think the people you talk to do not understand you, your Speech Pathologist will be able to tell you what the problem is and help you solve it.

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5. GETTING YOUR VOICE BACK

TIPS FOR THE TELEPHONE  Whichever voice you choose, it would be suitable for telephone conversations and if required, Telstra will supply special telephones. There is a National Relay service available through the Australian communication exchange. Trained operators will act as interpreters and ‘respeak’ if you need to make telephone calls and your listener cannot understand you. It is available 7 days a week, 24 hours a day and is called speech to speech relay. You may contact them through 1 800 555 660 or www.aceinfo.net.au.

If you have difficulty with making telephone calls The National Relay Service (NRS) provides a number of different call types, depending on customer needs. All of these calls involve an NRS relay officer assisting with relaying part or all of the call. NRS customers can use the NRS for all or some of their inbound and outbound calls, including emergency calls. Your nearest Telstra Shop will provide details and an application form or you can ring Telstra.

You should hold the mouthpiece higher than usual - say about level with your top lip - and cup your hand around the mouthpiece. This is because the sound of breathing from your stoma can mask your voice. If you use a speech aid its noise can confuse your listener if it is held too close to the mouthpiece. It is a good idea to work out a code of tapping sounds with your listener - say one tap on the mouthpiece for no, two for yes, three for say again. This can help you when your voice deserts you - as it will sometimes. This could be when you answer the phone without your speech aid, or have not had a chance to get your voice going. Gooseneck telephone holders are helpful if you need to write while on the phone, or if your arm tires during long conversations. Hands Free telephones are often very useful.

6. RELATIONSHIPS OLD AND NEW

These Laryngectomees are sharing a yarn using their different methods of speech: a pneumatic artificial larynx using air from the stoma, a TOP prosthesis, an electrolarynx.

Getting used to your new self and resuming or forming relationships with other people is one of the first personal tasks a Laryngectomee has to do. Remember what we said earlier: thousands of other Laryngectomees have faced the same problems and overcome them. Don't worry that you will never be able to do the same; it just takes a little time.

The first feeling you'll have to beat is that since the operation you are disfigured and unattractive. This is not true. In fact the average Laryngectomee looks quite normal after the operation. Any physical changes are fairly minor. Accept your new self for what you are and work on resuming normal relations with friends and family, and on regaining your voice. Once you are able to speak again you will be surprised how quickly things fall into a familiar pattern.

STRESS AND ANGER  You and your partner will face some stress in the weeks ahead. You because you won't have a normal voice to discuss things as you used to; and your partner – because they know the strain you are under and are trying hard to help and please you at the same time. You will both have to make allowances for these temporary strains and accept that most of them
are caused by frustration at not being able to say easily what you mean. While the Laryngectomee is working at regaining their independent communication, it is common for the sympathetic or over-solicitous partner to be tempted to speak on their behalf or to finish their sentences. This can be a source of frustration and misunderstanding and you will need to come to an accommodation. You'll probably both find yourselves apologising a lot. It is a period when you should let time and nature take their course.

Remember that some people think that you are in pain when you speak - telling jokes or just directly reassuring them will make them more comfortable.

HOW OTHERS REACT While your friends and family will learn fairly quickly to accept the new you, the reaction of strangers may throw you off balance. By nature we are inquisitive and a stranger showing surprise at your different voice is only being curious. Some Laryngectomees turn this situation to their advantage by asking the person if they have any questions and then explaining the reason for the different voice.

YOU'RE NOT DEAF OR STUPID Some people think Laryngectomees are deaf or stupid. This of course is completely wrong but it can be difficult to overcome, particularly if you meet someone who does not want to listen. Do all you can to stop people thinking this way, as it will help not only you but other Laryngectomees.

SEX AND THE LARYNGECTOMEE A common fear of Laryngectomees is that they will not be able to enjoy sex or that their partner will find them sexually unattractive. These fears are groundless - if your partner found you attractive before the operation, you will be attractive after it. You might have some small problems such as noisy breathing from the stoma.

If having sex is physically uncomfortable try different positions. Be patient with yourself and your partner as it may take a little time for you both to accept your physical changes. Don't forget that simple actions such as touching, stroking and holding are important too. Accept your partner’s honest reactions and be as open as you can about your feelings. Frank discussion will more often than not clear up any of your worries.

Similarly, a laryngectomy won’t destroy your marriage. If you find you have marital problems they were probably there before your operation. The strength of your relationship will determine the effect a laryngectomy will have on your marriage. If after a reasonable period you still have problems, ask your doctor to refer you and your partner to someone specialising in relationships. A few visits may be all it takes to get things back on the rails.

7. GETTING BACK TO NORMAL

BACK TO WORK? Returning to normal life and/or getting back to work are very important to Laryngectomees. How quickly you do this depends on your operation. If the surgery was not too extensive or complex you can expect to get back to your normal routine in a reasonable time. If your doctor suggests radiotherapy after surgery this may make it a little longer before you can return to a normal lifestyle. It is important, however, that you take the right mental attitude towards your return to day-to-day life. You must accept that it won't happen overnight and that you will have to make certain adjustments.

There are few jobs you cannot expect to return to immediately but remember that you will have to make allowances for your new condition. For instance if you work in a dusty, or a very hot or cold atmosphere, or where there are fumes, you may not be able to return to your old job. These conditions may irritate your trachea or lungs. If you need to speak a lot in your job obviously you will need to be able to speak again before you return to work.

You might have to change the way you do your job. You will find your employer willing to help you with your work, or even change the type of job to suit you. If your work requires heavy lifting you may find that you need to do your job another way as you probably won’t be able to lift heavy weights easily. Your doctor may be able to suggest a new approach to this type of work.

If your job involves working in a noisy place, making yourself heard will be difficult, even after you get your voice back. If it involves using the telephone a lot, you will have no problems as once you have your new voice it is amplified on the telephone and is quite easy to understand. You will, however, need to be patient and accept that you have to make allowances for your condition. Some of your friends and relatives may also need time to adjust.

If you have retired, it is important that you maintain your circle of friends and carry on with your leisure activities. Your friends will want to help you as much as possible and they can be a great encouragement after the operation.

It is also very important to have some time on your own. A quiet break will help you get your thoughts and feelings together, even within the family circle.
You may find it will help to explain your condition to your old friends and to the new ones you will make. People are very curious and are interested to learn about your condition. Don’t be afraid to tell them, because the more people who understand what a laryngectomy is, the more people there are to help you and other Laryngectomees.

It is also important to assure your friends and employer and workmates that cancer is NOT contagious. Above all be reassured that the depression some Laryngectomees feel after the operation does go away. Because you feel you look differently, because you can’t speak for a while, perhaps because swallowing is difficult at first, or you find speech therapy tiring or because you associate cancer with death you may become intolerant, frustrated and angry. These feelings may create depression.

Being aware of these feelings helps you recognise the source of the depression and work to overcome it. Returning to work, rejoining your old circle of friends, and going on outings are some ways of overcoming depression. However, if you find it continues, you should ask your doctor, social worker or speech pathologist to recommend someone skilled in helping people adjust to difficult and strange personal situations.

Many Laryngectomees find the help they need through a Laryngectomee association where they meet others who have had the same operation. By talking to them and their partners, you can overcome any early negative feelings. One of the best ways to be positive is to remember that other people have had similar operations and have adjusted well to their new life. Try to remember that practically all your old routine will be your new routine.

If you enjoyed sport, in most cases you’ll be able to return to it. The only exception is water sports, where, because of the risk of water entering your stoma and lungs, you’ll probably have to watch rather than take part. For keen swimmers, a type of snorkel is available but you should discuss it with your doctor. If you enjoyed fishing and boating, you will need to take extra care against falling in the water.

If you enjoyed travel, there’s no reason you should stay at home. For aircraft travel, notify the airline well ahead of your flight so they can arrange for a special oxygen mask to fit over your stoma if the need arises.

FINANCIAL PROBLEMS If you feel you might have a financial problem after leaving hospital, discuss it with your social worker. You should not worry about having to bear the cost of speech aids as hospitals in most States provide or lend them to patients. You may also qualify for Commonwealth rehabilitation or sickness benefits, or may be eligible under the provision of EnableNSW. The products available to Laryngectomees, the conditions and forms that apply may be found at www.enable.health.nsw.gov.au. These may be more generous than thought. If you come from the country it may be possible to get assistance for travel and accommodation. Seek advice from a social worker at your hospital.

RESUSCITATION AND BREATH TESTING Because you don’t breathe through your mouth, you can’t be resuscitated normally. Instead of mouth-to-mouth resuscitation you will need mouth to neck resuscitation. Ambulance services know they should check if a person is a Laryngectomee before trying to resuscitate them, but you should carry a card in your wallet or handbag indicating you are a Laryngectomee (sometimes referred to as a neck breather) in case of emergency. Wearing a bracelet stating you are a neck-breather is a good idea.

It is physically impossible for you to be breath tested for alcohol if you are required to by a police random breath testing unit. You should ask your doctor or surgeon for a letter stating this but remember that you should not mix alcohol and driving anyway. Police can ask you to have a blood test if they think you are over the limit. See December 2010 Newsletter Random Breath Testing

A reply from NSW Police to the president’s letter (October’10 Newsletter)

THE NEED FOR CHECK-UPS After you leave hospital you will need regular checkups to ensure that you are healthy. At first these check-ups with your surgeon or doctor will be once a month and will gradually extend until you have twice-yearly or annual checkups. However don’t wait for a check if you have any suspicions about your health, and be particularly alert for:

- Continuing throat discomfort.
- Change in speech quality or clarity.
- Difficulty in swallowing.
- Sudden, unexpected weight loss.
- Lump or thickening in the breast or elsewhere.
- Continual unexplained headaches.
- Unexplained pain.
- Change in a mole or wart.
- Change in bowel habits and or presence of blood in your motions.
- The thyroid gland may require monitoring.
7. GETTING BACK TO NORMAL

Laryngectomees pursuing their normal interests

Brian Gardner Fishing

Noel Gildea Golfing

Roy Eyre taking the catch

Colin Bolton teaching

8. THE STOMA

When your larynx was removed, your surgeon created a stoma, an opening in the base of your neck to enable you to breathe. The stoma opens into your windpipe (trachea) and then through to your lungs. Your stoma is the opening to your airway only. You do not speak or eat through it. You still do this through your mouth. It is the most obvious physical difference between you and people with their larynx and it will need special care from now on.

Some people will wear a tube in their stoma; this can be removed for cleaning if you are a Laryngectomee but if your operation was a partial laryngectomy YOU MUST NOT REMOVE THE TUBE unless you have been specifically instructed.

The first time you go out on your own you may be very conscious, perhaps even anxious about your stoma - this is natural and the feeling will eventually go away. You should cover your stoma. Leaving it uncovered will attract attention and may cause discomfort to others. If uncovered, you are likely to breathe in dust and foreign bodies such as loose hairs which will make you cough. As you now cough - some people describe it as huffing - through your stoma, a covering is a good way of preventing embarrassment to yourself and others in case you cough up mucus.

A cover helps keep your trachea humid and will reduce the amount of mucus you produce.

Women Laryngectomees will be especially aware of their stoma, because they will want to cover a part of their neck that they normally left uncovered. They will need a wardrobe of neckwear so they can wear their favourite necklines.

You should tell your doctor as soon as possible if your stoma is smaller than one centimetre across. A small stoma will make breathing and cleaning secretions from your stoma difficult.
In cold weather it is very unpleasant to have cold air blowing in to your stoma and you should keep it covered at all times to warm the air that you breathe. Exposing it to cold weather and wind can make the skin inside bleed, especially where the skin is thinnest. This is normal but if it worries you talk to your doctor. At first you will find an increase in the secretions from your trachea. This is only natural and is because warm, moist air reached your trachea before the operation. With time it will get used to the drier, cooler air and the secretions will diminish.

**LIVING WITH YOUR STOMA**

**MUCUS** It is important that you know how to identify when your mucus is likely to cause you a problem. It may be too thick, infected or forming crusts in your stoma. Unless you have a previous lung problem your mucus will not cause you a problem if you manage it well. Signs of a problem are colour change to yellow or green, thick and sticky mucus or crusts that cannot be coughed out.

**BATHING AND SHOWERING** Take extra care to stop water entering your stoma. While small drops of water will make you cough, larger amounts can be dangerous and - if you become completely submerged - can cause drowning. Your stoma cannot stop water entering your airways the way your mouth does. Be careful in the bath not to slip under the water and use a non-slip mat on the floor of the tub. If you do slip under the water, some of it will enter your stoma. Do not panic. Lean over as far as you can to help the water drain out. You should try to get your head below the level of your lungs - if need be get yourself in an upside down position. If you prefer a shower, there is no need to change your washing habits. Some tips you will find handy:

- In the shower face away from the flow of water. Let the water run over your back and not your chest.
- A face cloth held over the stoma with one hand, or between your teeth when washing the hair will keep water out of your stoma.
- A shower shield is also available to stop water from getting into your stoma.
- Some Laryngectomees find a hand-held shower is ideal, particularly for hair washing.
- Above all, never lock the bathroom door in case you need help in a hurry.
- If you do, slap the wall with the wet open palm of your hand, it makes more noise than a closed fist.

**COVERING YOUR STOMA**

Several methods of stoma protection are available including:

- Stoma covers - crocheted or sewn from fabric or foam and worn around the neck.
- Foam filters or patches - held in place with double sided adhesive tape. They may be proprietary prepackaged or DIY made from suitable bulk tape and foam available.
- Cravats and scarves.
- T-shirts or skivvies worn back to front or cut down to "dicky" size.
- Heat and Moisture Exchanger (HME) button/capsule fitted to a stoma tube, button or stick-on-patch housing an open-pore foam pad in a removable disposable capsule. It has been found to reduce mucus production. Can be obtained via EnableNSW

Laryngectomees have their own preference and it is a good idea to try different stoma covers until you find one that suits you. The Association holds supplies of these consumables for sale at cost.

It should not only look neat, but also should be designed so that you can move it quickly if you have to cough into a handkerchief or tissue.

Nylon or silk are not good fabrics for covers as they can seal the stoma when moist. Cotton or polyester/cotton are suitable - what you wouldn't put over your mouth, don't put over your stoma. Clothing that covers the stoma area should be chosen so that you will have access to your stoma when you cough.

**GROOMING** At the hairdresser it is important that loose hairs don't get into the stoma as they make you cough. Ask the hairdresser to take extra care and put your hand up underneath the cover to protect your stoma. You should also warn them that hair sprays and talcum powder can make you cough if they get into your stoma.

Men who shave with soap and water or aerosol shaving creams should be especially careful that they do not lather up too much - lather in the stoma will cause coughing.

**COUGHING, SNEEZING AND COLDs** As you now cough and sneeze through your stoma you may find it difficult to cover a cough or sneeze as your hand may continue to automatically go to your nose or mouth. For this reason stoma coverings are added protection against embarrassment even after you have learned to stifle a cough or a sneeze with a handkerchief.
HUMIDIFIERS Now that the air you breathe is not moistened as it was when it passed through your nose or mouth you may find it necessary to moisten it by other means. A stoma cover will help by recirculating the moisture present in your breath. At night a humidifier in the bedroom will help prevent crusting around the stoma. In extreme cases - such as in dusty areas or on very dry hot days - you can wet the stoma cover and wrap it out firmly. This will help moisten the air as you breathe in. Foam covers are particularly helpful here.

REMOVING MUCUS OR CRUSTS FROM THE STOMA If there is too much mucus in the trachea, try to cough it out. If this doesn't work try putting a warm, damp - but not wet - cloth over your stoma and inhale, or run hot water in the hand basin and inhale the steam. Mucus crusts or plugs can be removed from the stoma with forceps, round-ended tweezers or a clean handkerchief, but be careful not to insert anything deep into the stoma. You must use a mirror to ensure you don't injure yourself. If none of these ways work, the crust should be removed by your doctor.

If you have a lot of mucus, stand in a steaming shower for a few minutes to help loosen it. You could also try putting a vaporiser (or a pan of steaming water) on a low stool while you sit on a chair in front of it. Drape a large towel over your neck, shoulders and vaporiser to enclose the steam and breathe for 15 to 20 minutes. Repeat as often as necessary. Use of a nebuliser will require a tracheal mask and you should follow your medical team's instructions. Putting a thin layer of Vaseline jelly around the edge of your stoma before bedtime will make the stoma easier to clean as it prevents the build-up of crusts. If you get a lot of crusts, you should increase humidification by wearing a moistened stoma cover or using a humidifier. You may run a vaporiser at night to increase humidity.

SLEEPING Don't worry about covering your stoma and smothering in your sleep. Your reflexes will make you push the covers away. And you won't snore anymore!

PROBLEM CHESTS Some Laryngectomees - particularly those with bronchitis - complain of difficulty in getting rid of mucus. With your natural coughing mechanism gone this can be particularly uncomfortable and can create a lot of noise. Leaning forward at an angle of 60 degrees and huffing or coughing works for some people. Other Laryngectomees find that getting down on the floor on all fours and coughing is another way of getting rid of excess mucus. Another way is to lie on one side, breathe deeply several times and cough. Then lie on the other side and repeat. If the problem persists you should see your doctor.

8. THE STOMA

Asthmatics can obtain adaptors for nebulisers to help their breathing. If all this seems a bit much, take heart. Many Laryngectomees report that they get influenza and colds a lot less following their operation. These would have mostly infected via nasal tissues, now bypassed, when drawn in with the breath.

Flu vaccinations are recommended - consult your doctor.

TUBES For a few weeks after your operation you might have to wear a tube - called a tracheostomy tube - in your stoma. This makes a clear passage for air as you breathe and makes sure your stoma will stay the same size and heal properly. Eventually you can take the tracheostomy tube out altogether. Tubes range from rigid long tubes to short soft buttons. Tell your doctor if the one you have causes excessive coughing. Your doctor, sister or Speech Pathologist should be able to suggest one which you find comfortable. Your Speech Pathologist may cut a hole in the tube, if you use a voice prosthesis, to help you to speak. You will get instructions for the fitting and care of the tube with it.

TASTE and SMELL As a Laryngectomee, you will no longer breathe through the nose so that the nasal tissues will no longer have air carrying smells drawn over them. Your senses of smell and taste will most likely be affected and changes noticed particularly in the first months after the operation. This can be ameliorated somewhat by, from time to time, temporarily fitting a tube between your stoma and mouth so that, with a little practice, breathing through the stoma can draw air into the nasal and then mouth cavity to the stoma, thus stimulating the smell sense in the nasal cavity.
9. GLOSSARY

ANAESTHETIST - A person who specialises in administering drugs to induce sleep or numbness before or during an operation.

ARTIFICIAL LARYNX (SPEECH AID) - A device, usually battery or air powered, which produces a sound which the user learns to convert to speech.

BIOPSY - The surgical removal of a sample of tissue, usually under anaesthetic, for further, more detailed examination by a pathologist.

BIVONA - A brand name for an artificial larynx.

BLOM-SINGER - See "Voice Prosthesis".

CANCER - A general term for a large group of diseases characterised by uncontrolled growth and spread of abnormal cells.

CANNULA - A tube through which another tube is passed.

CANDIDA - See Thrush.

CARCINOMA - A cancer.

CATHERETER - A tube to drain fluids, such as urine, from the body.

CHEMOTHERAPY - Treatment of disease by chemical means.

CRUSTS, CRUSTING - The dried mucus which forms in and around tracheostomas and stomas. Can be removed by round ended tweezers or by coughing.

ELECTROCARDIOGRAM (EEG) - A recording made of the activity of the heart.

ELECTROLARYNX - A battery driven artificial voice device.

ENCrustations - See "Crusts, Crusting".

FISTULA - A surgical purpose-built duct (channel/tunnel) inside the stoma in the neck for holding a voice prosthesis joining the windpipe/trachea to the foodpipe/oesophagus. Can also refer to a small, sometimes blind opening near the incision line which slows the healing process.

HEAT and MOISTURE EXCHANGER (HME) - A button/capsule fitted to a stoma tube, button or stick-on-patch housing an open-pore foam pad in a removable disposable capsule. It has been found to reduce mucus production.

HUMIDIFIER - A machine used to add humidity to dry air.

HYDROGEN PEROXIDE - A chemical used in sterilising.

LARYNGEAL - Of the larynx.

LARYNGECTOMY - The surgical procedure of removing the larynx.

LARYNGOSCOPY - Inspection of the Larynx under anesthetic.

LARYNX - The human organ of sound, sometimes called a voice box. Made of cartilage and muscle which vibrate to make voice or to cough. It is lined by a mucous membrane similar to that lining the mouth and nasal passages.

Laryngectomee Association of NSW (LANSW) - A self-help group of Laryngectomees.

MILTON - Proprietary preparation which can be used for sterilising tracheostomy tube, stoma button, and voice prosthesis.

MUCOUS MEMBRANE - Skin covered by a mucus secretion.

NASO-GASTRIC TUBE - A tube which passes into the stomach via the nose to allow feeding of a patient who is unable to take food by mouth.

NEBULISER - A machine which makes fine mist out of a liquid. Generally used to help with breathing difficulties.

NECK BREATHER - A phrase sometimes used to describe a Laryngectomee.

Nu-Vois - A brand name for an artificial Larynx.

OESOPHAGEAL VOICE - Sound, or voice made in the oesophagus or throat.

OESOPHAGUS - The food passage which passes from the mouth to the stomach and which carries food and liquid. Also known as the gullet.

PHARYNX - The area between the back of the mouth and the oesophagus.
PHYSIOTHERAPIST - A health care professional trained to plan, organise and
deliver treatment to restore functional mobility, relieve pain and prevent or
limit permanent disability for those suffering a disabling injury or disease.

PROSTHESIS - An artificially constructed device to restore a deficiency in the
human body. Dentures, and artificial legs are prostheses.

PROVOK - A brand name for an artificial larynx.

RADICAL NECK DISSECTION - Surgical removal of lymph glands and some
surrounding structures within the neck (see also MODIFIED RADICAL NECK
DISSECTION).

RADIOThERAPY - Treatment of cancer with high energy radiation. An
alternative or adjunct to surgery for cancer of the larynx.

ROMET® - A brand name for an artificial larynx.

SERVOX - A brand name for an artificial larynx.

SHOWER SHIELD - See "Stoma Protection". (page 24)

SODIUM BICARBONATE - A chemical used in cleaning the tracheostomy tube,
stoma button, voice prosthesis.

SPEECH AID - See "Artificial Larynx".

SPEECH PATHOLOGIST - A specialist in the evaluation and treatment of people
with communication disorders.

STAGING - Term used by doctors to refer to the method by which they decide
how advanced a carcinoma is. It helps them decide the best treatment.

STENT - Tube implanted to enlarge opening.

STERNUM - The breastbone.

STOMA - A surgically created opening or hole on the surface of the body (see
TRACHEOSTOMA).

STOMA BUTTON - A plastic insert for the stoma used to keep the opening at a
given size.

STOMA PROTECTION - Covers made of foam or fabric to cover the stoma to
prevent inhalation of foreign bodies such as hairs. A special stoma cover
called a shower shield can be used to prevent water entering the stoma during
showering.

SUCTIONING - Removal of excess lung fluid by passing a suction tube down the
trachea.

THRUSH - A fungus, normally present in the human gut, which attacks silicone
in the voice prosthesis.

TRACHEA - The windpipe.

TRACHEO-GASTRIC TUBE - Similar to a naso-gastric tube except it passes
through an opening in the trachea to the oesophagus and then into the
stomach.

TRACHEOSTOMA - The stoma or opening into the trachea formed as part of
laryngectomy.

TRACHEOSTOMY - The surgical procedure of creating a stoma or
tracheostoma.

TRACHEOSTOMY TUBE - A tube inserted into the stoma to keep the opening
at a given size.

TRACHEO-oesophageal Puncture - The hole made during surgery
through which the tracheo-gastric tube passes.

TruTone™ - A brand name for an artificial larynx.

TUMOUR - An abnormal tissue swelling or mass which may or may not be
cancerous.

VOCAL CORDS - Two small bands of muscular tissue within the larynx which
vibrate when air passes between them making the sound we know as voice.

VOICE BOX - The larynx.

VOICE PROSTHESIS - A small plastic tube which is fitted to a
tracheoesophageal puncture so air can be passed from the lungs into the
oesophagus to make voice.

WINDPIPE - The trachea.
10. HELPFUL CONTACTS

This booklet and webpage was produced by the self-help group of Laryngectomees, Laryngectomee Association of NSW (LANSW). It is available via their website stilltalking.org where you can find contact information for regular MEETINGS of both city and regional Laryngectomees, monthly Newsletters of the NSW and Victorian associations and their archives and much other useful information, images, videos etc.

For more information about cancer and support services generally contact your local cancer organisation listed below or ring toll-free 13 11 20.

Cancer Council NSW
153 Dowling Street
WOOLLOOMOOLOO
PO Box 572 KINGS CROSS
NSW 201
Phone: (02) 9334 1900

Cancer Council of Northern Territory
2/25 Vanderlin Drive
CASUARINA, DARWIN, NT 0810
PO Box 42719
CASUARINA NT 0811
Phone: (08) 8999 8470

Cancer Council Queensland
William Rudder House
553 Gregory Terrace
FORTITUDE VALLEY, QLD 4006
Phone: (07) 3258 2200

Queensland Cancer Fund
PO Box 201 SPRING HILL
QLD 4004
Phone: (07) 3258 2200

The Cancer Council ACT
Building 44
5 Richmond Avenue
FAIRBAIRN ACT 2609
Phone: (02) 6262 2222

The Cancer Council Victoria
1 Rathdowne Street
CARLTON SOUTH, VIC 3053
Phone: (03) 9635 5000

Cancer Council of Western Australia
46 Ventnor Avenue
WEST PERTH WA 6005
Phone: (08) 9212 4314

Cancer Foundation of Western Australia
140 Bathurst Street
HOBART TAS 7000
Phone: (03) 6233 2030

Cancer Council of Tasmania
202 Greenhill Road
EASTWOOD SA 5061
PO Box 929 UNLEY, SA 5061
Phone: (08) 8291 4311

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