



Going Home with a Laryngectomy Stoma: A Guide for Patients and Carers

Second Edition



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Disclaimer

This package has been put together using the latest research evidence and in consultation with multidisciplinary experts in laryngectomy care. It should still however, only be used as a guide. If you have any concerns or questions regarding the content of this package or your laryngectomy care, please speak to your doctor or nurse.

Contents

Page Numbers

The person with the neck stoma has stopped breathing	30
WHAT TO DO IN AN EMERGENCY	
Changing the tapes of the Stoma Vent	29
Cleaning the skin around the stoma	28
Nebulisers	27
Humidification	27
Clinical Care	
A note from the Primary Health (Community) Nurses	26
A note from the Clinical Nurse Consultant Continuum of Care	25
A note from the Social Worker	24
A note from the Occupational Therapist	22
A note from the Physiotherapist	20
A note from the Dietitian	19
A note from the Speech Pathologist (Communication & Swallowing)	
A note from the Hospital Nurses	17
A note from the Nurse Practitioner - Intensive Care Unit	16
A note from the Doctor	14
A note from the Care Coordinator	13
Your Support team	
After the operation	12
The operation	11
Radiotherapy and Chemotherapy treatment	9
Before the operation	8
What should I expect in the hospital?	
Why do I need a laryngectomy?	7
What is a laryngectomy?	6
Introduction	5

OTHER TROUBLESHOOTING (When things go wrong)

My sputum has changed colour	32
My sputum has become thick	32
My sputum is very runny	32
If you have difficulty breathing	33
If you develop difficulty swallowing	33
If your stoma reduces in size	33
If you notice changes to the skin around your stoma and/or Voice Prosthesis	33
Information for Patients with a Voice Prosthesis	
If your Voice Prosthesis falls out	34
If your Voice Prosthesis is leaking	34
If your voice changes	35
Information for Patients using an Electrolarynx	
If your Electrolaryngeal device stops working	35
Daily Considerations	
Constipation	36
Showering/Bathing	36
Clothes to wear	39
Sports and Social Activities	39
Travelling and Going Abroad	40
Travel Kits	41
Sexuality and Sex after laryngectomy	41
Useful Contact Numbers	42
Entertaining snippets & Information from the Internet	43
Units of Competency	46
Glossary	49
References	51

Introduction

With advancements in surgery, technology, nursing care and patient independence, it is possible to send patients with a laryngectomy stoma home safely.

At Liverpool Hospital, we have helped many patients and we can help you too, to go home and live in the community with a laryngectomy stoma. Some people are completely independent and are able to return to work. We believe that the best way to prepare patients and their families for this change is to give them both education and support in the hospital before going home. This package is an important part of the process and is yours to take home.

One of the most common concerns of patients and their loved ones is that they will just be told one morning that they can go home, and will be expected to know and do everything on their own.

We understand these concerns. You will not be discharged home until you are able to manage your stoma care independently and with the support of your family or carer.

We will help you before your surgery and whilst you are in hospital to make sure that your discharge home is a safe and happy one. Once you are at home, ongoing support and follow-up is available to you and your family members.

Best wishes from your support team.

What is a laryngectomy?

A laryngectomy refers to the surgical removal of the larynx (voice box) usually due to laryngeal cancer.

The surgery separates the trachea (windpipe) from the oesophagus (gullet or foodpipe) and re-directs the windpipe to a permanent opening in the neck, called the stoma. Having the operation means that you will no longer breathe through your nose and mouth, you will breathe through the hole in your neck. It also means that you will not be able to speak normally anymore, but we will help you find other ways of successfully communicating with people.

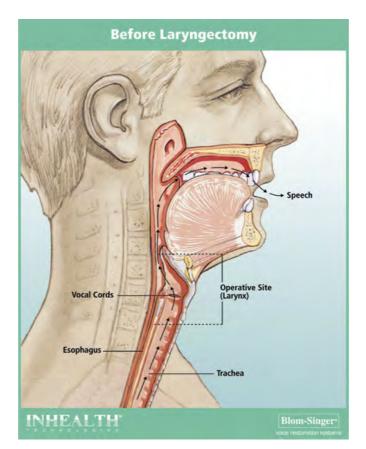
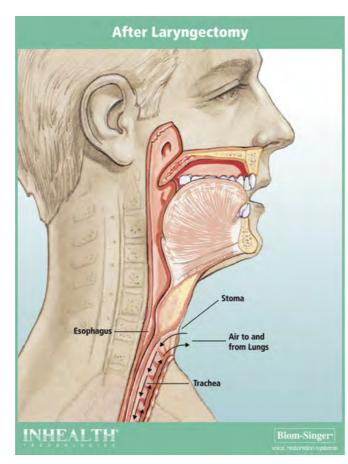
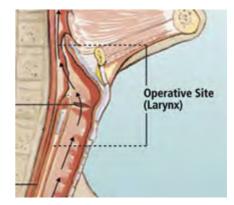


Image courtesy of InHealth Technologies





Images courtesy of InHealth Technologies

Why do I need a laryngectomy?

There are many different reasons why people may need a laryngectomy. Some reasons are:

- Tumour / Cancer
- Sudden swelling of the voice box (larynx)
- After injury or trauma to the voice box

The reason you need a laryngectomy is: _____

What should I expect in the hospital?

Before the Operation

Your specialist has determined that the best treatment for your condition is a laryngectomy. This means surgery or an operation to remove the diseased area. If a malignancy or cancer of the larynx has been diagnosed, the aim of surgery is not only to remove the cancer but to also prevent cancer from returning.

Different tests may need to be done leading up to the time of surgery because the team caring for you need as much information as possible. This may involve:

- A physical examination
- Nasendoscopy a local anaesthetic is sprayed into a nostril, then a fine tube with a light on the end (fibre optic) is inserted into your nose and throat
- Biopsy a small piece of tissue is removed to be examined under a microscope
- CT and PET scans which show the size and location of the cancer and determine if it has spread to other areas
- Other investigations to gain specific information about the type, size and location of the disease

Prior to the surgery, team members will help prepare you for the operation. Physically, this may mean improving your nutritional intake so you are in better condition to enhance wound healing. You may see a dietitian for this. You will see the speech pathologist to learn about the changes surgery will make to swallowing, breathing and speaking. The speech pathologist may arrange for you to meet someone who has had the same type of operation which can be very helpful for you. The visitor is a trained member of the Laryngectomy Association of NSW.

Psychological preparation means preparing yourself emotionally. Many people feel understandably shocked and upset when told they have to have surgery. If necessary, support can be sought from the social worker or clinical psychologist. There may also be practical considerations such as taking leave from work, making arrangements for pets to be cared for whilst you are in hospital or for you to stay with family once you are discharged home. This is a time to ask questions and to seek help with any concerns you may have.

Before your operation, you will be seen in the Head and Neck Pre-treatment clinic. You will be seen by the Care Coordinator, Dietitian, Speech Pathologist and Social Worker. This allows the team involved in your care to gain a better understanding of your physical and emotional needs right from the start so we can better support you throughout your treatment and follow-up.

You will also be seen in the Pre-admission clinic on a day prior to the date of surgery. This is to make sure you are physically well enough to cope with an anaesthetic or being put to sleep during the operation. If you have any questions ask your doctor or your Care Coordinator.

Radiotherapy and Chemotherapy treatment

Although the main treatment for cancer of the larynx is surgery, radiotherapy is often given.



Photos courtesy of H. Nolte

Chemotherapy may also be given in selected cases following your surgery. Radiotherapy and chemotherapy are ordered by specialist doctors; a Radiation Oncologist (radiotherapy) or Medical Oncologist (chemotherapy). Treatments are given as an outpatient which means you go home each day when the treatment is finished. Treatments are given from Monday to Fridays, not on weekends. Your oncology doctor will see you regularly.

The Cancer Council NSW⁽⁴⁾ has a booklet called "Understanding Head and Neck Cancers" with lots of information to help you and your family members understand the surgery and these other treatments.

The Operation

There are two types of laryngectomy operations, partial and total. Partial laryngectomy is where some of the voice box is retained and eventually the tracheostomy tube is removed. Total laryngectomy is where all of the voice box is removed and the tracheostomy is permanent (called a tracheostoma). The following is a simplified description of a total laryngectomy.

1) INTUBATION

As the main procedure is concentrated on your voice box, it is essential to establish an alternate way for you to breathe. As such, the first step is to create this alternate path by placing a tube through the skin in your neck into the wind pipe.

2) LARYNGECTOMY

The next step is to proceed with removal of the voice box. This is the major step. This usually takes one to two hours. It is performed through a wound above the temporary breathing tube. The wound normally extends from one side of the neck to the other.

3) PHARYNGEAL ANASTOMOSIS

After separating the voice box from the top of the gullet, the opening is closed so you are able to eat after recovery. Until you recover, nutrition is delivered via a tube placed into the stomach.

4) TRACHEOSTOMA

The top end of the wind pipe that has been separated from the voice box is attached to a hole in the skin at the base of the neck. This is a permanent opening which will allow you to breathe normally.

5) TRACHEO-OESOPHAGEAL FISTULA (TOF)

One of the final steps is to create an opening between the back of the wind pipe and the gullet. This is essential to help you speak using the gullet instead of voice box.

6) CLOSURE

Finally the skin is closed and drains are placed in order to drain the fluid that might accumulate after surgery.

After the Operation

Expect to have an intravenous (IV) drip in your arm and some drains in the skin around the surgical site. The drip is to make sure you don't dehydrate, and the drains in the skin are to empty out any remaining blood in the area. You will probably have a tube called a tracheostomy tube in the hole (stoma) in your neck. This is to prevent the stoma from closing due to swelling. Most of the tubes will be removed before you go home. The tracheostomy tube will be suctioned (a sucking tube is put down into the tracheostomy tube to clear out the airway of sputum), and the air you breathe will be humidified to stop the mucous and sputum from getting too dry.

You will probably have a machine called a PCA (Patient Controlled Analgesia). Nurses load these machines with pain relief, and anytime you get pain, you can press the machine button and it will deliver a small dose of the medicine through your drip into your vein. Usually the wound is not very painful, but you may notice that the skin of your neck is numb. This is normal, and is due to the loss of superficial nerves.

Nurses will be checking your vital signs (temperature, blood pressure etc) regularly and will be looking at the operation site to make sure everything is all right. All of this attention is perfectly normal. As the days go on after the operation, you will learn how best to deal with the sputum, and how to incorporate care of the stoma into your every day routines.

Your support team

A note from the Care Coordinator

The role of the *Care Coordinator* is to help people with head and neck cancer travel more smoothly through the health system. They are a specialist nurse who:

- Gives advice and answers patient and family members' questions
- Is a link between you and all members of your treating team
- Helps with any arrangements for tests or appointments
- Is available before, during or after your treatment has finished
- Can assist you with any difficulties you may have in the hospital or at home
- Helps you access people and services you may need for emotional support, counselling, transport to and from treatment, home care assistance, community nursing and so on.

Your Care coordinator will give you information, guide you through appointments, arrange support services if needed and can be contacted by phone.

Your Care Coordinator's name is: _____

Phone number: _____

These contact details are for Monday to Friday from 8.30am to 5.00pm.

For urgent assistance always ring an Ambulance or go to your local hospital Emergency Department.

A note from the Doctor

The decision to perform a laryngectomy is a difficult one and is only performed when absolutely necessary. Losing your voice box to cancer does not mean that life will be less fulfilling but there will be many challenges. The first challenge is to recover from a long operation, then to care for your stoma (breathing hole in your neck), then to learn to eat and communicate again.

Many people were involved in the decision to perform your operation. These people include Head and Neck surgeons, radiation oncologists, medical oncologists, speech pathologists, dietitians and specialist nurses. Many of these people will also be involved with your care after surgery. On the ward after your operation there are many doctors and nurses directly involved in your care. People are usually confused by the number of doctors that see them while they are in hospital. To eliminate this confusion I will quickly describe how medical teams work in a hospital setting. A team usually consists of junior and senior doctors, who are headed by a specialist. Junior doctors are either Interns or Residents who are in the initial phase of their training after completing medical school. Senior doctors are either Registrars or Fellows in advanced stages of training. Ward rounds are usually done by the junior and senior staff. The attending specialist is kept well informed of the progress of the patient but a family member can call the specialist surgeon if you have a concern that is not being attended to.

On the day of the surgery, you will be put to sleep for the operation by an anaesthetist. They will put a small drip in your arm to put you to sleep. At the end of the operation you will have several drips, tubes and catheters in many locations. Gradually, over a period of days they will be removed. There will be a tube (tracheostomy) in your neck that you will use for breathing. This will need to be suctioned to remove mucus from your wind-pipe every couple of hours. It is important to take deep breaths regularly to prevent collapse of your lungs and to sit out of bed, walk around and to move your feet to prevent blood clots. You will need to be an active participant in your own care and learn how to clean your stoma (breathing hole in neck) or it will get blocked. At first, this will be done by the nurses, but gradually you will take over responsibility for this, so that you can go home safely.

Initially, food will be given via a tube that goes to your stomach, possibly through your nose, neck or abdomen. After one or two weeks you will be allowed to start eating again normally if all of your wounds have healed. Communication will be difficult to begin with. Most patients use a miniature 'white board' or note-pad to write down what they want to say. The next phase will involve an electronic voice box placed on the skin of your neck or under your tongue. Finally, it may be possible to have a special valve placed between the wind-pipe and gullet that will allow sound to come out through your mouth. Your Speech Pathologist will work closely with you to help you choose the most suitable method to communicate.

Going home can be a little frightening, but generally patients do not go home until they are ready. The most common problem encountered at home is crusting of the stoma which may block the wind-pipe. This can usually be prevented by frequent cleaning and moisture (humidification). It is important to have some 'emergency' plans in case you have trouble breathing or a tube falls out. Most of these plans involve common sense solutions such as 'removing mucous blocking the stoma' or 'put the tube back in' and 'come to hospital'. Generally, if there is a problem it is best to come back to Liverpool hospital, but if you call an ambulance they may take you to the nearest hospital which may not have appropriate specialised care. Therefore, it is best to only call the ambulance in true emergencies. The Head and Neck team will continue to see you regularly for many years after your surgery to make sure that you are coping well and there is no recurrence of cancer. Finally, if you have been smoking, **now** is the best time to stop. Recovery is more complicated in patients who smoke and it is very likely the cancer will return.

A note from the Nurse Practitioner - Intensive Care Unit

After the operation you may have to spend a short time in the Intensive Care Unit (ICU). Your Surgeon and the Anaesthetic doctor will decide if this is necessary when you are in the Operating Room or in Recovery.

When in the ICU you will be attached to a monitor that records your heart rate, blood pressure and occasionally you may have a small tube into an artery near your wrist that allows us to take blood. This Unit has Specialist ICU Doctors available 24 hours a day.

The ICU Nurse Practitioner is available to assist with any difficulties and has extensive experience in managing the tracheostomy tube that you will have. The Nurse Practitioner will work in consultation with the Specialist Teams and other Clinical and Allied Health staff to optimise your care. The Nurse Practitioner will review you prior to discharge from the ICU and may see you in the ward area.

The Clinical Nurse Consultant (or CNC) is a nursing position that focuses on education, research, business planning, leadership and consultancy. The CNC does not usually provide direct patient care on the ward. The CNC for Head and Neck Surgery has considerable experience in ward nursing and care of the laryngectomy patient and may conduct the competency review (assessing the required care of the stoma) during your hospitalisation, and may assist with education for you and your carer/family about going home with the stoma. This person will also assist in coordinating your care and be a valuable resource for the nurses in the ward area.

A note from the Hospital Nurses

Although most medical and surgical wards care for patients with an established laryngectomy stoma, that is patients who have already been at home with a laryngectomy, Liverpool hospital has a specialty ward area that receives patients either before or after their laryngectomy operation. This ward is:

Clinical Building Level 5 E "Specialty Surgery Ward"

The role of the nursing team caring for you is set out below:

- Shift by shift education and supervision is given to the patient and the family
 prior to discharge with a stoma. Ward nurses support people caring for the stoma
 to make sure that everyone is safe and confident prior to discharge. The ward
 nurses may also assess patients and their carers using the competency
 assessments in this package.
- Ward nurses may arrange gate leave, so that patients can go home for short periods to build their confidence prior to being discharged.
- If you have any trouble with the equipment the ward has loaned you, or for any other non-urgent nursing queries, please call us.

Contact Liverpool hospital and ask for Nurse in Charge of Specialty Surgery Ward 5E

A note from the Speech Pathologist

A Speech Pathologist is responsible for assessing and rehabilitating difficulties with communicating and swallowing. Both of these fundamental and important skills are affected when a person has a laryngectomy.

Your Speech Pathologist will help you learn the best new way for you to communicate and address any problems or frustrations you are experiencing due to your communication changes. There are various options for communicating after a laryngectomy including:

- An artificial larynx
- Oesophageal Voice
- Surgical Voice Restoration (i.e. Voice prosthesis)
- Mouthing/Writing/Gesture







Photos courtesy of H. Nolte

Your Speech Pathologist will also provide strategies and/or modify your food textures so that you can swallow easily. Your Speech Pathologist will work in close consultation with the other members of your care team to coordinate your progress.

Your Speech Pathologist is:_____

Phone number:	
---------------	--

Your method/s of communication are:

Your recommended diet is:

A note from the Dietitian

Dietitians are not routinely involved with laryngectomy patients, but if you would like to see a dietitian whilst in hospital, please ask the nursing staff looking after you. Dietitians can assist you with any special dietary requirements or help you to maintain adequate nutrition if you are having problems with eating and if your intake is poor. For any concerns or questions about nutrition when you get home, please phone

Your Dietitian is: _____

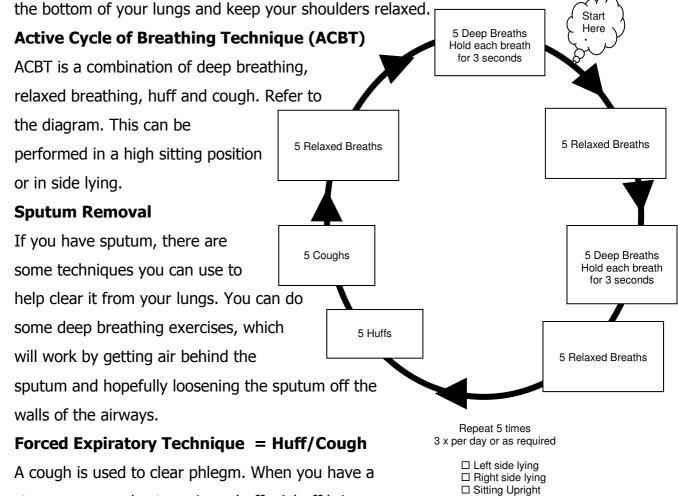
Phone number: _____

A note from the Physiotherapist

1) Chest Physiotherapy

Deep Breathing

This sort of breathing is used to increase the amount of air that gets down to the bottom parts of the lungs. Take a slow big breath in. Try to maintain this for one to two seconds by placing your finger over the end of your stoma. Then relax and let your body breathe out (don't force the air out). Remember to send the air down to



stoma you can also try using a huff. A huff brings the secretions from smaller airways to the bigger airways,

so that they can be cleared with a cough. To produce a huff take a medium-large breath in and using the stomach and chest muscles, blow the air out through the stoma as forcefully and for as long as you can.

2) Exercise

Exercise is important to improve your overall health and to improve your ability to carry out daily activities. Exercise can improve weakness and deconditioning. Walking and other activities increase the amount of oxygen and air entering the lungs and can also aid in removing sputum.

What sort of exercise should I do?

Any activity involving moving of large muscles in your body continuously whilst breathing faster. This could be activities you are already doing such as brisk walking, dancing, lawn bowls, gardening, housework etc.

How often and for how long should I exercise?

It is recommended that we exercise for at least 30 minutes each day (or at least most days). This 30-minutes can be done all in one go, it can be made up of three 10-minute bursts or whatever is manageable.

Warming up and cooling down

We should always warm up before we exercise and cool down after we exercise. This

involves some gentle walking and some gentle stretches before and after our exercise sessions. This helps to prevent strains/sprains and muscle cramps.

Some General Recommendations

- Wear suitable clothes/shoes
- Drink plenty of fluids
- Don't eat within one hour prior to exercising
- Try and exercise at a suitable time of day i.e. avoid extremes in temperature
- Don't compare yourself to others always check that you are improving against yourself



A note from the Occupational Therapist

An Occupational Therapist (OT) is concerned with a person's ability to perform everyday activities. Not all people who have a laryngectomy will need OT involvement. However if you are experiencing difficulty being able to safely or independently perform self-care tasks, leisure activities, work roles, or home duties, you may be seen by an OT who can assess and enhance your ability to carry out these occupations.

An OT can improve your participation in everyday activities in the following ways:

- Assess your ability to perform self-care tasks such as showering and dressing and determine the need for equipment to allow you to perform this activity independently and safely
- Assess the need for home modifications that will increase your safety and independence in everyday activities. For example, installation of a hand-held shower rose to help prevent water from entering the stoma during showering
- Provide education on how to manage your energy when returning to everyday activities. You may be in hospital for some time, and thinking about how you will be able to go back to all your previous occupations may be an overwhelming thought. Your OT can give you practical suggestions on how to return to these tasks in an energy efficient manner
- Assess the need for support services. If you require assistance with everyday tasks and do not have a family member or carer who can support you when you leave hospital, you may require services to assist with things like showering, home cleaning, laundry, and shopping. An OT can assess the level of assistance you may require and be involved in the process of organising services when you leave hospital along with your social worker.
- Assess the need for a personal alarm system. Following a laryngectomy, your ability to speak and communicate will change. If you live alone or are concerned with being able to access emergency assistance in the absence of a voice, your

OT can supply you with a list of companies who can provide personal alarms that can accommodate non-speech dependent systems.

If your doctors or nurses think you need to be assessed by an OT, this will be arranged during your hospital admission. However, if you were not seen by an OT during your hospital stay and would like to be assessed by one, you can contact the Occupational Therapy department at Liverpool Hospital

Your Occupational Therapist is: _____

Phone number: _____

A note from the Social Worker

Social Workers offer many sorts of emotional and practical support to hospital patients and their families, especially when dealing with cancer or other chronic illness. Advocacy is another key part of the social work role, and social workers can help to arrange family meetings with medical and health providers, ensure that both patient and carer views are considered in planning a patient's discharge, and arrange support services / home help during their recovery.

Each ward of Liverpool Hospital has a social worker assigned, and any patient or family member can be referred at their request. Some patients are automatically referred to a social worker.

Examples of the types of support provided by social workers are:

- Counselling and emotional support regarding a patient's medical diagnosis or prolonged hospital stay
- Assistance to adjust to life changes such as major surgery, loss of function or change in body image
- Addressing and resolving conflict amongst families
- Provision of advocacy and support letters for patients with special housing needs or immigration matters
- Referral to short or long term home help services, or to specialist support services
- Providing information and advice about what people might be entitled to (e.g. carer payments, support services, financial assistance)

Your Social Worker is: _____

Phone number: _____

A note from the Clinical Nurse Consultant (CNC) Continuum of Care/Complex Care

This position primarily focuses on the areas of discharge planning that assist to facilitate a safe, efficient and effective transition from hospital to home. The CNC provides consultation and advice to both patients/carers and staff with special or complex needs.

During your admission

The CNC for Continuum of Care/Chronic and Complex Care will work in partnership with other staff members to coordinate a family case conference if necessary. With your permission a number of hospital staff and community services providers will attend. The purpose of this case conference is to discuss your discharge needs and allows both you and your family/carer the opportunity to ask any questions or concerns that you may have regarding your current management and discharge plans.

Prior to Discharge

You will be assessed and deemed competent in Laryngectomy care by the nursing staff.

On Your Discharge

You will be provided with a care plan that all staff have contributed to. This will provide you with a list of contact details for both hospital and community staff, along with a list of recommendations and management goals for you to safely manage and care for your stoma at home. You will be given 1 month's supply of equipment to help in your care.

Please feel free to contact me for advice or any concerns you may have.

CNC Continuum of Care is:

Phone no:

Can be contacted: Monday to Friday from 8:00am to 4:30pm

A note from the Primary Health (Community) Nurses (PHN)

The community nursing service can offer a follow up/support service on discharge. We liaise and work closely with Liverpool hospital and your GP, who will be your primary care manager to ensure your continuity of care from hospital to home.

There are a number of Community Health Centres within NSW, however depending on your residential address this will determine the appropriate Community Health Centre you are referred to.

Primary Health (Community) Nursing Services

Primary Health Nurses (PHN) are part of the team and play a pivotal role in continuity of care. PHNs are available for a range of tasks and should be involved in the discharge process for more clinically complex cases.

Community Health Centre	Hours of Operation Monday to Friday	Contact Details
Bankstown	10 am to 4 pm	8760 1300
Campbelltown	9 am to 4 pm	4633 4177
Fairfield	9 am to 4.30 pm	8717 4009
Hoxton Park (Liverpool)	8:30 am to 9 pm	9827 2222

The nurses can be contacted on the numbers below:

Clinical care

Humidification (warming and moistening sputum)

Normally, your nose and mouth filter and humidify the air that you breathe. Since the stoma now bypasses the upper airway, the air is going straight from the stoma to the lungs and is not getting filtered or humidified so you need machines and devices to assist with this process. With the help of nebulisers and other techniques, you will not need the big humidifiers that we use at the hospital. We will advise you how often you will need to use the nebuliser and the other devices. Just like anything new, you will find that once your body adjusts, you will know how often you need to use the devices by assessing how cold the air feels and how moist your sputum is. You may also find that the time of the year, or where you are, may affect how often you need to use the devices. For example, in winter, you may need to use the nebuliser more often. If you stay in air conditioning a lot, you may also have a greater need to use nebulisers and the other devices.

<u>Tip</u>: Need instant humidification? Turn the hot water tap on for the shower, bath or basin and steam up the bathroom.

Nebulisers

Nebulisers with normal saline (sterile salty water) can help break up sputum and assist in clearing it. We will help you to organise a nebuliser for when you go home. This is a simple device to use – it is the same type that people with asthma use every day. We will show you how to set it up and keep it running while you are still in the hospital.





Photos courtesy of H. Nolte

Cleaning the skin around the stoma

Cleaning around the stoma each day (or more often if it is needed) is important in keeping the skin healthy. Have a look at the skin area every day. If it begins to look red or swollen, ask the nurse or doctor to have a look at it.

The skin around the stoma can become fragile and inflamed. This may be due to sputum continually moistening the area, or because the stoma is newly formed, causing local damage. Radiotherapy can also make the stoma look red and sore.

We suggest you use a clean, damp face washer or clean water-soaked gauze to gently clean around your stoma. Use something that is not used for cleaning anything else (for example, do not use a face washer that is used for washing your body). Whatever equipment you use to clean the stoma, it should be:

- Clean (to minimise infection)
- Free from any loose fibres (so that the fibres do not enter the stoma)
- Soft (so that it doesn't damage the skin)

Sometimes crusts develop around the stoma. If this happens, use Saline on a cloth and wipe gently to loosen the crusting or you can use a clean pair of tweezers to gently remove them. This may prevent them from going down into the windpipe. Remember to be careful though – picking off crusts may damage the skin and cause bleeding. If a small amount of bleeding occurs, apply direct pressure with a clean cloth until it stops. Using Vaseline (very carefully) can protect the surrounding skin.



Photos courtesy of H. Nolte

Changing the tapes of a Stoma Vent





Photos courtesy of H. Nolte

The Velcro tapes that are around your neck are helping to keep the stoma vent in position.

The tapes should not be too loose or too tight around the neck. They should perform the job of keeping the tube in place, but at the same time, shouldn't cut off circulation. A good way to remember the correct tension is to remember that you should just be able to insert 2 fingers between the tapes and the neck.

To change the Velcro tapes:

- Thread the Velcro through the back of the hole in the side of the stoma vent
- Repeat on the other side
- Attach the Velcro making sure that the collar fits properly (not too tight, not too loose)
- One of these pieces can be cut and shortened if the collar is too big
- Make sure that the stoma vent is still in the centre and that it feels comfortable.

The Velcro ties can be washed and reused, but remember that the adherence of Velcro starts to deteriorate after a while. If the Velcro is no longer sticking, it won't be doing its job very well, so get a new Velcro tie from the manufacturer.

WHAT TO DO IN AN EMERGENCY

The person with the neck hole (stoma) has stopped

breathing:

REMEMBER THIS IS THEIR ONLY AIRWAY!



- Check area for *danger* first such as hazards or risks to safety, to yourself and others
- Check person for *response* (Shake and Shout)
- If person not responding call Ambulance
 Phone 000 and/or send for help
- Lay person on back to expose neck stoma
- Tilt head backward and keep head straight
- If a tube is in stoma leave in place (unless blocked) to keep the hole open for breathing and resuscitation
- Check person for breathing look, listen and feel for the chest movements of breathing
- If not breathing, the rescuer should give 30 compressions place heel of 1 hand in centre of person's chest (lower half

of breastbone) and place other hand over the top. Press down about 5cm or a third of the depth of the chest. Allow complete recoil of the chest after each compression

- Rescuer to then place their mouth over the stoma, and give 2 breaths - allow about 1 second for each breath in (watch chest rise)
- If chest fails to rise, there may be a poor seal over stoma or the stoma or tube is blocked – if tube is blocked remove tube and give mouth to stoma breaths. If stoma is blocked use forceps or finger to remove any dried sputum plug/foreign object and give mouth to stoma breaths looking for rise and fall of chest
- Rate of compressions is about 100 per minute (almost 2 compressions per second)
- If rescuer unwilling or unable to give breaths, continue with compressions only, at a rate of 100 per minute
- Keep repeating 30 chest compressions followed by 2 breaths until person responds or starts breathing normally, a health care professional arrives and takes over, or for as long as you can.

(1, 2, 3)

OTHER TROUBLESHOOTING

(When things go wrong)

IF YOU EXPERIENCE CHANGES WITH YOUR SECRETIONS (e.g. Colour, Type, Quantity):

My sputum has changed colour

Sputum that has changed from white to yellow or green is usually a sign of infection. Visit your GP or local Doctor for advice.

My sputum has become thick

This may be due to a few different factors. You may have a cold, the weather may have changed, or it may be that you aren't using the nebuliser as often as usual. Increase the number of times that you use the nebuliser each day. If that still doesn't work, contact the Community Nurse.

My sputum is very runny

This may be due to similar factors. You may have a cold, the weather may have changed, or it may be that you are using the nebuliser too often. Reduce the amount of nebulisers that you have during the day. Do it gradually – until your sputum goes back to normal, don't just stop using the nebuliser altogether. If changing the number of nebulisers used doesn't help, ask the Community Nurse to see you.

IF YOU HAVE DIFFICULTY BREATHING:

- Inform your GP or local Doctor and Speech Pathologist IMMEDIATELY for advice
- If your symptoms are severe, or occur outside office hours, attend the closest Emergency Department

IF YOU DEVELOP DIFFICULTY SWALLOWING:

- Contact your Speech Pathologist for advice and a review appointment
- You may require a review with your ENT/Head & Neck specialist
- You may require an x-ray of your swallowing to determine the cause of the problem

IF YOUR STOMA REDUCES IN SIZE:

- Inform your Speech Pathologist IMMEDIATELY for advice
- You may require a review with your ENT/Head & Neck specialist
- If this occurs outside office hours and you are having difficulty breathing, go to the closest Emergency Department

IF YOU NOTICE ANY CHANGES TO THE SKIN AROUND YOUR STOMA AND/OR YOUR VOICE PROSTHESIS: (e.g. bleeding, scabs, blisters)

- Inform your Speech Pathologist IMMEDIATELY for advice
- You may require a review with your ENT/Head & Neck specialist
- If this occurs outside office hours, go to the Emergency Department

INFORMATION FOR PATIENTS WITH A VOICE PROSTHESIS

IF YOUR VOICE PROSTHESIS FALLS OUT:

- Lubricate the end of your dilator or catheter, insert into your trache-oesophageal fistula
- Tie a knot at the end and tape securely to your neck
- Remember this will be much easier to do if you can keep your mouth open to avoid swallowing your saliva
- If you are unable to insert the catheter:
- Remain strictly Nil By Mouth
- Contact your Speech Pathologist as soon as possible to arrange a review. If it is outside office hours, go to the Emergency Department

If you have been trained in the insertion of your voice prosthesis:

- Clean your voice prosthesis
- Reinsert your voice prosthesis (using the steps in the "Changing your Voice Prosthesis" handout)
- If your voice prosthesis is falling out regularly or you have difficulty reinserting it, insert your dilator or catheter, tape it to your neck and contact your Speech Pathologist. If it is outside office hours, go to the Emergency Department

IF YOUR VOICE PROSTHESIS IS LEAKING:

- Clean your voice prosthesis as recommended by your Speech Pathologist to make sure no food particles are lodged in the valve
- If your voice prosthesis continues to leak, remove it and replace with another voice prosthesis if you have been trained to do so
- If it continues to leak drink thickened fluids ONLY and contact your Speech Pathologist for a review as soon as possible

IF YOUR VOICE CHANGES:

- Clean your voice prosthesis as recommended by your Speech Pathologist
- Have a drink of warm water
- Check that your voice prosthesis is in correctly (you may wish to remove it and reinsert it to make sure if you have been trained to do so)
- Check that your voice prosthesis is well-fitting (i.e. not loose or protruding from the trache-oesophageal fistula)
- If your voice quality does not improve after following the above steps, contact your Speech Pathologist for advice and a review appointment

INFORMATION FOR PATIENTS USING AN ELECTROLARYNX

IF YOUR ELECTROLARYNX DEVICE STOPS WORKING:

- Clean the device as shown by your Speech Pathologist and as per the manufacturer's instructions
- Charge or replace the battery
- Contact your Speech Pathologist for advice
- You may need to return the item to the manufacturer for assessment and repair (Ratified by Speech Pathology 09/04/2009).

Daily Considerations

Constipation

This may be a problem with a stoma as you may have more difficulty "bearing down". If you are able to eat and drink, continue to have a well balanced diet with plenty of fibre (and a lot of fruit). If you are not restricted in your fluid intake (like people with heart failure are), then make sure you have plenty of fluids too. If constipation develops, you may need to speak to your Community Nurse or GP/local Doctor about stool softeners/laxatives.

Showering/Bathing

The main concern with showering and bathing is stopping water entering into your stoma. Covers are available, and we will discuss these with you.

A cover over the stoma will prevent water spray from accidentally going into the tube BUT using a cover over the stoma does <u>not</u> mean that you can immerse yourself in water, and it does not mean that you can forget about where the water is being directed. Care must still be taken when around water.

Some people when showering, will have a hand held shower hose, and shower only up to the chest. Some use the bath and do the same. Others will find inventive ways of washing hair and the upper body. The nursing staff may be able to give you ideas about showering while you are in the hospital. While you are still in the hospital, think about what your bathroom is like at home, and discuss any concerns while you are still in hospital. We may recommend that an Occupational Therapist attend a home visit to assess the home environment to determine your needs by offering some advice about equipment and ways for you to move around the house easier.

Assorted Shower guards available



Rubber shower collar Inhealth



Blom-Singer shower guard Inhealth

Showering tips from people with laryngectomies (from popular websites)

1. I make sure the water falls on my shoulders and do this by bending forward a little bit when I cannot lower the shower head itself. I do have a shower at home which can go up and down. That is a lot easier. I wash my hair by bending forward with head down under the water so it falls on my head and neck and won't go into my stoma. I use this since the day after my surgery. That is almost 14 years now and still counting. Marianne Peereboom

2. In order to save a few dollars I have recommended baby bibs which are terry cloth on the inside and plastic on the outer side. Of course this does no good shampooing but one can just bend over to do that.

Martha Reed

3. I shower without a stoma shield, turn my back to the spray to wash my hair that way and tilt my head back to rinse. A shower spray that can be taken down and held in the hand can also be used for rinsing. When I turn to face the spray, I occlude and step right into the shower stream. When I was a new lary, I used a shield every day and then only when I washed my hair until later I quit using it at all.

Pat Sanders

4. I tried some sort of shower guard early on, but gave it up as too clumsy. Now I just keep a dry clean washcloth handy to cover up while getting that area wet. If I do get a little water down the pipe, well, it's only water and it's good for us to keep the plumbing moist, no? In other words, simple is good. Which is good news for simple folks like me. AND ... conserve water! Shower with someone you love! Paul Sampson

5. I haven't seen the showering tip that helps me avoid getting water into my stoma when showering--I leave the foam square on until I'm almost done with the shower. It gets wet, but so far in 4 and ½ years it has served me well. One other thing, instead of a standard shower head I found an extension that drops the shower head down about 14 inches with a swivel head and a shut off right before the shower head. I found it at one of the home center stores. Al Keneda

6. I found that if I stand under the shower and bend my head slightly forward when I'm directly under the spray, no water gets in my stoma, and I'm even able to wash my hair, with hardly a cough. Also, a hand held shower attachment (that screws in easily in place of the shower head) is much better. It saves a lot of fancy footwork on a slippery porcelain surface trying to get the right angle of water attack while avoiding direct hits to the stoma. I've tried the shower covers (the tie-on, bib-like things), but for me they were a lot more trouble then they were worth. Tom Harley

7. I have long hair -- below my shoulders most of the time, and I have long mutton chops which sometimes touch my chest. So a two handed shower is vital for me -- I need a shower guard. The ones that Lauder sells last forever -- I have one that is about ten years old and it is just fine -- and I have one in each bathroom of each house and one in each vehicle I own --just in case. Paul Galioni

8. Of the two types that Inhealth sells, I personally prefer the nylon one because the shape seems to conform better to the neck (and is more watertight), and the Velcro strap is larger than the rubber one and lasts longer. It does, however, get dirtier because of the nature of the material on the inside, and eventually cracks at the point above your stoma. To cope with its getting dirtier, I wash my neck with a washcloth before putting it on. David Blevins

9. I do use the rubber shower guard and have right along. Because I have a small neck, I clipped off about 1-1/2" of the Velcro and had it sewn back onto the collar above where the original Velcro began. This allows me to have a snug fit and to stand straight up under the shower head while washing my hair. Since I'm often still waking up while showering, I don't have to think about moving at angles to keep the water out. It works for me. Libby Fitzgerald

10. I do not use a shower guard. Never have. If I stick my face full in the shower, then I use one hand to cover my stoma. Other than that, my chin tends to protect it. I occasionally will get a drop or two of water, then cough some, and don't worry about it. Philip Clemmons

11. All I do is lean forward under the shower to wash my hair and the water washes down over my chin and not into the stoma. If a little water gets into the stoma, a robust cough clears it, no problem. It took some time to get it perfect but time and patience works every time. Doris Gifford

12. In Lauder's "Self Help for the Laryngectomee", he mentions a mirror -- and I did find that useful -found one cheap in a second had store, plastic frame -- hung it right below the shower head. It helped me visually locate my stoma right after the surgery. Now I have its location memorized. (Smile) Also, a hook in the wall above the shower head -- I hang my shower guard there. I have just discovered the amazing properties of a nice new shower head -- it adjusts much better than most -- I think it was about \$20 -- and a lever moves it easily from lots of small jets to three pulsating jets - I can simply reach up, turn the stream to the three large pulsating ones, put my thumb over my stoma, and blast away. I know that showering was an adventure in the beginning -- now I don't even think about it.

Paul Galioni

13. For people who wear a shower guard and have small necks. The Velcro opening may be too roomy even with adjusting it down as small as it will get, so I cut off about 1-1/4" from the part that hangs off the latex. That cut-off part can then be sewn back by machine onto the same side above the pre-attached Velcro and you now have a snug fit. Libby Fitzgerald

Clothes to Wear

The clothing that you wear is your decision – as long as it is not restrictive around the neck. Some people find ways of disguising the stoma by putting a light scarf or a cover over it. Be aware that fibres can enter the stoma, and if the material draped over it is too thick, it can cause suffocation. Before putting anything over the top of the stoma, check with a staff member to determine its suitability.

Another thing that you may want to wear is a medi-alert bracelet or necklace, warning people that you have had a laryngectomy and are a 'neck' breather.

Sports and Social Activities

Everyone is different – including people after a laryngectomy. Some will be able to enjoy an active lifestyle after discharge - enjoying sports, work and time with friends. Others may not be as fortunate. Regardless of where you are up to in your daily activities, below are some Do's and Don'ts to think about.





Photos courtesy of the Laryngectomee Association of NSW





Photos courtesy of the Laryngectomee Association of NSW

Do:

- Try to keep mobile
- Get outside when the weather is nice
- Enjoy what you can do

Don't:

- Go into smoke filled rooms, and try to keep away from people who are smoking
- Spend too much time with people who have respiratory infections
- Swim in the ocean or pool. You can wade in water, but do not leave yourself open to the potential of getting water into the stoma. If you are going to wade in water, make sure that you have someone with you.
- Play contact sports

Travelling and Going Abroad

After laryngectomy you still need to travel. This travel may consist of going to doctors appointments, or it may mean travelling to the other side of the globe for a well deserved holiday. The distance and frequency that you travel from home will be dependent on your physical health. If you would like to travel, and are concerned about it, talk to your doctor or nurse about it.

Travel Kits

The key to travelling stress free with a stoma is preparation. If you have all of the necessary equipment at hand, then any challenges that arise should be reasonably easy to overcome. Any equipment that you have at home should be packed for travel, or better still, there should be a "travel bag" at the ready for any times you leave home. Pack the bag if you are going out – regardless if it is for 5 minutes or 5 hours, and don't be complacent about it – an emergency can happen anywhere, not just at home.

Sexuality and Sex after laryngectomy

It is safe to resume sexual activity once the surgical area is comfortable, unless your surgeon tells you not to.

The laryngectomy surgery changes the way you speak, breathe and your appearance. This can lead to a loss of confidence regarding sex such as feeling conscious of the stoma and thinking that your partner finds it unattractive. Covering the stoma with a stoma cover, scarf, tie or high necked top might make you feel more comfortable. Talking to your partner if you can about your worries may help both of you get used to your new situation. This is important because returning to sexual activities within a special relationship can help you feel a sense of mastery over your cancer and like a 'whole' person again.

Difficulties with speaking may affect lovemaking. Remember that talking is not necessary during many sexual situations, eye contact and touch are important ways to show your feelings. Supportive counselling can help you to explore these issues and help build emotional strength and self confidence. Ask to talk to the social worker or care coordinator who can make the appropriate referral. For women, there is also the "Look Good Feel Better" program which runs sponsored workshops at the hospital. These workshops run by trained volunteers show you how to use cosmetics, hats and scarves to enhance your appearance^(5, 6).

Useful Contact Numbers

•	Specialist Doctor's Name:
•	Phone Number:
•	Address of Rooms:
•	Local Hospital Phone Number
•	Speech Pathologist's Name and Phone Number:
•	Head & Neck Care Coordinator's Name and Phone Number:
•	CNC Continuum of Care's Name and Phone Number:
•	Ward Name and Phone Number:
•	Other contacts:

Entertaining snippets & Information from the Internet

Liverpool Hospital is not affiliated with any laryngectomy websites on the Internet, and does not endorse any recommended treatment measures you may find on the internet web sites. If you have any questions about how to manage your stoma, please contact your doctor or nurse.

Typing 'laryngectomy' into search engines like Google will result in loads of websites for you to look at. Below are some snippets of what is available:

Below are some of the more hilarious questions asked of laryngectomees when folks hear our new "voices" or see our "stoma." These have been contributed by numerous members:

- * When are the doctors going to close the hole up?
- * What do you put in there when you swim?
- * Is that where you put your food now when you eat?
- * Is that where you talk out of now?
- * Can you still pick your nose?
- * Are you a robot?
- * Will your voice box grow back?
- * If you don't use your nose any more, what are you going to do with it?
- * Oh, I'm sorry I made you talk!
- * Don't despair Jesus loves you.

* I can hear and understand you perfectly. And you are apparently not dead, so you must be breathing. You speak and you breathe, I don't see where the disability is. I am afraid that I am going to now have to require four physician statements and a statement from a rehabilitation counsellor before I can even begin to consider your request for reassignment of duties.

- * Maybe you should learn sign language?
- * Is that where you drink your beer now?
- * Mom, Mom, with that hole in your neck, do you think you should eat broccoli?

* I became almost hysterical when my neighbour wanted me to go swimming with her and thought I could just put a cork in there to plug the hole while I swam! She said "Just breathe through your nose!"

* My God, what happened to YOU? Did you get shot in the neck in a drive-by shooting or something?

- * Oh .. OK, I understand. I guess that means you can't EAT anything either, right?
- * Well, I'm sorry I stared ... I just had never seen anyone talk through their thumb before ... is that where your microphone is located?
- * Does your neck get sore if you talk too much?
- * I still think the funniest question we have all gotten is : You are in your room immediately after the

surgery...you need help...you push the button for the nurse...then you hear "Can I help you?" over the loudspeaker. So you keep pushing the call button....and you keep hearing "Can I help you?" * When my daughter was in first grade, one of her friends asked me if they cut my head off and then sewed it back on.

* I've had at least two men say to me "I bet your husband's glad" meaning he doesn't have to listen to me talk. When I had my first biopsy, back when I still had my natural voice, I wasn't supposed to speak for a day or so. I ran into a builder/investor that I used to market and sell homes for. He was obviously glad to see me. When I wrote him a note to say that I was glad to see him, and that I was writing because I'd had a biopsy that morning, he immediately took the pen and legal pad from my hand and wrote me a note. I took it back and with a large smile on my face wrote a message back to him asking if he'd also had a biopsy that morning, and if not, I went on to explain that a biopsy wasn't contagious and he could go ahead and talk normally, but I would still be writing down my answers. We both laughed and he spoke normally after that! Herb Simon

Now, for a story that just took place a couple of hours ago. My friend and I went to Denny's to have brunch. Next to our table was a young couple with a little boy about 5-6 years old. I noticed him watching me. Then he got up and went over to his dad and I knew they were talking about me. A couple of minutes later the little boy and his dad approached my table and the dad told me his son was very interested in the way I was talking and wanted to know if I would mind showing him how it was done. I showed the boy my Servox and then showed him how it worked. I even let him try and talk with it. While we were eating the boy kept looking at me and smiling real big. When they left the boy came over and thanked me for showing him and gave me a kiss goodbye. Folks, in my opinion, it don't get much better than that. God Bless. Amy Jo Kiger,

Last month was the first anniversary of my laryngectomy. My surgeon admitted me into the hospital for an 'in and out' procedure, he wanted to look deep into my lungs, go down my oesophagus and possibly take some biopsies just to make sure the big C was not in evidence. I had the shot and was basically in 'lala' land when they rolled me into the exam room. I had a sheet pulled up around my neck so the OR nurse did not see my stoma. She placed the oxygen mask over my nose and mouth and I immediately started to move it over my stoma. She yelled, "Don't touch that, I have to give you oxygen." I then occluded my stoma and told her I might as well roll over and she could put it on my butt since I would get just as much oxygen there. Needless to say the entire OR gang was really roaring!!!!!!!

I had to have a re-puncture recently and as soon as they rolled me into the OR this little nurse said, "Mr. Gillette, roll over and pull up your gown and I will hook you up to your oxygen". Same nurse and she had not forgotten. Then, she told the rest of the OR staff what had happened last year when they scoped my throat and lungs. A good laugh is like a warm ray of sunshine. There are moments as a lary that can be very entertaining! Ron Gillette

A new laryngectomee wrote in and asked what the 'limitations' and 'restrictions' were going to be as one of us. I wrote back:

Here are some 'restrictions' on, or 'disadvantages' of becoming a laryngectomee: (1) you can no longer snore. It is now impossible. So if your bed partner (human or otherwise) is lulled to sleep and reassured by your snoring, they will just have to adjust to this new quiet you (2) you cannot choke on food any more. The 'Heimlich Manoeuvre' is useless on us. So if a loved one has taken the course on that, it is wasted knowledge for you, as was learning mouth-to-mouth resuscitation. So you both will just need to learn mouth-to-stoma rescue breathing instead (3) if you run over a skunk with your car, the odds are that you will not be able to smell it.

(4) if you used to tell the seasons of the year by bouts of allergic reactions to pollen, leaf mould, etc., you will probably just have to get yourself a calendar since we are less likely to have these problems since we no longer breathe through our mouths and noses

(5) if you count each year on bolstering your immune system by coming down with whatever respiratory illnesses or other airborne diseases are making the rounds, you will probably be disappointed because you are less likely to get them (same reason as #4)

(6) you may drive your significant other batty because you can kiss them without coming up for air (and they may get tickled by the feel of your breath on their neck while doing it and giggle...thereby destroying the mood)

(7) instead of having one way to speak, you may get confused by having two or more methods available

(8) if you enjoy speaking quickly and without much thought, you may be bothered since many of us need to take a second to find our artificial larynges or occlude our stomas before we can say something. As a consequence, we may also find that we are spending more time listening to others rather than talking

(9) if you are a man, you might have to give up wearing those tight neckties you love wearing around your neck since you will need access to your stoma

(10) if you enjoy amusing others, chocolate milk or other beverage can no longer come out your nose when someone says something funny while you are drinking.

(11) You may find yourself a member of another organization and have a whole new set of friends. David Blevins

Competency: Cleaning the Stoma Vent

AIM: This competency aims to assist all patients and/or care givers in acquiring the relevant skills to perform cleaning of the stoma vent.

CRITERIA	Observed	Oral questioning (if applicable)
States equipment needed to clean the stoma vent		
States the frequency of cleaning required (minimum 3 times per day and as required)		
Explains why abrasive items should <u>not</u> be used to clean the stoma vent		
Demonstrates the ability to remove, clean and then re-insert the stoma vent		
Ensures stoma vent is dry prior to re-insertion		
Describes signs of infection		

ASSESSMENT OUTCOME

Assessment decision: 🗌 Competent	Not yet compete	nt
Action/further education required:		
Date of reassessment (if required)		
Assessment undertaken in ward/unit		
Patient/Carer's signature:		
Assessor's signature:	Designation:	Date:

Competency: Securing of Stoma Vent

AIM: This competency aims to assist all patients and/or care givers in acquiring the relevant skills to perform securing of the stoma vent.

CRITERIA	Observed	Oral questioning (if applicable)
States frequency of tape changes		
Is able to list equipment needed		
Demonstrates preparation of tapes		
Demonstrates and explains removal of old tapes		
Ensures tube is central and explains importance of central positioning		
Identifies risk factors associated with using tapes for securing vent		
Demonstrates and explains observations required post procedure		

ASSESSMENT OUTCOME

Assessment decision : Competent	Not yet competition	etent
Action/further education required:		
Date of reassessment (if required)		
Assessment undertaken in ward/unit		
Patient/Carer's signature:		
Assessor's signature:	Designation:	Date:

Competency: Humidification

AIM: This competency aims to assist all patients and/or care givers in acquiring the relevant knowledge and skills to provide humidification to the stoma.

CRITERIA	Observed	Oral questioning (if applicable)	
States indications for humidification/nebuliser (e.g. dry secretions, increased work of breathing)			
States frequency for humidification/nebuliser on discharge (as per current requirements and alter as necessary)			
Demonstrates competence in setting up, using and cleaning nebuliser			
Explains why saline and not water is used for humidification (water is a known airway irritant)			
States indications for increasing/decreasing frequency of humidification (e.g. thick or runny sputum, change in weather)			
States indications for seeking assistance (e.g. sputum not responding to change in humidification techniques, sputum plugs, blood in sputum etc.)			
ASSESSMENT OUTCOME			
Assessment decision: 🗌 Competent 🗌 Not yet competent			

Action/further education required:

 Date of reassessment (if required)______

 Assessment undertaken in ward/unit______

 Patient/Carer's signature:

 Assessor's signature:
 Designation:

Glossary

Anaesthetic – local or general medicine to induce loss of sensation

Aspiration – when food and/or drink goes down the wrong way into the lungs instead of the stomach. This cannot happen if you have had a total laryngectomy and don't have a tracheoesophageal fistula (TOF) for voice prosthesis use

Chemotherapy - the use of anti-cancer (cytotoxic) drugs to destroy cancer cells

CT scan – computerised tomography scan. This type of scan uses x-rays to create detailed pictures of parts of the body

Decondition – to weaken

- Dehydrate to lose water or moisture
- Dysphagia difficulty swallowing
- **Epiglottis** the small cartilage flap that normally prevents food from going into the trachea when a person swallows
- **Gullet** the food pipe or passage by which food passes from the mouth to the stomach. Situated behind the windpipe, also known as the oesophagus

Humidified - moistened with water

Laryngectomy – an operation to remove the larynx or voice box

Larynx – the voice box

Lymph nodes – or lymph glands are small bean-shaped structures which act as filters for foreign bodies. There are many of these in the neck

- **Oesophagus** the food pipe or passage by which food passes from the mouth to the stomach. Situated behind the windpipe, also known as the gullet
- **PET scan** positron emission tomography scan. A specialised imaging test that uses a radioactive glucose solution to identify cancer cells in the body
- **Radiotherapy** the use of high-energy x-rays to destroy cancer cells in the treated area

Sputum – mucous matter coughed or spat up from the respiratory passages

Stoma – means "hole". In this booklet, stoma means the hole in the neck

Trachea – windpipe

Tracheostomy tube – a tube that is put into the windpipe

Y-suction catheter – a piece of tubing that is put down the tracheostomy tube to suck out any sputum

Yankeur sucker – a device used for sucking up any secretions *around* the tracheostomy tube

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