Caring for a stoma and voice prosthesis after a total laryngectomy

Speech and Language Therapy information for patients and carers

This leaflet explains more about returning to your everyday activities after your laryngectomy. If you have any further questions, please speak to a doctor or nurse caring for you.

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Introduction

This booklet will provide you with information relating to your communication, breathing and swallowing following your total laryngectomy (removal of voice box).

This information will complement any information you have been given verbally from the team.

If you have any other questions that the booklet does not answer, or would like further explanation, please ask your speech and language therapist whose details are in the back of the book.

What is a total laryngectomy?

A laryngectomy involves the removal of the voice box (larynx), separating the trachea (wind pipe) from the oesophagus (gullet). This procedure involves the creation of a permanent tracheal stoma (hole in the neck), through which you will breathe.

How will my breathing be affected?

The body has natural filtering and humidification systems in the mouth and nose. These heat, add moisture and filter the air that we breathe. After a laryngectomy, the air that you breathe will no longer pass through these systems.

To help maintain a healthy respiratory system, there are specially designed humidification systems which you will need to wear (see stoma care and humidification sections on pages 4 – 6 for further information).
Use of Heat Moisture Exchanger (HME)

The HME (Heat Moisture Exchanger) is a device which aids the humidification and filtering of the air you breathe.

There are various HME systems available; most commonly we use either the stoma cover 'bib' (ties around the neck), the stomafilter (sticky base plate with cassette), or both. Your therapist will recommend which is right for you.

It is important that you wear the HME system 24/7. The HME ensures that the air you breathe is warmed and filtered. This will in turn help to minimise the mucous you produce and minimise coughing and sputum plugs. It will also help keep the mucous thin and watery.

HMEs are available on prescription; your therapist will give you the details for this.

Stomafilter baseplates are available in different sizes, shapes and adhesive strengths. Your therapist will help to work out which one fits you best.

Applying and removing the Stomafilter

- Clean and dry the skin around the stoma
- Apply a skin prep and let this dry
- Peel the backing off the baseplate. Try not to handle the sticky side, as this will reduce its adhesive property
- Line up the hole in the baseplate with your stoma, gently stick it down and smooth out the sides, working from the inside outwards
- Rubbing the baseplate when stuck down will help the glue stick to your skin, making for a better seal
- Avoid creating air bubbles as these will reduce the stickiness of the baseplate
- Place the filter cartridge into the baseplate.

How often should I change the baseplate and filter?

The filter cartridge should be changed daily as required; more frequently if it becomes blocked with mucous.
The baseplate should be changed every 24 hours however there are some baseplates that are licensed to remain in place for up to 48 hours. Please check the manufacturer's guide.

Remove the baseplate if it becomes soiled with secretions/mucous, otherwise your skin will become very sore and irritated.

When you remove the baseplate, be gentle so that you do not pull or damage your skin. If you have a voice prosthesis, ensure that you secure the tab of the valve with your other hand to prevent accidentally pulling out the valve.

What should I do for extra humidification?

Sometimes you might require extra humidification, especially in winter when the air is very cold and dry. Humidification will help keep your secretions thin and watery and prevent crusting.

- Increase the frequency of your nebulising.
- Ensure you are well hydrated - drink plenty of water.
- Inhale steam through the stoma. (Fill a basin with hot water from the tap, then gently breathe in the steam vapour)
- Spray a fine mist over the stoma cover with an atomiser bottle. These empty bottles are available at most chemists, or speak with your speech therapist.
After surgery

The team involved in your care will teach you how to look after your stoma and the voice prosthesis. It is important to ensure that routine care is performed daily.

The following sections will show you how to care for your stoma and valve, including humidification, troubleshooting common problems and emergency procedures.

Care of the stoma

Remember - your stoma is your airway. Look after it.

Your stoma must be cared for regularly and on a daily basis. Cleaning should be performed a minimum of twice daily.

In the beginning, the stoma and voice prosthesis will require more frequent care and attention, because secretions often accumulate around the stoma and valve.

It is important that you become familiar with your stoma and know what it looks like. This way you can monitor things like secretions, the size, shape and colour of the stoma.

Humidification

Because of the change in how you breathe and the loss of the body’s natural air filtering system, it is important to ensure that you maintain a safe and healthy respiratory system. The team will recommend a regime which will include daily nebulising to help loosen and clear secretions. In the beginning you will need to do this more frequently compared with someone who had their surgery months or years ago.

As a minimum you should nebulise in the morning and at night to loosen any dried secretions and prevent mucous plugs.
Cleaning the stoma

Make sure you have all your necessary equipment to hand:

- A good light source
- Mirror
- Forceps (tweezers)
- Warm water
- Gauze/tissues/large cotton buds
- Waste bag
- Tape
- Clean hands
- Dilator/catheter
- Small pocket torch.

- A good light source and mirror allowing clear view into the stoma will make life much easier. Preferably have these free standing so that you have two hands free to perform the cleaning/care tasks. A small torch is also useful for checking inside the entrance to your stoma for debris.

- Work from the outside - inwards. Start with cleaning the skin on the outside of the stoma, working towards the inside and the voice prosthesis.

- Use warm water and gauze or swabs to moisten/loosen any crusted secretions or mucous from around the stoma and neck.

- Gently remove secretions with forceps and/or large cotton buds. If you have a voice prosthesis, be careful not to pull it out when doing this.

- Take care not to let any debris fall into the airway.

- If you have excessive crusting, try a nebuliser first to help loosen secretions and then use the tweezers.

- Do not probe too deeply and be careful not to remove crusts without loosening them first.

Changes to the appearance of the stoma

It is important that you become familiar with the normal appearance of your stoma. If the stoma is changing in size, shape or colour, you should contact your speech and language therapist or head and neck surgeon.
Showering and bathing after laryngectomy

It is important to ensure that water and soap do not enter the stoma when you are bathing or showering.

If possible use a shower hose rather than fixed shower head. Alternatively redirect the shower head so that the water falls below chest level.

Stand with your back to the direction of the water spray.

Shampoo and rinse your hair while bending over.

Your speech therapist will provide you with a special cover to wear when showering. You can also order a waterproof shower cover, available on prescription.

*Please note only certain baseplates are suitable to be used in the shower. Please check the manufacturer’s guide and ask your therapist for information.
What is Surgical Voice Restoration (SVR)?

Surgical Voice Restoration (SVR) is the method of using a tracheoesophageal voice prosthesis to produce voice after a total laryngectomy.

A small hole (puncture) is made in the back of the wind pipe (trachea) creating a channel between your trachea and the swallowing passage (oesophagus), through which air can pass. A voice valve (tracheoesophageal prosthesis) is inserted into the puncture.

This procedure can be done at the same time as your laryngectomy (primary procedure) or after your laryngectomy (secondary procedure).

We aim for most people to have the option of SVR. In some cases this is not recommended. This might be due to the extent of the surgery, or other factors which may affect the individual person’s ability to care for or achieve speech with this method.

Your speech therapist and surgeon will discuss this with you.
Routine care of the voice prosthesis

Make sure you have all your necessary equipment:
- A good light source
- Mirror
- Forceps (tweezers)
- Dilator/catheter handy
- Voice prosthesis cleaning brush
- Warm water
- Gauze/tissues/large cotton buds
- Waste bag
- Tape
- Clean hands
- Small pocket torch.

It is mostly recommended to clean the valve while it is still in the tract (in situ). If this is not recommended your clinician will tell you.
- The voice prosthesis should be cleaned as often as the stoma.
- Make sure you have a good light source and that you use a magnified mirror so you can see the valve clearly (using a small pocket torch will also help).
- Use the cleaning brush provided by the speech therapist.

Take care not to be too harsh with cleaning as this may cause damage to the valve.

1. Moisten the cleaning brush with water, shaking off any excess water

2. Gently insert the cleaning brush into barrel of the prosthesis. Do not push it too far, as this might damage the valve

3. Use a continuous turning motion

4. Gently withdraw the brush from the barrel, maintain turning motion, taking care not to dislodge the prosthesis

5. Clean the brush and repeat as often as necessary

Change the tape securing the valve safety tab as frequently as required.
How can I maximise the life of my voice prosthesis?

As you will be aware, your voice prosthesis has a limited life span and will eventually require replacement. This is because the mechanism that allows you to swallow safely and assist voice production begins to fail. When this happens, you may experience leakage of fluids through the valve into your airway on swallowing, or difficulties with your voice. Often these issues arise due to a build-up of candida (a type of fungus) amongst other micro-organisms on the back of the valve. The life span of a voice prosthesis varies, however there are a number of things you can do to help extend the life of your valve and thus reduce the frequency of your changes:

- **Oral hygiene** - Brush your teeth at least twice a day and preferably after meals
  - Floss every night
  - If you wear dentures or a removable plate, clean and sterilise them as you have been advised by your dentist

- **Dental hygienist** – ensure a visit to the hygienist at least once in six months

- **Diet** – avoid excessive alcohol, white bread in large amounts and food/drink high in sugar content, as these encourage the growth of candida

- **Voice prosthesis care** – keep this clean throughout the day and brush through the prosthesis after eating to clear any debris that may accumulate around the back

- **Dry mouth** – if you suffer from a very dry mouth, try the following:
  - drink lots of water and try sparkling water
  - request a prescription for Biotene gel or artificial saliva agent e.g. Xerotin
  - rub the inside of your mouth with olive oil

- **Diabetes** – if you suffer from this, ensure it is well controlled either through diet management or medication. Seek advice from your GP and/or Diabetes Nurse.

**Cleaning your laryngectomy accessories:**

It is very important to keep very clean your cleaning brush and any stents you may have for your stoma (e.g. lary tubes, buttons, stoma studs etc.). To ensure this, follow these steps daily:

1. Using soapy water, wash your prosthesis brush and stoma stents. Clean off any dirt, mucus etc., especially from the bristles of the brush. For stoma stents, use a soft sponge brush to clean through the stent as well

2. Immerse the brush and stents in a small amount of Corsodyl mouthwash (0.2%) for 15 minutes

3. Rinse with water and air-dry
Problem: the voice prosthesis has come out

Don’t panic!

Remember to keep your mouth open and try not to swallow when there is nothing in your TEP. Try to insert either the **dilator or catheter** immediately and tape securely to your neck. Contact your speech and language therapist (SLT) Monday to Friday, 9am-5pm on 020 8725 1163.

If you cannot contact your speech and language therapist, make sure the dilator or the catheter is secure in your TEP.

The catheter may be a more comfortable option if you cannot see a speech and language therapist that day.

If using the catheter, make sure you tie a knot in the free end and tape firmly to your neck.

Within working hours, if you cannot insert the dilator or catheter, go directly to the ENT Clinic in Lanesborough Wing.

The puncture will close within 1-2 hours if there is no dilator, catheter or voice prosthesis in place.

**Out of Hours arrangements:**

1. If possible, phone 020 8672 1255 (hospital switchboard) and ask them to bleep the ENT doctor on call. The ENT doctor will arrange a time to see you in the A&E department.

2. If you cannot use the phone or in an emergency, go to A&E and ask to see the on-call ENT doctor.

The ENT doctor will insert a catheter to keep the puncture site open. They will then leave Speech and Language Therapy a message and we will make an appointment to see you during working hours to fit a new voice prosthesis.
Problem: leaking voice prosthesis

How do I know my voice prosthesis is leaking?
The most common symptom of a leaking valve is coughing when drinking.

What should I do?
☐ Check to see if the valve is leaking
☐ Give it a clean
☐ Check it again

How do I check for leaking?
☐ Get a drink - preferably something coloured (e.g. Ribena, orange juice, raspberry juice, tea)
☐ Set up the mirror and light so that you can see the voice prosthesis clearly
☐ Take a small sip of liquid, then look for any liquid coming through or around the prosthesis as you swallow
☐ If there is liquid coming through the prosthesis, give it a clean. Sometimes food particles can get stuck and hold the flapper open
☐ Check for leakage again after cleaning the valve
☐ If liquid is leaking around the voice prosthesis or it continues to leak through the middle after you have cleaned it, contact the speech and language therapy team for an appointment.

NOTE: If the prosthesis is leaking, it is important that you don’t delay having it seen to. Continual leaking can potentially cause a chest infection.

What causes leakage?
The most common reason for a leaking valve is general wear and tear. The valve will need to be replaced.

There are other reasons a valve will leak, e.g.
☐ food stuck in the flapper valve holding it open
☐ an inverted flapper due to excessive cleaning or pushing the cleaning brush too far through the valve
☐ Candida (fungal) invasion of the valve.

It is important to recognise and learn to troubleshoot some of these problems so you can manage them at home.
Problem: my voice has stopped working

Sometimes the voice can stop working. Often this is because the valve has become blocked.

- Check that the valve is securely in place and not protruding from its usual position
- Give it a good clean
- Have a drink of something
- Check that you are not losing air from the stoma as you voice
- Try the voice again
- Try not to force the voice as this can cause the muscles in the back of the throat to tighten and restrict the voice even more.

If you have tried and repeated all of these steps, you should contact the speech and language therapist.
Essential equipment

You should carry the following items with you all the time:

- Spare HME (e.g. baseplate and cassette, stoma cover)
- Torch, mirror
- Dilator or catheter in case the valve comes out
- Voice prosthesis cleaning brush
- Tissues/gauze and large cotton buds

Emergency resuscitation

Due to the anatomical changes post-surgery, mouth-to-mouth resuscitation would prove useless in an emergency situation. In the event of an emergency, mouth-to-stoma resuscitation is required. For further information, please consult the ‘National Association of Laryngectomee Clubs’ Emergency resuscitation leaflet.
What support will be available once I go home?

GP:
As always, your GP is responsible for your general medical care.

District Nurse:
He/she will visit you very soon after you leave hospital, to make sure that you are managing at home and to help you with caring for your laryngectomy if necessary.

Speech and Language Therapist:
He/she will continue to see you to help you with developing your new method of communication, as well as any swallowing issues and problems with your laryngectomy stoma.

Combined Head and Neck Clinic:
The whole Head and Neck Team is available at this clinic. After your surgery, you will attend this clinic approximately once every 4-6 weeks for the first year.

Contact us
If you have any questions or concerns, please contact **St George’s Hospital Head & Neck Team** on 020 87251163 (Monday to Friday, 8:30am to 4:30pm). Out of hours, please ring the hospital and ask to speak to the ENT SHO.

Contact details

Speech and Language Therapy 020 8725 1163
Dietetics 020 8725 0518
Clinical Nurse Specialist 020 8725 3263 / 3401
ENT appointments 020 8725 0007

Where can I order my laryngectomy supplies?

Countrywide Supplies 0800 783 1659
Fittleworth Medical 0800 023 2851

Your Speech & Language Therapist will advise you with which company you have been registered.

Useful sources of information
If you require any further information, speak to your speech and language therapist, doctor or clinical nurse specialist.
The following websites are useful for specific information about laryngectomy (NALC) and more general information about cancer (Macmillan).

National Association of Laryngectomee Clubs (NALC) - www.laryngectomy.org.uk

Macmillan Cancer Support - www.macmillan.org.uk

For more information leaflets on conditions, procedures, treatments and services offered at our hospitals, please visit www.stgeorges.nhs.uk

Additional services

**Patient Advice and Liaison Service (PALS)**
PALS can offer you on-the-spot advice and information when you have comments or concerns about our services or the care you have received. You can visit the PALS office between 9.30am and 4.30pm, Monday to Friday in the main corridor between Grosvenor and Lanesborough Wing (near the lift foyer).
**Tel:** 020 8725 2453  **Email:** pals@stgeorges.nhs.uk

**NHS Choices**
NHS Choices provides online information and guidance on all aspects of health and healthcare, to help you make decisions about your health.
**Web:** www.nhs.uk

**NHS 111**
You can call 111 when you need medical help fast but it's not a 999 emergency. NHS 111 is available 24 hours a day, 365 days a year. Calls are free from landlines and mobile phones.
**Tel:** 111

Space for notes and questions