

Living with Laryngeal Cancer - A Quick Guide



Contents

This is a brief summary of the information on 'Living with laryngeal (voice box) cancer' from CancerHelp UK. You will find more detailed information on the website.

In this information there are sections on

- Coping with laryngeal cancer
- Breathing stomas
- Speaking after laryngectomy
- Diet after cancer of the larynx
- Sex after laryngectomy
- What to ask your doctor
- Laryngeal cancer organisations

And how do you find the words? You may have children to think about.

The coping with cancer section of CancerHelp UK has lots of information you may find helpful. There are sections on

- Your feelings
- Talking to people: who and what to tell
- Talking to children
- How you can help yourself
- Who else can help you
- Financial support
- Mortgages, pensions, loans and insurance

Coping with laryngeal cancer

It can be very difficult to cope with a diagnosis of cancer, both practically and emotionally. You are likely to feel very upset and confused at first. You may also have to come to terms with no longer being able to speak and breathe normally. Having your larynx removed can be very upsetting and it takes time to adjust to this.

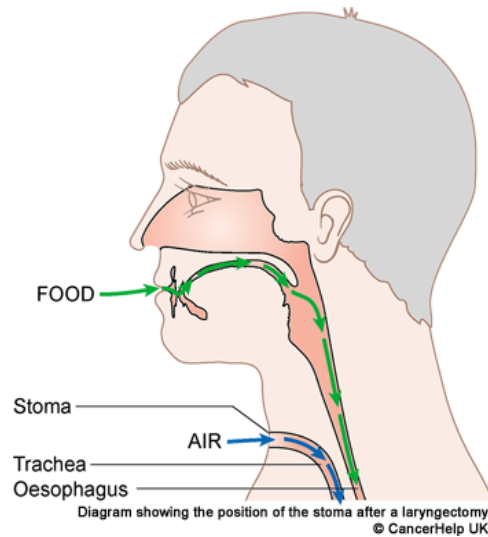
As well as coping with the fear and anxiety that a diagnosis of cancer brings, you have to work out how to manage practically. There may be money matters to sort out. Who do you tell that you have cancer?

There is a network of clubs for people who have had their larynx removed. You can get details of your local club from the National Association of Laryngectomee Clubs.

Breathing stomas

Starting out with a breathing stoma

A breathing stoma is a hole (opening) made in the skin in front of your neck to allow you to breathe. It is at the base of your neck. Through this hole, air enters and leaves your windpipe and lungs.



If you still have your voice box and this hole is temporary, it is called a tracheostomy. The stoma is held open by a tracheostomy tube. If you have had your whole voice box removed, you will have a permanent (laryngectomy) stoma to breathe through. You need this because the connection between your windpipe and mouth has gone.

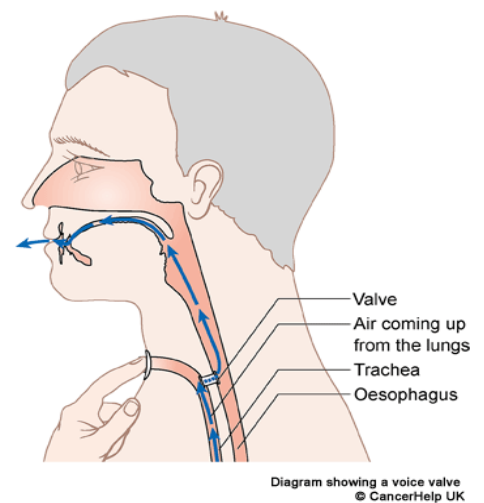
Stoma tubes

If you've had your whole voice box removed, you will have a laryngectomy tube in your stoma at first. This keeps your new airway open. The tube can come out once your stoma heals. This may take a few weeks.

Both laryngectomy and tracheostomy tubes can have a small opening. If you've had a tracheostomy, you can put your finger over this hole so that you can speak. If you don't do this, air won't pass up into your voice box. If you have had your voice box removed, you block the hole when you want to use your speech valve.

If you have a speech valve, you may want to use a hands free tube later on. This automatically closes the stoma when you are using your speech valve. So you won't have to put your hand up to cover the hole when you want to say something.

Below is a diagram of a voice valve.



Life with a breathing stoma

Before you leave hospital, your physiotherapist and nurses will teach you how to look after your stoma and breathing tubes. It helps to practice as much as you can. You will then know what to do when you get home. It helps if someone you live with or see regularly also learns what you have to do.

Looking after the stoma and tubes

Your stoma nurse will arrange to visit you at home to check on how you are getting on. You will need to keep the air that you breathe in moist. It helps to drink plenty of fluids, and spray sterile salt solution (saline) into the tube, or use humidifiers in your home. Some people use filtering and moistening systems. It is a good idea to



cover your stoma to keep out dust, pollen and other objects. You will need to keep the stoma, tubes and speech valves clean.

Your sense of smell and taste

When you have a laryngectomy, your sense of smell will not be as good as it used to be. You can learn a technique called the polite yawn to improve it. Learning this technique can help improve your taste too. You can also add more flavouring (using spices or herbs for example) to your food.

Showering, shaving and swimming

You will be able to shower and have a bath but must not get water into your stoma. Shower covers are available. Your neck may be numb for a few months after your surgery. To avoid cutting yourself while shaving, it may be best to use an electric razor. If you want to swim, you will need to have special equipment and training. Other water sports may not be possible.

Effects on daily life

When you have a stoma it is difficult for you to lift heavy things. It is important to avoid constipation because you can't strain when you go to the toilet. Stopping smoking will improve your general health and reduce your chance of getting another cancer in the head and neck area.

Speaking after laryngectomy

If you have had your larynx completely removed you will lose your voice. Before your operation a speech therapist will discuss the possible ways you can communicate after your surgery. There are three main ways to learn to speak again.

Voice prosthesis (Tracheo oesophageal puncture – TEP)

This is the most common way to restore speech after laryngectomy. Your surgeon makes an opening between your windpipe and food pipe (oesophagus), at the back of your stoma. They put a small, one way valve into the opening. It allows you to make sounds by pushing air from your lungs through the valve and up into your mouth. With practice, you may be surprised at how well you can be understood.

Oesophageal speech

To speak in this way, you move air down into your foodpipe (oesophagus) and then back up into your mouth and you shape your mouth to create speech. Nowadays, many people find it easier to use a voice prosthesis, but oesophageal speech has the advantage of not needing any equipment.

Electrolarynx

An electrolarynx (electronic larynx) is a battery operated machine that produces sound for you. They are usually about the size of a small electric razor. You hold the machine against your neck, or fit a small tube into the corner of your mouth. When you press the button on the machine, it makes sound. If you move your tongue and mouth you can form the sounds into words.



Example of an electrolarynx

Diet after cancer of the larynx

Cancer of the larynx can affect how you eat and drink.

Difficulty swallowing

Radiotherapy can make your throat very sore and you will almost certainly have difficulty swallowing for a while. Surgery to your throat will also make swallowing difficult until you recover. You may find a soft diet easier to manage if you have a painful throat. There is information about soft diet in the coping physically section of CancerHelp UK.

Loss of taste

If you have a laryngectomy, your sense of smell will be poorer than it was. In turn, this reduces your sense of taste. You may find you need to eat more strongly flavoured foods. Gravies and bottled sauces can help to add flavour to a meal. Or try adding garlic, lemon juice, herbs and spices.

Weight loss

People have often lost quite a bit of weight by the time they are diagnosed with laryngeal cancer. After your treatment, you

need to build yourself up again. You (or whoever usually provides your meals!) may need to re-think your diet. If you are really off your food, eating little and often is easier to cope with than a huge plate of food. Ask your doctor to prescribe some special drinks that you can sip through the day as well as eating meals.

Sex after laryngectomy

A laryngectomy changes the way you speak and breathe and also your physical appearance. These changes may make you feel less confident about sex.

You may be very conscious about your stoma and think that your partner finds it unattractive. Covering your stoma with a scarf, tie or high necked jumper may help you to feel less aware of it. If you are able to talk to your partner about your worries, this can help you both to gradually get used to your new situation. Things will start to feel less awkward. A caring and loving partner can help to ease your concerns.

Sometimes difficulties with speaking will affect your lovemaking. If you have learned another way of speaking, then you can use this. But it may take more effort and can change some of the spontaneous moments you and your partner may be used to. Remember, talking is not necessary during many sexual situations. Eye contact and touching are very powerful ways of showing your feelings. There is more about sex after cancer in the coping with cancer section of CancerHelp UK.



What to ask your doctor about living with laryngeal cancer

- How will my treatment affect me?
- Will I ever get back to normal, or will I have some long term effects?
- How will my speech be affected?
- How will I communicate with people after my operation?
- How will my breathing be affected?
- Who can help me with my breathing stoma at home?
- If I have difficulty eating, who can I go to for help?
- Will I need a special diet?
- Is there anything I shouldn't eat?
- Will I need any extra vitamins or other diet supplements?
- How do I see a dietician?
- Will I be able to go back to work?
- Where can I get help with claiming benefits and grants?
- What practical help is available?
- Why did this happen to me?
- Are my children at risk of getting cancer of the larynx?
- Where can I get help dealing with my feelings?
- Can you refer me for counselling?
- Do I have to pay for counselling?
- Could you refer me to a Macmillan nurse?

National Association of Laryngectomee Clubs
 Phone: 020 7730 8585 (9.00am - 4.00pm, Monday - Friday)
 Website: www.laryngectomy.org.uk

The Cancer Laryngectomy Trust
 Phone: 01422 205522
 Email: info@cancerlt.org
 Website: www.cancerlt.org

Royal College of Speech and Language Therapists (RCSLT)
 Phone: 020 7378 1200
 Website: www.rcslt.org
 Email: info@rcslt.org

Changing Faces
 Phone: 0845 4500 275
 Website: www.changingfaces.org.uk
 Email: info@changingfaces.org.uk

Laryngeal cancer organisations

Cancer Research UK
 Main website: www.cancerresearchuk.org
 Patient information website:
<http://cancerhelp.cancerresearchuk.org>
 Cancer Information Nurses phone: 0808 800 4040



Notes

More information

For more information about laryngeal cancer, visit our website
<http://cancerhelp.cancerresearchuk.org>

You will find a wide range of detailed, up to date information for people affected by cancer, including a clinical trials database that you can search for cancer trials in the UK. You can view or print the information in a larger size if you need to.

For answers to your questions about cancer call our Cancer Information Nurses on
0808 800 4040 9am till 5pm Monday to Friday

Adapted from Cancer Research UK's Patient Information Website CancerHelp UK in January 2012. CancerHelp UK is not designed to provide medical advice or professional services and is intended to be for educational use only. The information provided through CancerHelp UK and our nurse team is not a substitute for professional care and should not be used for diagnosing or treating a health problem or disease. If you have, or suspect you may have, a health problem you should consult your doctor. © Cancer Research UK 2012. Cancer Research UK is a registered charity in England and Wales (1089464) and in Scotland (SC041666).