

# Glossectomy

## Information for patients, relatives and carers

### Introduction

This booklet is designed to give you information about glossectomy. We hope it will answer some of the questions that you or those who care for you may have at this time. This booklet is not meant to replace the consultation between you and your medical team, but aims to help you understand more about what is discussed. If you have any concerns about your illness or your treatment, please contact your surgeon or clinical nurse specialist (CNS).

### What is glossectomy?

Glossectomy is the surgical removal of part or all of the tongue. This may be used to remove cancer. Some healthy tissue around the edge of the tumour will also need to be removed. This is to help reduce the risk of any cancer cells being left behind. How much of the tongue is removed depends on the size of the cancer and where it is.

- If the cancer is small when it is removed, the hole will be either stitched or left to close naturally
- If the cancer is larger, the hole will be filled by a piece of skin and/or muscle known as a 'flap'

A flap is a piece of tissue that is transferred from one part of your body, such as your forearm or thigh, to the tongue. Your plastic and reconstructive surgeon will tell you more about how this is done.

We will send tissue samples of your cancer removed during the operation to the laboratory so they can be examined under a microscope. Depending on the results, you may need further treatment.

Your individual treatment will be carefully planned and the medical team will explain this to you. Please remember that this leaflet is a general guide and your needs may be slightly different.

The average length of stay in hospital for a glossectomy is usually one to two days, however, it can be up to two weeks if you have reconstructive surgery with a flap.

### What happens before I come into hospital?

The doctors will discuss the surgery with you at your outpatient appointment. Please ask if you do not understand any terms they use. You will also be given the opportunity to see your head and neck CNS. He/she will be your key worker and will be available for advice and further information. Please ensure you bring a list of your current medications to all appointments.

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## **Pre-assessment**

You will also have two pre-treatment assessments. The first assessment is to check your current health issues and factors that may affect the surgery. It involves being assessed by nurses and, sometimes, an anaesthetist. You may have blood tests, a chest x-ray and a tracing of your heart called an ECG (electrocardiogram).

The second assessment is to meet key members of the head and neck team, including the:

- clinical nurse specialist (CNS)
- speech and language therapist (SLT)
- dietitian

This will help you to get to know the head and neck team and understand their role in your treatment and recovery. The roles of these professionals will be further described later in the leaflet.

The second pre-assessment is also an opportunity to do further assessments. We will aim to arrange assessments for the same day or on days when you are attending the hospital for other investigations or appointments to reduce your number of visits.

## **Consent**

We will ask for your consent before we perform any surgery. Your doctor will carefully explain the procedure involved, although details will vary according to each individual case. We will then ask you to sign a consent form. No medical treatment can be given without your written consent.

If you do not understand what you have been told, let the staff know straight away so they can explain again. You may also find it useful to write a list of questions before your appointment and to have a relative or friend with you to help you remember the discussion when the treatment is explained.

All clinical communications copied to your GP may also be sent to you, at your request. Please discuss this with your CNS.

## **Second opinion**

You may wish to get a second opinion about your treatment and diagnosis from another specialist. Please discuss this with your surgeon.

If you do not know who to contact, we can suggest appropriate specialists for you to consider and will provide copies of your medical notes, x-rays and scans to them. This may help you avoid having to repeat unnecessary tests. If you wish, we will also make the referral for you.

Please note that getting a second opinion may delay the start of your treatment so discuss this with your surgeon.

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## What are the possible risks with this operation?

There are risks with any operation, so it is important that you are aware of them. If you have any concerns please discuss them with your surgeon, CNS or SLT. This list describes some common risks associated with surgery, but this does **not** replace the discussion you will have with your surgeon about the risks relevant to your particular case. You may experience **some** of the following:

### **Blood clot**

Drain tubes are put in during surgery to drain off excess fluid to help prevent clots from forming. However, blood may collect under the skin and form a clot (haematoma). If this occurs it may be necessary to return to the operating theatre to remove the clot and replace the drains.

### **Numb skin**

Occasionally, you may find that the skin around your jaw/neck may be numb after the surgery and this can last for several months. This may improve gradually but you should not expect the numbness to disappear entirely.

### **Speech and swallowing**

Your jaw is used for speech, chewing and swallowing. It is likely that after surgery there will be some difference in how your speech sounds. Swallowing may also be different. You may need to see a SLT for advice.

### **Altered taste**

Your taste may be affected depending on how much of your tongue is removed.

### **Flap failure**

The reconstruction of the tongue often requires microsurgery. The flap has to be attached to very small blood vessels in the neck to re-establish blood flow. Sometimes this blood flow is interrupted and the flap 'fails'. This will mean that further surgery is needed which may result in an additional or larger scar.

The following risks are possible after any major operation. These include:

### **Chest infection**

You can help by practising deep breathing exercises and following your physiotherapist's instructions. If you smoke, we strongly advise you to stop.

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## **Wound infection**

Antibiotics will usually be given through a drip to help reduce the risk.

## **Deep vein thrombosis (blood clot in the leg)**

Major surgery carries a risk of clot formation in the leg. A small dose of heparin (blood thinning medication) will be injected once or twice daily until you go home. You can help by moving around as much as you are able and regularly exercising your legs. You may also be fitted with some support stockings for the duration of your stay in hospital. If you smoke, we strongly advise you to stop.

## **Pulmonary embolism (blood clot in the lungs)**

Rarely, a blood clot from the leg can break off and become lodged in the lungs. This is treated with anticoagulant (blood thinning or clot dissolving) medication. Your doctor will explain more if this rare event occurs.

## **Bleeding**

A blood transfusion may be needed. Very rarely, further surgery may be needed to stop the bleeding. If you are unable to receive blood products, please discuss this with your CNS.

## **How can speech and language therapy help me?**

The effects of surgery on your speech and swallowing will depend on how much of the tongue is removed and how it is repaired. You may find you have difficulties with speaking and swallowing after your operation. Once you are feeling stronger after surgery, the SLT will visit you on the ward. He/she will be able to:

- help you understand the changes in speech and swallowing that you may experience
- offer advice and support to help you adapt to these changes
- provide you with support and advice once you go home, if this is needed

The two main areas the therapists may help you with are:

### **Speech/communication**

- Exercises to improve the strength and range of tongue movements
- Exercises to improve your speech, even if all of your tongue is removed. There are various alternative communication options which could help you if needed

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## Swallowing

Assessing your swallowing, he/she will identify if there is any risk of food and drink going down the wrong way into the lungs. Advise you on various head positions and different swallowing techniques which may make swallowing easier and safer. Along with the dietitian, they will advise you on foods which are enjoyable, safer and easier for you to swallow

## How can the dietitian help me?

Working closely with other members of the team, the dietitian will advise you on the most suitable way for you to meet your nutritional requirements. He/she will assess your usual eating habits and will advise on changing to different types of food, if necessary.

If you are unable to take anything by mouth, you may need to have a feeding tube. This will be one of the following:

- a nasogastric (NG) tube passed through your nose into your stomach during the operation
- a radiologically-inserted gastrostomy (RIG) tube passed through the wall of your abdomen into the stomach. This can be carried out either pre- or post-operatively. This is only needed if you are likely to need help with nutrition for a longer period of time. We will give you a separate leaflet about RIG tubes

The dietitian will advise you on what will be given through the feeding tube. The tube will remain in place until you are managing enough food by mouth. The dietitian will check your progress regularly and discuss it with you.

## Will I have a scar?

Glossectomy doesn't usually leave you with a scar on your face. It is sometimes necessary to have the lymph glands in the neck removed at the same time, to prevent the cancer spreading. This is called a neck dissection. This will mean that you will have a scar on your neck which will be visible. We have a separate information leaflet about this operation.

If you have flap reconstruction, then you will have a scar on the area of the body where the flap was removed from; this will improve with time but will remain visible. If the flap was taken from your arm or thigh, the hair will grow on the new area of your tongue.

If scarring is a concern to you, your CNS can offer you help and advice on ways of hiding the scar once the wounds have fully healed.

## What happens during the operation?

Every person has a slightly different recovery depending on the extent of the operation. Your tongue and neck may be quite swollen after the operation. Generally, you will return to the ward after your surgery, but you may need a short stay in the intensive care unit or high dependency unit for the first 24 hours after surgery.

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Occasionally, you might need to have a temporary opening in your windpipe called a tracheostomy to help you breathe; your CNS and/or surgeon will explain more about this. It may be required for a few days after the operation until the swelling has improved.

The following sections outline the general stages you will experience before and after your operation.

### **Before surgery**

Try to build yourself up before surgery and eat and drink healthily (fruit, vegetables and protein). If you have lost weight or are underweight, have regular high energy/protein snacks.

If you are a smoker and/or you drink alcohol or drink alcohol above the recommended guidelines (14 units a week), try to cut down and stop if possible.

### **Enhanced recovery programme (ERP)**

Some patients will take part in the ERP. The programme will be discussed with you in greater detail at your pre-treatment appointment, if appropriate.

If it is recommended and you agree to take part, we will ask you to drink some carbohydrate drinks the day before and the day of surgery. We ask you drink four pre-op carbohydrate drinks the evening before surgery, and two pre-op carbohydrate drinks on the morning of surgery. This is safe to do and has been agreed by the surgical and anaesthetic team.

### **Day of surgery**

You will need to have nothing solid to eat from midnight before the operation; you can, however, have clear fluids (water, squash tea with no milk) up to four hours before the surgery. The exception to this is if you are taking part in the ERP, in which case you will be asked to have two pre-op carbohydrate drinks two hours before the surgery.

The operation will take approximately one to two hours if no reconstruction is required and eight to ten hours if reconstruction is needed.

After the operation we will take you to the recovery unit where we will monitor you until you're fit enough to return to the ward.

### **Day 1**

After your operation you may have the following:

- an intravenous infusion (drip) in your arm for replacement of fluids and giving your medications such as pain relief
- a catheter to collect your urine
- a feeding tube
- a tracheostomy in your neck to help with your breathing

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- a plaster cast if your flap was taken from your arm or a dressing if taken from the hip or thigh
  - a warming blanket
  - drains collecting fluid from your operation site in the neck

Your relatives may visit you according to the ward visiting times. Please check times with the ward.

You will initially need to be nil by mouth (nothing to eat or drink) but, if you have a feeding tube, then you can be started on a small amount of food through your feeding tube.

## **Day 2**

- The next day you will be more alert
- You will continue to be monitored hourly if you had a flap, or every four to six hours if no reconstruction was required
- The nurses may help you to sit in a chair
- If you are mobile enough, we will remove your urinary catheter
- If only a small amount of your tongue was removed then you may be able to go home once you are eating, drinking and your pain is well controlled

## **Day 3–5**

- The nurses will continue to monitor you every two to six hours
- Your catheter, drains and warming blanket may be removed
- If you have a tracheostomy this may be removed
- Intravenous fluids may be stopped
- The physiotherapist will help you increase your mobility if necessary

## **Day 6-10**

- Nurses will continue to monitor you every four to six hours
- The speech and language therapist and dietitian will help you work out what food and fluids you can manage, with guidance from your surgeon

## **What happens after the operation?**

You will be seen by the doctors, nurses, dietitian, speech and language therapist and prosthetist regularly to review your progress and offered support and advice. The doctors will let you know when you can begin to eat and drink. At first your tongue will be bulky and swollen inside your mouth but this will reduce gradually. Any stitches on the tongue are usually dissolvable.

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Stiches to the nose and face will be removed five to seven days after surgery. Any stitches or clips in your neck, arm or leg are usually removed after about 10 days. If you have a plaster cast on your arm this will be removed before you go home.

A discharge date will be discussed and decided depending on your recovery. The nurses on the ward will plan any extra care you may need after you leave hospital, such as visits from the district nurses if you need a dressing.

## Will the operation be painful?

There will be some pain in your mouth and neck initially after your surgery. The nurses will be monitoring your pain regularly and will give you painkillers as necessary. With any operation, it is normal to experience some pain however, we aim to ensure that this is well controlled; please let the nursing staff know if you experience any problems with pain. In some cases, we may give you a Patient Controlled Analgesia (PCA) pump which allows you to give yourself painkillers by pressing a button.

## What will happen after I go home?

Once you are able to go home, we will give you an initial supply of medication and dressings if you need them. If you need further supplies you will need to get them from your GP. You may need to attend your GP surgery for dressings for your leg or arm wounds. If you are unable to get to your GP for any reason we will arrange for a district nurse to visit you at home.

You will receive a follow-up appointment to attend the week after you have left hospital to check on your progress and to discuss the results of your operation. At this appointment we will discuss whether or not further treatment is needed.

Any additional treatment usually involves radiotherapy (specialised x-ray treatment) and possibly, chemotherapy (drug therapy). If you need further treatment the doctors will discuss this with you and give you further written information then. These treatments can be given at Charing Cross Hospital or your local oncology unit.

It is important that you make a list of all medicines you are taking and bring it with you to all your follow-up clinic appointments. If you have any questions it may help to write them down as you think of them. It may also help to bring someone with you when you attend your outpatient appointments.

## When can I go back to work?

This depends on the type of surgery you have had and if you need further treatment. You should discuss this with your surgeon. You should not lift heavy items for a minimum of four weeks after you go home. Ask the nurses on the ward for a fitness to work certificate to cover you while you are in hospital. If you need more time off work you can get further certificates from your GP.



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## When can I drive?

Do not drive until your strength and speed of movement are back to normal, as you must be able to perform an emergency stop and turn your neck sufficiently for good visibility. You should also make sure that you are not drowsy from any painkillers and that your concentration is good. Discuss this with your doctor before driving if you are not sure.

It is important to tell your insurance company that you have had an operation to ensure that you are covered in the event of an accident.

## When can I have sex?

In most cases, you will be able to have sex once you have recovered from your operation and your wound is fully healed. This type of surgery may affect the way you feel about yourself. If you would like to discuss any concerns, please speak with your CNS.

## How to contact us

Imperial College Healthcare NHS Trust has a **Macmillan navigator service**, which can answer questions on behalf of the relevant CNSs. Navigators, will also refer you to CNS teams, and to other specialist clinical staff, as needed. The service is available Monday to Friday 08.00–18.00.

Telephone: **020 3313 0303**

Outside of these hours, please contact your GP or phone NHS 111.

## Further sources of support and information

### Macmillan Cancer Support

Support Line: **0808 800 000** (Monday to Friday, 09.00-20.00)

[www.macmillan.org.uk/](http://www.macmillan.org.uk/)

### Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith hospitals

The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide support, practical and signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs.

The centre is located on the ground floor of Charing Cross Hospital, telephone: **020 3313 0171** and is open (except bank holidays):

- Monday and Friday 09.00-17.00 (volunteers only on Fridays)
- Tuesday, Wednesday, Thursday 09.00-16.00

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The infopod is located on the ground floor of the Garry Weston Centre at Hammersmith Hospital, telephone: **020 3313 4248** and is open (except bank holidays):

- Monday and Tuesday 09.00-17.00
- Wednesday, Thursday, Friday 09.00-16.00

### **Maggie's Cancer Caring Centre**

Maggie's is a cancer charity that provides the emotional, practical and social support that people with cancer may need. The centre combines striking buildings, calming spaces, professional experts offering professional support and the ability to talk and share experiences with a community of people who have been through similar experiences. Designed by leading architects, Maggie's centres are warm, friendly and informal places full of light and open space with a big kitchen at their heart.

Maggie's west London is located in the grounds of Charing Cross Hospital but is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information please call **020 7386 1750**.

### **How do I make a comment about my visit?**

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at [imperial.pals@nhs.net](mailto:imperial.pals@nhs.net) The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street  
London W2 1NY

Email: [ICHC-tr.Complaints@nhs.net](mailto:ICHC-tr.Complaints@nhs.net)

Telephone: **020 3312 1337 / 1349**

### **Alternative formats**

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team: [imperial.communications@nhs.net](mailto:imperial.communications@nhs.net)

### **Wi-fi**

Wi-fi is available at our Trust. For more information visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)