

Maxillectomy (partial or total) without reconstruction

Information for patients, relatives and carers

Introduction

This booklet is designed to give you information about partial or total maxillectomy without reconstruction. 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 maxillectomy?

A maxillectomy is the surgical removal of part or all of the upper jaw. This is to remove the cancer. Some healthy tissue around the edge of the tumour will also need to be removed, to help reduce the risk of any cancer cells being left behind. How much of the upper jaw is removed depends on the size of the cancer and where it is. Removing part of the upper jaw may include some teeth. The area removed is then replaced in one of the following ways:

- making a special denture called an 'obturator' which fills the space left by the surgery, which is removed daily for cleaning
- filling the space with a skin, muscle and/or bone 'free flap'. This is known as autologous reconstruction. 'Free flap' is the name for the tissue that is transferred from one part of your body, such as your arm, back or leg to the jaw. Your plastic and reconstructive surgeon will explain how this is done and explain the pros and cons of each type of flap. There is a separate patient information leaflet to discuss maxillectomy with free flap reconstruction.

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 only a general guide and we will give you information specific to your particular needs.

The average length of stay in hospital for a maxillectomy is usually five to seven days.

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 words or terms they use. You will also be given the opportunity to see your head and neck CNS. They will be your key worker and can give you advice and further information. Please ensure you bring a list of your current medication to all appointments.

Pre-assessment

You will have two pre-treatment assessments. The first assessment is to check your current health 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 electrocardiogram (ECG).

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)
- dietician
- maxillofacial prosthetist

This will help you to get to know the head and neck team and understand their role in your treatment and recovery. You can find out more about the roles of individual members of the team later in the leaflet. This appointment also allows us 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 can 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.

What are the possible risks with this operation?

There can be risks with any operation and 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 upper 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.

Tightening of the jaw muscles

The muscles of your jaw will be affected by the surgery, and you may experience pain or difficulty opening your mouth wide. You will need to see your prosthetist or SALT for advice.

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

Chest infection

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

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.

What is the role of the maxillofacial prosthetist?

Before surgery you will have dental impressions taken by the maxillofacial prosthetist in the oral surgery clinic. These impressions will be used to construct a temporary splint and denture that will be altered during your surgery to fill the gap in your mouth. The splint is used to hold a healing dressing and bung in place.

The maxillofacial prosthetist will attend your surgery, visit you while you are on the ward and attend your outpatient follow-up appointment. Throughout this time, they will make adjustments to your obturator to keep you comfortable. If you are having discomfort or nasal leakage, the prosthetist can be contacted for help and advice with your obturator on 020 3311 1470.

How can speech and language therapy help me?

The effects of surgery on your speech and swallowing will depend on how much of the upper jaw is removed and how it is repaired. Because the splint following your initial surgery is temporary, you may find your voice sounds different and you may get fluid leaking from your nose when you eat or drink. Once you are feeling stronger after surgery, the SLT will visit you on the ward. They 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 your speech
- exercises to help maintain and improve jaw opening

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 dietician, 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 get your nutritional requirements. They will assess your usual eating habits and will give you advice on changing to different types of food if necessary.

If you are unable to take anything by mouth for a long time, you may need 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.

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 dietician will check your progress regularly and discuss it with you.

We will give you a separate leaflet about RIG tubes.

Will I have a scar?

Maxillectomy is performed in different ways and the scars left are dependent on the way the surgery is performed. This will be discussed with you by your surgeon. The operation may leave a scar from your upper lip to your nose, along the crease line of your nose and occasionally along the lower eyelid on the same side. This should fade over time. 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 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?

You will have a temporary splint used to hold a healing dressing/pack and bung in place. This is a special denture that helps fill the gap left by the surgery. It will have metal clips on it that fit around your teeth to help hold it in place. This will stay in place until 10 to 14 days after your maxillectomy.

10 to 14 days after your first operation you will need another small operation to remove the packing and have further impressions taken so that a more permanent and better fitting obturator can be made.

Every person has a slightly different recovery depending on the extent of the operation. Your face 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.

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)

We recommend the ERP as a way to help you recover quickly and safely. It is designed to aid your recovery and an important part of the programme is nutrition.

We will discuss the programme in greater detail at your pre- treatment appointment. If 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, pre-op carbohydrate drink) up to two hours beforehand. No further liquids after 06.30 am.

The operation will take approximately two hours.

After the operation, we will take you to the recovery unit where you will be monitored until you're fit to return to the ward

Day 1

After your operation you may have the following:

- an intravenous infusion (drip) in your arm to replace fluids and give you your medications such as pain relief
- a catheter to collect your urine
- a feeding tube

Nurses will check you every two to four hours to monitor your recovery. Your relatives may visit you according to the ward visiting times. Please check times with the ward.

If you need to be nil by mouth and 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 every four to six hours
- you may be able to start on sips of water and possibly other drinks
- the nurses may help you to sit in a chair
- we may remove any drips, drains and catheter

Day 3–5

- the physiotherapist will help you increase your mobility if necessary
- the SLT and dietitian will help you work out what food and fluids you can manage and aim to get rid of your feeding tube

What happens after the operation?

You will be seen by the doctors, nurses, dietitian, SLT and prosthetist regularly to review your progress and offer support and advice. The doctors will let you know when you can begin to eat and drink. Any stitches inside the mouth are usually dissolvable. Stitches to the nose and face will be removed five to seven days after surgery. 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.

How do I care for my obturator?

Approximately 10 to 14 days after surgery, you will have a very small operation to remove the temporary denture and to take a further impression of the operated area. This impression is used to construct a more permanent and better fitting obturator. It will replace any front teeth that were removed during surgery due to the tumour, but may not have any back teeth on it, as the tissues need to heal first. As it is a closer fitting, it will give your voice a stronger sound and

there should be less fluid escape. You will be taught how to look after your mouth, cavity and obturator.

You will also need to have several appointments in the oral surgery/prosthetics department so that the obturator can be adjusted to fit you comfortably. This will depend on each person and their needs. The inside of your mouth will feel and look different when the obturator is not in place as there will be a hole in your palate (the roof of your mouth) where the cancer has been removed. You may find it difficult to make yourself understood or to eat without the obturator in place.

If you need to have radiotherapy after your surgery, this can affect and change the shape of the inside of your mouth and the cavity created by surgery. The maxillofacial prosthetist will adjust your obturator to try and keep you comfortable throughout your radiotherapy treatment. At the end of your radiotherapy treatment and when any reaction inside your mouth has settled down, your obturator will be adjusted, and replaced if necessary. This will have both front and back teeth on. You will have follow-up outpatient visits, and your obturator will be checked and periodically changed if needs be to accommodate any natural changes to the cavity associated with wound healing and the natural aging process. This will be discussed by the prosthetist at your follow-up outpatient appointment.

Will the operation be painful?

There will be some pain in your mouth 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, but we aim to ensure that this is well controlled. Please let the nursing staff know if you have any 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.

10–14 days after your surgery, you will be re-admitted for a small operation to remove the temporary bung and fit your obturator.

You will receive a follow-up appointment to attend the week after you have left hospital following your second operation to check on your progress and to discuss the results of your operation. At this appointment you will learn if 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 done 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 fit for work certificate to cover you while you are in hospital. If you need more time off work you can obtain further certificates from your GP.

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 sexual intercourse 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 08.00–17.00.

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

Helpline: **0808 800 000** (Monday to Friday, 09.00-20.00) 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 (Volunteer only Fridays)
- Tuesday, Wednesday, Thursday 09.00-16.00

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** 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**

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.patient.information@nhs.net

Wi-fi

We have a free wi-fi service for basic filtered browsing and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK_FREE or WiFiSPARK_PREMIUM