Information about your Surgery and the Enhanced Recovery Programme

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Introduction

This booklet will give you some information about your proposed surgery and an understanding of the Enhanced Recovery Programme. The aim of the Enhanced Recovery Programme is to get you back to full health as quickly as possible after your surgery, and we encourage you to play an active part in your recovery.

Research shows that after surgery, the sooner you move about and the earlier your body receives nutrition, the speedier your recovery. You are also less likely to develop complications after surgery.

If there is anything in this booklet you are not sure about, please ask.

This booklet contains some line diagrams but if you would like to see more detailed pictures please ask your doctor or specialist nurse.

As you have cancer your doctor has advised you that you need major surgery involving your oral cavity or oropharynx. The next section tells you more about both of these.

What are cancers of the oral cavity or oropharynx?

Cancers of the oral cavity can develop on your lips or inside your mouth.

Inside the mouth, cancer can develop on the buccal mucosa (the lining inside the lips and cheeks), teeth, gums, the floor of the mouth (under the tongue), the front two-thirds of the tongue, the retromolar trigone (area behind the wisdom teeth) and the hard palate (bony roof of the mouth).

Oropharyngeal cancer can develop in the oropharynx (the part of the throat directly behind the mouth) and includes areas such as the base of tongue (back third of the tongue), the soft palate (the soft part of the roof of the mouth), the tonsils and the posterior pharyngeal wall (back wall of the throat).

Both the oral cavity and oropharynx help with breathing, eating, chewing, swallowing and speaking so any surgical procedure can affect these areas.

Your surgeon will fully explain the surgery you need. Later in this booklet there is a brief outline of what your surgery may involve.
Stress and fear
One of the most dreaded fears people have is being diagnosed with cancer and it is a natural reaction for people to think they are going to die. Many patients with cancer experience this fear at some point during their illness, but we must stress that many cancers are now curable and we offer every patient the best chance of cure. However, if the cancer is advanced and cure is not achieved, modern treatment can still control your symptoms and can help improve your quality of life.

Your emotions
The time waiting for your surgery can often be a stressful time and while some patients find it helps to talk about how they are feeling, others prefer to cope on their own or within their family group. Everyone copes in different ways but it is essential that you try to voice any concerns you may have and ask questions.

Whichever way you choose to cope with these feelings, please remember that the nursing and medical staff will listen to your worries and fears and will be able to answer any questions you may have. You may find that it helps to write these questions down so you don’t forget. Sometimes this information needs to be given several times, as it can be difficult to remember. The staff will give you this information as often as you need.

Benefits advice
Many patients often worry about their finances, especially when you need to be off work for some time following your surgery. The time you need off work can vary from 3 to 12 months, and will depend on the extent of your surgery, the need for further treatment and the type of job you do. If you wish we will refer you to a Macmillan Benefits Advisor to help with any financial concerns.
Things that affect your health

Stopping smoking

If you are a smoker we encourage you to stop. We understand that trying to stop at this stressful time is especially difficult; however it is important for your enhanced recovery and your future health. Stopping smoking reduces complications such as chest and wound infections.

As part of the Enhanced Recovery Programme we would strongly encourage you to stop smoking before your admission. Help is available in different forms for people who want to stop smoking. Talk over these options with your specialist nurse or named nurse, your community pharmacist (local chemist), or contact your GP. Although there are lots of options, lozenges, chewing gum and micro tabs are not suitable for some people.

For further information and help on stopping smoking, please contact:
Smoke Free Services ...................... 0141 201 9825 (answer machine service after 5pm)
Smokeline .................................. 0800 84 84 84
Quitline ................................. 0800 00 22 00 (NHS 24 hour Helpline)

If you are unable to stop before coming into hospital then we will offer you nicotine replacement therapy to keep cravings at bay and make you more comfortable.

A separate pack to help you stop smoking is available from your specialist nurse.

Stopping drinking

If you drink alcohol, please do not drink for a minimum of 7 days before your surgery. To help us care for you in the best possible way we need you to be honest about how much alcohol you take to prevent any serious complications.

We may offer you medication to prevent any adverse reactions to a sudden withdrawal from alcohol.

After your surgery we encourage you to remain alcohol free or at least keep alcohol to a minimum as it is important for your future health.

A separate pack about stopping drinking is available from your specialist nurse.

Meeting other patients

Although you may know or meet people who appear to have the same type of condition or undergo similar surgery or treatment, it is important to remember that all patients are treated as individuals. Two patients with similar cancers may receive alternative treatments and experience different side effects. It is therefore not always helpful to compare yourself with others.

However, it may be possible for your specialist nurse to arrange for you to meet a patient who has had similar surgery and can discuss with you their experiences and how they coped. If this is something that you think would be helpful please ask your specialist nurse.
Before your surgery

Pre-assessment
Before your surgery you will attend the pre-assessment clinic. This may be a few weeks before your surgery.

At this clinic you will meet the members of the team looking after you, including the surgeons, anaesthetist, dietician, speech and language therapist, physiotherapist, occupational therapist and your specialist nurse. The clinic nurses will assist in organising all your tests and co-ordinating your appointment.

You may also attend an out-patient clinic a few days before your surgery to answer any last minute questions you may have and for you to sign your consent form. Or this may be done when you are admitted to the ward the day before surgery.

Seeing the doctor
The doctor will examine you and explain about your surgery. They will arrange for some tests to be carried out such as X-rays, heart tracing, breathing tests and blood tests. These tests will help to assess your general state of health.

Seeing the anaesthetist
The anaesthetist will discuss your general health and assess your fitness for a general anaesthetic. They will discuss with you your care during your surgery and answer any questions or concerns you may have.

Seeing the Dietitian
Nutrition before and after surgery is a very important part of your treatment plan. The dietician will assess and discuss your dietary needs with you before and after your surgery. Research studies have shown that carbohydrate drinks, as part of the Enhanced Recovery Programme, can help you feel better after surgery and improve your recovery. We will give you four carbohydrate drinks to take the evening before theatre and two on the morning of theatre.

After surgery we will give you nutrition via a naso-gastric feeding tube. The dietician will plan a feeding regime for you to start on the evening of surgery.

Seeing the Nutritional Nurse Specialist
If your surgeon feels that your treatment will have an effect on your ability to swallow either in the short or long term, we may consider the insertion of a gastrostomy tube.

This means that a feeding tube goes directly into the stomach through the skin. This is carried out as a routine procedure in hospital.

This tube can be used to provide liquid feed, water and medication as needed. A feeding pump is often used to give the feeds through the tube.

There is more than one way to place a gastrostomy tube and the nutritional nurse specialist will discuss this with you in more detail.
Seeing the Speech and Language Therapist
The speech and language therapist will assess you before your surgery and discuss with you any concerns you may have regarding your speech and swallowing following surgery.

Seeing the Macmillan Head and Neck Nurse Specialist
At pre-assessment and during your time in the ward one of the Macmillan head and neck nurse specialists will visit you. If you or your family have any concerns and wish to speak with the specialist nurses please ask the nursing staff and they will contact them for you.

Seeing the Physiotherapist
The physiotherapist will assess your breathing and respiratory function. They will teach you deep breathing and coughing exercises and assist you to mobilise (move about) to help your recovery after the surgery. You will also receive neck and shoulder exercises to prevent stiffness.

Seeing the Occupational Therapist
An Occupational Therapist will see you and offer you advice on how to cope with the effects of your cancer on your day to day activities.

Dental Assessment
As part of preparing for surgery a specialist dentist will assess your teeth and gums. If you need any treatment this can often be done before or at the same time as your surgery.
It is important that you have a clean and healthy mouth and you will see the dental hygienist who will advise you on your oral care regime.

Research Studies
To try to improve patient care for the future the team are involved in research studies looking at different aspects of care.

We may ask you to consider participating in some research studies and your doctor, specialist nurse or the research nurse will fully explain this to you. We will give you written information on any of the studies that you may be eligible for and give you time to consider whether you would like to take part or not. You do not have to take part.

On admission
On your admission to the ward a member of the nursing staff will welcome you and show you to your bed. A team, led by your named nurse, will be responsible for your care throughout your stay in the ward. The nurse will discuss your care and treatment with you (and your family if you want), plan your needs, and together with yourself and the other nurses in the ward, co-ordinate the delivery of this care. Your nurse will not always be on duty, but the nurses looking after you will introduce themselves to you and can answer any questions you or your family may have.

Preparing for theatre
You will need to fast for 6 hours before your surgery but you can drink clear fluids including your carbohydrate drinks up until 2 hours before you go to theatre. We will give you a small injection of Clexane at 10pm. This helps reduce the risk of blood clots. We will give you the injection each day while you are in hospital.
Day of surgery

On the day of your surgery you will shower and we will give you a gown and special support stockings to wear to reduce the risk of blood clots. Remove all jewellery, false teeth, etc. The nurse will complete a checklist to make sure all your details are correct. We will then take you to theatre on a trolley escorted by a nurse. The nurse in theatre will re-check your details. They will be with you as you receive your anaesthetic.

Surgery procedures

There are several different types of surgery used to treat oral cavity and oropharyngeal cancers. One or more of these may be involved in treating your cancer and this depends on the size, type, location and extent of your disease. The following pages contain short summaries of the different procedures which may be involved. It is important to remember that they may not all relate to your individual surgery. The medical and nursing staff will be able to advise you on which sections are relevant.

Surgery for mouth cancer

Your mouth is a highly complex part of your body and is responsible for vital functions such as speech, chewing and swallowing. Surgery to remove a cancer from the oral cavity is likely to affect these vital functions; the exact extent and for how long depends on which part of the mouth is affected (e.g. tongue, jaw, gum, floor of mouth, palate or cheek) and on how much is taken away. Advances in surgical technique mean that the mouth can nearly always be successfully rebuilt even after very large areas of the mouth have been removed in the surgical treatment of the cancer. Your surgeon or specialist nurse will discuss this with you.

At first your mouth will feel very strange, as the area will be swollen and numb, and you will experience an increase in saliva production. However, the swelling will gradually decrease, sensation will slowly return and the excessive saliva will diminish. These all take time and the head and neck team will be on hand to support you through this difficult time and on your way to recovery.

After treatment, you may find that your dentures become loose and ill fitting. The head and neck team can provide specialist advice and treatment should you have any mouth problems after the surgery.

Access procedures: Lip-split mandibulotomy

Sometimes, in the course of the surgery it may be necessary to improve the surgeon’s access to where the tumour lies. They do this by using the lip-split mandibulotomy procedure where a cut is made through the lip and the lower jaw is opened up temporarily. At the end of the surgery, the surgeon takes great care to repair the lip and jaw. In time, the scars on the lip and chin will fade. Your surgeon will discuss the details with you before your surgery.

Location of stitch line for lip split mandibulotomy/mandibulectomy
Reconstruction after head and neck cancer surgery

The aims of reconstruction following head and neck cancer are to restore structure and function to achieve the best quality of life for you. Occasionally (with small tumours) it is possible to remove the tumour and then simply close the wound directly or use some neighbouring tissue to close any defect. However, it is often necessary to reconstruct your mouth, face, jaw or throat using a piece of your own tissue taken from a distant site (graft or flap) and this is a more complex procedure. This is usually done at the same surgery. All the most up to date reconstructive options are available and can be tailored to suit your individual requirements to achieve the best possible function and appearance for you.

Free flaps

Following oral cancer, a common method of rebuilding the mouth lining is by using a piece of skin from your forearm (forearm flap) to resurface the tongue, gum or floor of mouth. This is very specialized surgery and involves microsurgery to reconnect the blood supply (which is called a ‘free flap’). If greater bulk is needed, we can take tissue from the abdomen, back or the side of the thigh.

Should you need your lower jaw to be rebuilt following cancer surgery (which is called mandibulectomy), this can be done very successfully by taking a bone graft (complete with its own blood supply as a free flap) from the hip, lower leg, shoulder blade or wrist. Most patients cope very well following jaw reconstruction and progress to successful oral rehabilitation. Should you need your upper jaw to be removed (which is called maxillectomy), reconstruction can be achieved either by a bone graft free flap or by fitting a special denture called an obturator.

While healing takes place, packing is laid over the cavity with the obturator placed over it. This obturator is a temporary prosthesis as the defect will change its shape over time and a more permanent prosthesis will be made at a later date. It is essential that you are taught how to insert and remove your obturator before your discharge home. We will also teach you how to clean both the cavity and the obturator itself. Graft and flap sites will be protected by dressings. These will usually be left intact and undisturbed for a number of days to allow natural healing to take place. They will only be removed on the instructions of your surgeon. Many patients find these areas more sensitive and can be uncomfortable and itchy. This is just part of the natural healing process and this discomfort will lessen in time.
Chest flap: Pec major
Depending upon the extent and site of your cancer it is occasionally necessary to replace diseased tissue using the skin and muscle from your chest. This is called a chest flap (also known as pec major). Due to the repositioning of this muscle you may experience some stiffness, numbness and discomfort in your chest, neck and shoulder. You will receive gentle exercises from the physiotherapist to ease these symptoms. You will have a large stitch line down and across part of your chest. Just after your surgery you may find this quite shocking to look at, as it will appear red and swollen. Owing to the pathway of the stitch line, the position of your nipple on the side of your surgery may be altered.

You may feel self-conscious regarding your appearance, but it is important to remember that in time the scarring will fade and will not be as noticeable as it seems at this present time. Your surgeon will discuss this with you before the surgery.

Neck dissection
You may need to have surgery on your neck (neck dissection). It may be necessary to have this surgery on one or both sides of your neck. A neck dissection is surgery to remove lymph nodes or glands and perhaps other structures such as nerves, blood vessels and muscles in your neck. The lymph glands are removed if the cancer has spread to your neck or when there is a chance of this happening.

There are different types of neck dissection that are carried out depending on the extent of tissue removed from the neck. Your surgeon will try to protect as much tissue as possible to help maintain good neck and shoulder movement after the surgery.

A selective neck dissection involves removing only a few lymph nodes.

A modified radical neck dissection involves removing most of the lymph nodes on one side of the neck between the jawbone and collarbone along with some muscle and nerve tissue.

A radical neck dissection involves removing the nodes along with more muscle, nerves and veins. We will explain the type of surgery you need. Your doctor will tell you at this time how much actually needs to be removed. Surgery involving your neck may affect how you move your head, neck and shoulders. Further on in this booklet is a list of exercises, which may help to ease the pain and stiffness you may experience, as a result of surgery.
Sentinel lymph node biopsy
Your surgeon may arrange for you to have a sentinel lymph node biopsy before your surgery. A sentinel lymph node is the first lymph node to which cancer cells are most likely to spread from a primary tumour.

A sentinel lymph node biopsy is a procedure in which the sentinel lymph node is identified, removed, and examined to determine whether cancer cells are present. This biopsy may help to avoid more extensive lymph node surgery and so this procedure allows your surgeon to plan the best treatment to treat your disease.

Your doctor will fully explain your surgery and tell you how much actually needs to be removed. Later in this booklet there is a list of exercises, which may help to ease the pain and stiffness you may experience, as a result of surgery.

After your surgery
We will nurse you in the intensive care unit for at least 24 hours after your surgery. Thereafter, we may transfer you to the high dependency unit. This is normal practice and it is to make sure that you receive one to one nursing care. Once your condition is stabilised you will return to the ward.

Swelling
It is natural to have some degree of swelling of your face and neck after this kind of surgery. This can sometimes be a shock for those close to you when visiting for the first time. This swelling is temporary and will eventually decrease as wound healing takes place. If you have had lymph glands removed, especially on both sides of the neck, the swelling will take longer to reduce.

Breathing
To prevent any breathing problems owing to swelling of the surrounding tissue, you will have a tracheostomy tube (a plastic breathing tube) placed in your windpipe through which you will breathe.

Once your swelling decreases and you are able to breathe through your nose and mouth, this tube will be removed according to your surgeon’s instructions. We will apply a simple dressing to the area until the wound heals.

Immediately after your surgery you will have an oxygen mask attached to the tracheostomy tube directing oxygen through the tube into your lungs. This warms and moistens the air, which can help prevent secretions becoming dry and forming crusts, which can obstruct your airway.

For the first few days after your surgery there will be an increase in your secretions coming from the tracheostomy tube and an increase and collection of saliva in your mouth. The nurse can remove these by suctioning them out from the tracheostomy tube and gently from your mouth. This will make you cough but the procedure itself only lasts a few seconds. Eventually you will be able to cough up or clear these secretions and wipe them away.
with a tissue. You will probably find this messy and embarrassing but you will adapt and in time, the secretions will decrease.

As part of your Enhanced Recovery Programme after your surgery, when you wake up it is important that you do deep breathing exercises. These exercises should be done at least five times an hour and your physiotherapist will show you how to do these.

**Moving about**

We will encourage you to be mobile with assistance from the nursing staff, physiotherapist on the first day after your surgery.

The staff will help you out of bed on the first morning after your surgery. The aim is for you to spend at least two hours out of bed each subsequent day. We will encourage you to walk up and down the full length of the ward 3 - 4 times a day after surgery. By being out of bed in a more upright position and by walking regularly, you improve your lung function and there is less chance of developing a chest infection.

Try to wear your normal day clothes, such as low or loose neck, short sleeves tops, and casual elastic waist trousers, e.g. jogging bottoms, after your surgery, as this can help you with your recovery.

**Drains**

You will have one or two small tubes (drains) under your skin leading out from your wound site (see illustration). These help to drain blood and other fluids collecting underneath the surface and so help to prevent swelling. The drainage tubes drain into a bag and staff closely monitor and measure the amount drained each day. When the amount drained is minimal your doctor will ask for them to be removed. This is usually two or three days after your surgery.

When you return from theatre you will have a urinary catheter (drainage tube in your bladder) leading out to a drainage bag. This is to monitor exactly how much urine you pass following the surgery. It will usually be removed within the first couple of days.

**Your wound**

Your wound may be closed with any combination of stitches, staples or glue. Your doctor will advise when to remove the stitches and staples but it is usually after 7-10 days. We will tell you and show you an example of the position of your stitch lines or wounds.

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What can I expect after a free flap reconstruction?

The use of free flaps has revolutionised reconstructive surgery following head and neck cancer. A free flap is a piece of tissue (skin, muscle, bone) which is taken from one area of the body, complete with its blood supply, then moved to the head and neck region to rebuild the tissue that has been removed due to cancer surgery. Using microsurgery techniques the blood supply is re-established to the flap tissue making sure survival of the transferred tissue at its new site.

Using these techniques the lining of the mouth can be rebuilt with a free flap from the forearm or the jaw can be rebuilt using bone and skin from the lower leg or hip. Free flap reconstructions
are very reliable but occasionally in the early post-operative period it may be necessary to return to theatre to attempt to rectify a problem that may develop with a flap. Your surgeon will discuss this with you and will also discuss with you alternative methods of reconstruction should a free flap prove not to be a suitable method of reconstruction.

**Radial forearm flap**
With this flap, a graft of skin and, or bone is taken from your forearm area, usually from the non-dominant side e.g. if you are right handed then the flap will be taken from your left arm. This leaves a defect in the forearm that may be closed by using a separate skin graft or by closing the tissue directly.

If a skin graft is used you will have a bandage or even a plaster cast on your forearm. The dressing is normally changed 7-10 days after your surgery and this will be done on the ward before you return home. The clinic staff and your district nurse will keep a close eye on this graft once you have returned home. After the forearm flap, you may find that your grip strength decreases and that you have a patch of skin numbness at the base of your thumb and back of your hand. This is to be expected and with appropriate physiotherapy your grip strength should improve.

**Rectus flap**
The rectus flap is taken from your anterior abdominal wall. It can be used as a muscle only flap or with muscle and skin together depending on the bulk of tissue required to repair the defect. After surgery you will have stitches or skin clips on your abdominal skin and these will be removed after 7-10 days. Initially you may find it difficult when moving from lying down to a sitting up position. This will improve greatly over the subsequent weeks. Your physiotherapist will advise you on the correct exercises to speed your recovery.

**Lat dorsi flap**
This flap uses the large muscle on the outer aspect of your back - lat dorsi, often in conjunction with the overlying skin, to rebuild soft tissues in the head and neck region. You will usually have a drain in place for 2-3 days and your stitches or skin staples will be removed after 10-14 days. Your physiotherapist will guide your recovery to make sure you regain the maximum range of movement and function of your upper limb.
Lateral thigh flap
This flap is taken from the lateral (outer) aspect of the thigh. A skin graft is usually not required and once healed you should not be restricted in your activity. A straight scar is left on the outer side of your thigh.

Composite fibula flap
The fibula is a long, non-weight bearing bone in the lower leg and the central portion can safely be removed to reconstruct the upper or lower jaw without producing any ill-effects to the knee or ankle joints.
You will usually experience some short term difficulty with walking but with appropriate physiotherapy this should return to normal.

DCIA flap - hip bone graft
The upper and lower jaw can be reconstructed by using a piece of bone taken from the hip (DCIA flap). One of the abdominal muscles (internal oblique) is often used at the same time to resurface the mouth lining.
Surgical drains are left in place for a few days. As soon as possible, your physiotherapist will start to mobilise you with care. In the short term you are likely to find it difficult to walk steadily and you are likely to need the use of a walking frame for a few days. By the time you are discharged at 2-3 weeks the vast majority of patients are moving about freely and unaided.
Scapula flap

This flap uses a portion of the shoulder blade bone (scapula) in conjunction with the overlying skin, to rebuild complex defects in the head and neck region. A drain is in place for 2-3 days and stitches or skin staples are normally removed at 10-14 days. Initially your shoulder movement will feel stiff but with physiotherapy you can expect to regain excellent shoulder function.

Looking after your flap immediately after surgery

After your surgery the nurses and doctors looking after you will check inside your mouth regularly to look closely at your flap. They will check that the flap remains healthy and that the blood flow through the flap is okay. They will record your observations on your chart at your bedside.

Care during your recovery

Oral hygiene

When you have had surgery to your mouth it is very important to keep your mouth clean to prevent any infection. We will give you a mouth rinse to use (usually Corsodyl or Chlorhexidine) and you may find that using a soft toothbrush or foam sticks will help you to clean your mouth while you still have a degree of swelling of your face. This should only be done on the instructions of your doctor, especially if you have had reconstructive surgery. If you still have natural teeth, you should continue to use fluoride toothpaste twice per day as usual. If you need extra help with your oral hygiene, you can ask to see our dental hygienist.

If you have had your teeth removed during surgery or you wore dentures beforehand, you may not be able to wear them as before. Owing to the changes in your mouth, you may find they no longer fit. It also may be some time before you can be fitted with new dentures as it is important that natural healing takes place within the oral cavity. Your surgeon will discuss this with you.

Fluids

You can expect after such surgery to have a drip into a vein in your hand. This replaces the body fluids lost during your surgery. Your surgeon will decide when you may start to drink. This can vary from a few days to several days after your surgery depending upon the type of surgery you have had.

It may be necessary for you to be fed either through a tube in your nose leading to your stomach, or a tube leading directly into your stomach. This will be used to feed you liquid diet while you are not allowed to eat and drink normally. When you are able to tolerate tube feeding, your drip will be removed. As part of the Enhanced Recovery Programme tube feeding will be started on the day of your surgery.

Pain

As you recover from your anaesthetic it is likely you will experience a degree of pain and so your anaesthetist will prescribe some painkillers. This may include a PCA (Patient Controlled Analgesia) pain machine which has a button that allows you to give yourself pain relieving medication whenever you feel the need. When this is stopped you will be able to have your painkillers down your feeding tube. We encourage you to tell the nursing staff when you are sore and need painkillers.
**Constipation**

If you have been given strong painkillers, or you are not moving about well, you may experience constipation. If this is a problem for you it is important that you tell the nursing staff, and record it in your Enhanced Recovery Programme booklet. They will arrange a laxative for you.

**Communicating with others**

As you will have a tracheostomy tube in your throat after your surgery, you will be unable to talk. This will mean you will need to communicate using pen and paper. You will find this very frustrating in the first few days after your surgery.

Once your tracheostomy tube is changed, you may be able to speak by covering this tube with your finger. This will depend on how much swelling you have around your neck and the amount of secretions you produce. Once your secretions decrease you may be able to use a speaking valve which attaches to the end of the tracheostomy tube. Speech may be difficult at first dependent upon the extent and site of your surgery. You might feel angry and frustrated when you first try to speak. You must try to be patient as it may be difficult to understand you and it does help if you speak slowly and use short phrases.

**Your appearance**

As soon as possible, after your surgery, we encourage you to look at your face and neck in the mirror. You may wish to have someone with you the first time. They will be able to explain what to expect and give advice about the healing process. You may feel very upset when you first see yourself but remember that the swelling will reduce and the scars will fade in time. If you have had a radial forearm free flap, you may feel that the area affected will be quite unpleasant to look at initially. As with your face and neck, this will become less inflamed and in time the scarring will fade. As you see the progress, you will become more accustomed to how it looks.

**Dietary advice**

We will check your weight before your surgery as weight loss during this time can delay recovery and healing.

After your surgery you will be fed via a nasogastric or gastrostomy tube. During this time the dietitian and nutritional team will visit you to make sure you are receiving adequate nutrition. When you are allowed to take oral fluids and diet you may find this difficult at first. The speech and language therapist may be able to offer you advice about swallowing techniques and different food textures.

While you are unwell or recovering from surgery it is important that you eat and do not lose your appetite. You should eat foods that you like and will give you calories. If you are unsure what to have or feel you are not getting enough, discuss this with the nursing staff and the dietitian.

**Speech and Language Therapy advice**

The type and severity of speech and swallowing difficulties will depend on where and how much surgery you have had and the surgeon’s reconstructive procedure. It is important for each patient to be individually assessed and given information in coping with any speech or swallowing difficulties that may arise.

Your speech and swallowing may be affected and you may have some difficulty in moving food around your mouth. This may lead to food becoming trapped on the floor of your mouth. Muscles in the mouth are used for both speaking and swallowing and although surgery will vary it can give rise to changes in these two everyday activities. Initially, if only part of your tongue has been removed the remaining part may be swollen and the face muscles stiff and sore. This makes speaking quite an effort. Your speech may also be slurred and hard to understand. It can be difficult to control the saliva in your mouth and this can make your speech slushy and indistinct.
It is helpful to try to speak more slowly and have pen and paper to hand. The tongue is used to control food in the mouth and prepare it for swallowing. The speech and language therapist can assess if you have any difficulty in swallowing and can advise on ways of making swallowing easier.

**Exercise following surgery**

To help you if your movement is restricted following surgery, see the Physiotherapy advice on the following pages.

**Physiotherapy advice**

**Exercise**

As part of the Enhanced Recovery Programme, we encourage some activity from day one following surgery. You should plan to take regular exercise several times a day and gradually increase during the weeks following your surgery.

**Neck and shoulder exercises following neck surgery**

After this type of surgery you may find that your neck and shoulder movements are restricted. It is important that you do not allow your joints around your neck and shoulders to stiffen up as this can cause problems later with your everyday activities e.g. looking over your shoulder or reaching up to a cupboard. To regain full movement of your neck and shoulders you can do some simple exercises. Staff will tell you when you should start the exercises shown. Remember, it is better to do exercises little and often rather than doing one long, heavy session which may make you sore. Try them 3 times a day. Your exercises will be individually tailored to suit your requirements.

**Neck Exercises**

Sit up straight supported in a chair.

1. Turn your head to one side as if looking over your shoulder, until you feel a stretch. Hold for 3 seconds and then relax. Repeat to the other side. Do 10 times to each side.

2. Tilt your head so that your right ear stretches down towards your right shoulder. Hold for 3 seconds and then relax. Repeat to the left side. Do 10 times to each side.
3. With your elbow bent, swing your arm forwards and backwards as if using a saw. Aim to do 20 seconds for each arm.

4. With your elbow bent, lift the point of your elbow up to the side and down as if flapping your wings. Aim to do 20 seconds for each arm. Move on to lifting with your arm straight.

5. Try to place your hand behind your back and move it upwards as if to scratch between your shoulder blades. Hold for 3 seconds and then relax. Repeat with your other arm. Do 5 times to each side.

6. Try to place your hand behind your head and move it down the back of your neck. Hold for 3 seconds and then relax. Repeat with your other arm. Do 5 times to each side.
Neck Exercises continued

7. Lift your arm forwards, keeping your elbow straight and letting your thumb lead the way. Stretch as high into the air as possible, lower your arm and repeat with your other arm. Aim to do 20 seconds for each arm.

8. With hands at shoulder level, slowly stretch out your arms forward and together. Then slowly stretch them apart, out to the side and backwards, as if you were doing the breast-stroke. Repeat 10 times.

9. Stand facing a wall with your arm outstretched as if you are stopping the traffic. Place your palm against the wall and using the wall as support, slide your hand up the wall as far as you can. It may help to place your other hand on your affected shoulder when doing this exercise to prevent your shoulder from rising up. Repeat 10 times.

10. Keeping your hand on the wall turn your body stepping round to the side. Repeat the same exercise.

Points to remember
As the exercises get easier try to do more repetitions. Do these exercises so that you feel a good stretch. If you find these exercises difficult or too painful, please contact the physiotherapist for further advice.
Self-care after your surgery

We encourage you to take an active role in your care during and after your treatment. This will help you recover more quickly and will help you cope better with the after effects of surgery.

What side effects can I expect following surgery involving the oral cavity and oropharynx?

Every patient is different and effects of surgery can vary greatly from one person to the next. The following section will discuss possible effects of surgery and how best to manage them. Your doctor will have told you of the effects you can expect following your surgery.

Swelling

You will have some swelling of your face and neck immediately after your surgery. This is usually temporary and will eventually reduce as your wounds start to heal. If you have had a radical neck dissection, especially on both sides of your neck, the swelling will be more evident and will take longer to reduce. Your physiotherapist may offer some advice regarding exercises or massage to help reduce your discomfort.

Numbness

You may find that your face, neck and your ear may feel numb on the operated side. This can feel quite strange and rubber-like. This will improve to some degree, perhaps after several months.

Oral problems

Mouth opening

Following surgery some patients may have some difficulty with mouth opening. This is a condition called trismus. It can be difficult to open your mouth wide enough to carry out oral hygiene. If your mouth is not kept clean it may be at risk of infection and may delay healing. Trismus may also affect how you eat or speak. Your surgeon may recommend stretching exercises if this is a problem for you.

Swallowing

The problems you experience with swallowing will depend on the extent and location of your surgery. If you have had surgery to your oropharynx, you may experience problems swallowing food or liquids as sometimes they may go down the wrong way (aspirating). This may cause you to cough and feel as if you are choking. Sometimes if you have no sensation at the back of your throat, you may not be able to tell if you are swallowing properly.

If you have had surgery to your palate, you may find that food and liquids may occasionally come down your nose, which can be very frustrating and embarrassing. Your speech and language therapist will work closely with you to help overcome these potential problems in an attempt to allow you to swallow safely. You may have an X-ray to assess your swallowing. This is called a videofluoroscopy. During this assessment we will ask you to swallow different types and textures of food from fluids to solids. This allows your therapist to decide what you can safely eat and drink.

Eating and drinking

If your face is numb or is not moving as well as you feel it should, you may find some difficulty in eating. It can sometimes be difficult to sense or feel where the food is, if placed into the affected side of your mouth. This can result in food becoming trapped. Rinsing your mouth frequently with a mouthwash, especially after meals, will help to remove any food debris. Using foam sticks or a soft toothbrush will also help. It may be helpful at first, when eating, to place your food on the unaffected side of your mouth. Remember to have drinks with your meals to help wash the food down. Sometimes you may find that you will need to swallow a few times before you can clear your mouth and throat. If you find drinking from a glass or cup makes you dribble, you might find
it helps using a straw. You may need to use your fingers to help seal your lips whilst drinking, but this will prevent any embarrassing spills. You may, on the other hand, prefer to use a spoon which will allow you to regulate how much you take into your mouth.

**Delay in recovery**
Everyone is an individual and therefore, progresses at different rates. If your recovery does take longer, you may need to stay in hospital longer or go home with tube feeding. This can be very upsetting but as healing takes place, you may find that you will be able to eat and drink normally again. Remember, that if you have any problems and would like to discuss this, your doctor will be able to talk this over with you. Some patients, however, may never recover their ability to swallow and will therefore need to have feeding by tube permanently. This is now a much less common occurrence. Your doctor will be able to discuss your concerns regarding your recovery in more detail.

**Speech**
Following surgery to your mouth, you may find your speech is a little slurred or muffled. This can be very upsetting and frustrating. Your speech and language therapist will be able to offer advice to help improve your speech.

If you have had surgery to your palate, you may have a nasal quality to your speech but if you have an obturator this will help.

Following surgery to your mouth, you may find that you have problems initially swallowing your saliva and this can lead to some drooling. This can be very embarrassing and you may feel that you are spitting when speaking to people. You may be very conscious of this but others will probably not be aware of this happening. Your saliva will reduce as swallowing improves and your wound heals. In the meantime, you may find it necessary to carry tissues with you to wipe your mouth.

**Weakness**
If you have had a neck dissection, you may find that you have some weakness in your neck, shoulder and arm on the operated side. This may be caused by injury to the nerve to one of the muscles in the shoulder. You may find it difficult to lift your arm above shoulder level. If you have had a selective neck dissection you may find that your neck and shoulder movement will recover fairly well a few months after your surgery with continued physiotherapy.

**Your appearance**
After your surgery you may look different. How much your appearance changes will depend on the type of surgery and the amount of reconstructive surgery you have.

At first this may be very difficult for you and your family to accept. However remember that you are the same person you always were and those closest to you value you no matter the changes in your physical appearance.

Immediately after your surgery your face and neck may appear very swollen and red. This will eventually decrease and the scarring will fade to become less noticeable in time.

If you have had a neck dissection and depending upon the extent of the surgery, you may find that your neck will look a little flatter on the side of your surgery. You may feel a little self-conscious about your appearance but in time, the scar will fade and merge with the natural folds of your neck. As you accept and adapt to these changes in your appearance, your self-confidence will increase and you will be more able to deal with the reactions of others. At first you may find that people will stare at you while others turn away and ignore you. People react to cancer in different ways and these different reactions are often simply their own way of coping.
You may find the following helpful:

- Try to look at your changed appearance.
- If you would like to, it may be possible to disguise some of the changes with scarves or camouflage make-up.
- Don’t spend too long each day looking at your appearance or covering up the changes. The aim is to become as comfortable as possible with the changes, not pre-occupied with them.
- Try to continue with some socialising if you are well enough to do so. This will also allow you to feel more comfortable with others. Perhaps meet up with the people with whom you feel most at ease first of all.
- Be prepared for the various ways in which other people may react to any obvious changes to your appearance, and plan how you may respond. Work out what you will say if someone comments on your appearance and be prepared for the possibility that people may avoid you because they don’t know what to say.
- If you are having difficulty coping with changes to your appearance, including feeling distressed, avoiding looking at yourself, becoming pre-occupied with concerns about your appearance, or avoiding social contact, then please tell someone in your specialist team who may be able to refer you to a clinical psychologist.

Possible complications after surgery

Infection
The most common types of infection you may develop during your time in hospital are chest and wound infections. This may mean that you could be moved to a side room in the ward to protect you and the other patients from passing this infection on to each other. We will treat you with antibiotics and when you are well enough we will discharge you home.

Fistula
A rare but possible complication following surgery is that your wound may not heal as well as it should. It might even open up slightly and leak a little. This is called a fistula. A fistula is more likely if you have had radiotherapy before your surgery. If you develop a fistula, you may not be allowed to eat and drink by mouth until the fistula heals. This may mean that you are fed by tube for a little longer.
**Going home**

When you have recovered well from surgery, we will discharge you home. This may take a few days to plan this properly. This will allow the head and neck team looking after you to arrange any community support you may require e.g. district nurses and, or social services. Your head and neck nurse specialist will arrange a suitable date with you and your family to visit you at home. You will be able to talk about any concerns or problems you may experience with your nurse when they visit. We will also give you an appointment for the outpatients clinic to check that you are recovering well after your discharge home.

**At home**

**Wound care**

When you go home it is important to keep a check on your wound for signs of inflammation or infection such as redness, increased pain or leakage. Report any such changes to your doctor or hospital.

We will refer you to the district nurses, who will change your dressing for you. If you have had reconstructive surgery, you may need regular dressings to your flap and skin graft sites. These dressings will either be carried out by the district nurses at your home or if your surgeon prefers, then we may ask you to attend the hospital to have them dressed. You may require dressings for several weeks until healing takes place.

**Oral hygiene**

We advise you to continue using the mouthwash you were using in the ward. This is usually Corsodyl or Chlorhexidine mouthwash. It is especially important to rinse after meals to remove any trapped food. You may find that using a soft toothbrush or foam sticks is still the best way of keeping your mouth clean and healthy. If you have your own teeth you should continue to use fluoride toothpaste twice per day as usual. The dental hygienist is available at the clinic if you need extra help and support.

**Skin care**

You may find that your face and neck feel numb on the operated side. This can feel quite strange and rubber-like. Whilst you have no feeling in this area it is important to take care. For example, we advise men to use an electric razor when shaving to prevent cutting the skin.

You may find that exposure to extremes of temperature irritates your face, ear and neck and so we advise you to try to protect your skin when outdoors. You may not always be able to feel if something is hot or cold, so take care when using appliances such as hairdryers.

If you have had reconstructive surgery and have flap or skin graft sites you must take extra care especially in sunny weather. Your skin will be more sensitive in these areas and you should use a total sun block for protection, particularly in the first year.

If you have had a chest flap, you may experience a skin reaction when exposed to the sun. You may need to cover up especially on hotter days. Donor sites may become red and itchy some months after your surgery. It is important to keep these areas moist with regular moisturising.

**General weakness**

You may find that you feel more tired and lack energy when you go home. This is only natural, as you are still recovering from a major surgery. Following some types of neck surgery, you may experience some difficulty in carrying out minor tasks, if they involve certain arm movements e.g. washing your hair, dressing and undressing, etc. You may also find problems turning your head, as this may cause some degree of pain and stiffness. Moving from one position to another, bending down or reaching up can cause some difficulty. These are common problems and initially you may need help with certain tasks. However, you will find ways of adapting to these problems and it is important to continue with your physiotherapy exercises as advised by your physiotherapist. This will help to lessen the problems you experience.
Mood swings
Everyone copes in different ways, but it is possible that you may have bouts of depression and loss of confidence following your surgery. You may also feel very angry that this has happened to you and you may experience mood swings. This can place your personal relationships under enormous strain. It is important that you try to voice your feelings and frustrations as your family and friends may not always be aware of how you are really feeling. It can also be difficult for your family as they are trying to cope and find ways of dealing with your diagnosis. It can often take a long time to adapt and adjust to the changes you may experience as a result of surgery. With time, things will seem much better as you notice the progress you make.

Your sex life
You may find that your surgery will have an effect on your love life. You may find that you lose interest in sex or that you are unable to make love in the same way you did before your illness. This may be due to tiredness, depression or the way you feel about the changes in your physical appearance. You may also find that your partner is concerned about resuming your sex life. They may be worried about hurting you or putting a strain on your wound sites.

You may be more self-conscious about kissing. The structure of your mouth may have changed after surgery and it may look and feel differently. You may also have a lot of saliva collecting in your mouth which may make you reluctant to be close to your partner and avoid intimate contact with them. This can be frustrating and isolating for both you and your partner. It is really important to keep communicating with each other and talk about how you feel.

The nursing and medical staff realise this may be an embarrassing subject for you to talk about. However, if maintaining a loving relationship with your partner is still important to you, then help may be available. If you feel that this is a particular problem for you, we can refer you to a relationship counsellor.

Socialising
You may find it difficult to control the food in your mouth, which may stop you from eating comfortably in public, owing to the embarrassment you feel. However, in time, this does improve and you will feel more able to socialise. If you are not able to take enough food by mouth, you may find you need to supplement this with nasogastric or peg tube feeding. This can also impact upon your normal social life.

Work
Some people are able to return to work following surgery, however it may take several months before they feel strong enough. If your job involves heavy manual lifting then it may not be possible to return to your normal work activities. Some patients may also find it difficult to return to work if their jobs involve speaking for lengthy periods of time.

Social Circumstances
If you are concerned about your social circumstances please talk to a member of staff and ask to be referred to a social worker.

Driving
We advise that you do not drive until you are confident that you can drive safely. It is important that any pain has resolved sufficiently to allow you to perform an emergency stop and turn the wheel quickly in an emergency.

Hobbies or activities
In general we advise that you take up your hobbies and activities as soon as possible again after surgery. It allows you to maintain your activity and will help your recovery. We would not advise restricting these unless they cause significant pain.
Will I need further treatment?

Radiotherapy or Chemotherapy

Your doctor will tell you if you need further treatment. If you need radiotherapy and, or chemotherapy, the nursing staff will be happy to discuss this with you and your family. Separate booklets are available.
**Support organisations**

Below is a list of useful addresses for further advice and support.

**Macmillan Cancer Support**
Telephone Number: 0808 808 0000
Website:
Provides an information line, website and offers one-off grants for a wide variety of needs.

**Changing Faces**
Telephone Number: 0845 4500 640
Website: changingfaces.org.uk
This charity helps provide practical and emotional support to patients and families who are affected by a change in their appearance.

**Maggie’s Glasgow Gartnavel**
Maggie’s Gartnavel can be found to the east of Gartnavel General Hospital and just up the hill from the Beatson West of Scotland Cancer Centre and its car park. Open Monday - Friday (9am - 5 pm
Telephone Number: 0141 357 2269
Email: glasgow@maggiescentres.org

**Maggie’s Glasgow Gatehouse**
Maggie’s Glasgow Gatehouse is situated on Dumbarton Road, at the entrance to the University of Glasgow beside Kelvingrove Park.
Maggie’s Glasgow Gatehouse is open 9am to 5pm on Monday, Wednesday and Thursday. On Tuesday the centre is open from 11.30am to 5pm and the centre is closed on Friday. Telephone Number: 0141 330 3311
Email: glasgow@maggiescentres.org

**Cancer Support Scotland (Tak Tent)**
Calman Cancer Support Centre
Gartnavel Complex
Glasgow
G12 0YN
Telephone Number: 0141 211 0122
Website: www.cancersupportscotland.org

Cancer Support Scotland “Tak Tent” offers information and support for cancer patients, families, friends and health professionals. “Tak Tent” runs a network of support groups across Scotland, meeting monthly in the evening, including a group specifically for people aged 16-25. Cancer Support Scotland “Tak Tent” also provides counselling and complementary therapies.