

# Life after an Oesophagectomy or Gastrectomy

## About our publication

The Oxfordshire Oesophageal and Stomach Organisation (OOSO) is committed to the provision of high quality information for people with a diagnosis of oesophageal and/or stomach cancer, as well as their family and friends.

This publication was written by patients and their carers gathering together our many years of knowledge from our experiences. All information is checked by members of the clinical team. We do not profess to be medically trained.

We make every effort to ensure that the information we provide is accurate but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult your doctor.

## Acknowledgements

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- Nick Maynard, Consultant Upper GI Surgeon
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- Emma Fox, Upper GI Specialist Dietitian
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- Alison Howard, Dietetic Team Leader
- Elaine Tustian, Enhanced Recovery Programme Facilitator

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## A thought ...

Cancer is a word that strikes fear into most of us but medicines and treatments have improved dramatically over the years. We can all help ourselves in our treatment and recovery by maintaining a positive mental attitude and getting ourselves as fit as possible.

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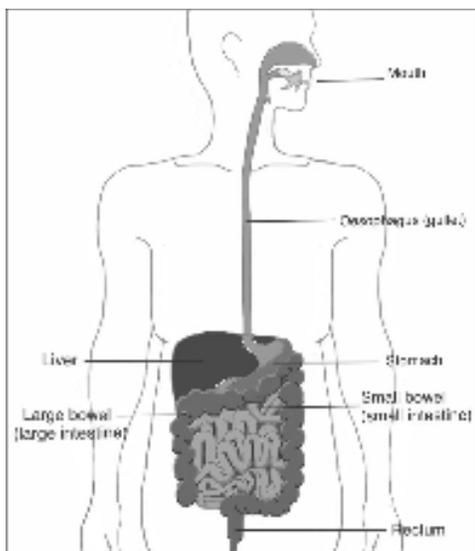
# Life after an Oesophagectomy or Gastrectomy

## Introduction

This booklet gives information and support to people who have cancer of the oesophagus or stomach, and their families and friends. Each year nearly 8,000 people in the UK are diagnosed with oesophageal cancer and approximately 7,000 with stomach cancer. In this booklet we aim to answer some of the questions you may have about its diagnosis and treatment.

## The Oesophagus

The oesophagus (pronounced *e-sof-fa-gus*) is also known as the gullet. It is a long, muscular tube that connects your throat to your stomach. It is at least 30 cm (12 inches) long in adults. When you swallow food, it is carried down the oesophagus to the stomach and the walls of the oesophagus contract to move the food downwards. The upper part of the oesophagus runs behind, but is separate from, the windpipe (trachea). The windpipe connects your mouth and nose with your lungs, enabling you to breathe.



A tumor can occur anywhere along the length of the oesophagus. Various lymph nodes (which filter fluid and can trap bacteria, viruses and cancer cells) are near the oesophagus, in your neck, in the middle of your chest and near the area where the oesophagus joins the stomach.

## Causes

Cancer of the oesophagus is becoming more common in Europe and North America. Men are affected more than women and it occurs generally in older people. There are two main types: **squamous cell carcinoma** and **adenocarcinoma**. The causes of oesophageal cancer are not always known, but it would appear to be more common in people who have long-standing acid reflux (backflow of stomach acid into the oesophagus). Damage to the oesophagus caused by acid reflux is known as **Barrett's oesophagus**. On occasion, patients undergo this surgery for non-cancerous conditions.

Barrett's oesophagus is a condition whereby abnormal cells develop in the lining of the lower end of the oesophagus. It is not a cancer, however, over an extended period of time a small number of people with this condition (around 1 in 100) may develop a cancer of the oesophagus.

Squamous cell carcinoma is more common among smokers and people who drink a lot of alcohol (especially spirits) or have a poor diet.

In most people, cancer of the oesophagus is not caused by an inherited faulty gene and so other members of your family are not likely to be at risk of developing it. However, a very small number of people, who have a rare inherited skin condition known as tylosis, may develop oesophageal cancer.

## Symptoms

Difficulty in swallowing (dysphagia) is a common symptom of oesophageal cancer. Usually, there is a feeling that food is sticking on its way down to the stomach, although liquids may be swallowed easily at first. There may also be some weight loss, and possibly some pain or discomfort behind the breastbone or in the back. There may be indigestion or a cough. These symptoms can be caused by many things other than cancer, but you should always tell your doctor, particularly if they persist beyond a couple of weeks.

## Breathing before your operation

If you are a smoker, it is vital to stop smoking as soon as possible; help is available from your GP and most pharmacies.

At one of your clinic appointments a Physiotherapist or an Advanced Nurse Practitioner (ANP) will teach you how to use an inspiratory muscle training device; this device will build up the strength in your breathing muscles so that they are fitter and more able to cope with your operation.

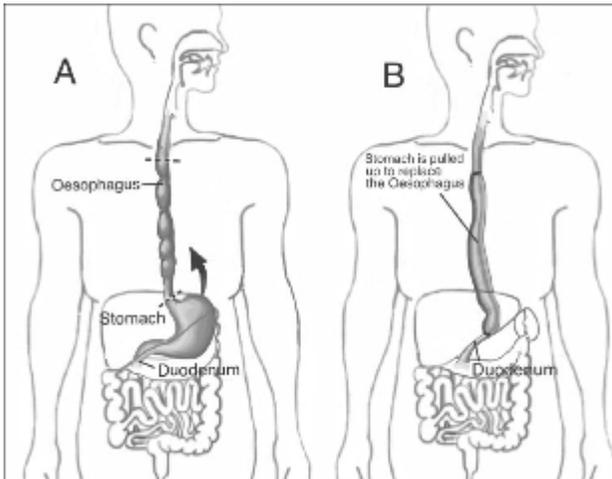
## Nutrition before your operation

It is very important to remain well-nourished before your operation. You can do this by choosing high calorie food, fortifying foods and modifying textures. You may be offered nutritional supplement drinks in the out patients clinic or by your GP. If you continue to lose weight, or it becomes increasing difficult to swallow, you will be referred to a dietitian. You may require a feeding tube (Jejunostomy tube) to be inserted into your small bowel but this will be discussed in more detail.

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## An Oesophagectomy

This operation involves the removal of part or most of the oesophagus and possibly part of the stomach, the amount of each varies according to the position and size of the tumor. The stomach is then moved into the chest and joined to the remainder of the oesophagus. The join may be near the neck or slightly lower and all or only part of the stomach may be in the chest.



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## The Stomach

The stomach forms part of the digestive system. The upper part is joined to the oesophagus and the lower part is joined to the beginning of the small bowel (see illustration on page 1).

When food passes down through the oesophagus and into the stomach, it is then mixed with gastric juices. This semi-solid food then passes into the small bowel where it is broken down further and nutrients are absorbed. The gastric juices are particularly important as they help the bowel to absorb important substances from our food.

As well as being part of the digestive system, the stomach is also connected to the lymphatic system. The lymphatic system carries out two main functions; (i) it helps to protect the body from infection, and (ii) it drains fluid from the tissues.

## Causes

The cause of stomach cancer is not clearly known. There is some evidence that a combination of risk factors come together to cause this disease, these are:

- Gender** – it is more common in men than in women.
- Age** – the risk increases with age. The majority of people with this disease are over 55 years old.
- H pylori infection (*Helicobacter pylori*)** – if this infection has been in the stomach over a long period of time, this may increase the risk of stomach cancer.
- Diet** – eating a lot of salty, pickled foods and processed meats such as sausages and bacon can increase the risk.
- General** – smoking; general medical conditions such as acid-reflux and Barrett's oesophagus; lower than normal levels of acid; family history and genes, all can contribute to the onset of this disease.
  - there are other reasons why you might need a gastrectomy, e.g. chronic acid reflux.

## Symptoms

Many of the symptoms are common-place, and many people with the following conditions will not have cancer, however, it is important that they are checked by their GP. Symptoms include heartburn or indigestion that is persistent; burping a lot; bloated feeling after having a meal; loss of appetite; difficulty in swallowing; unexplained weight loss; nausea and vomiting; dark blood in the stools; tiredness due to anemia.

## Breathing before your operation

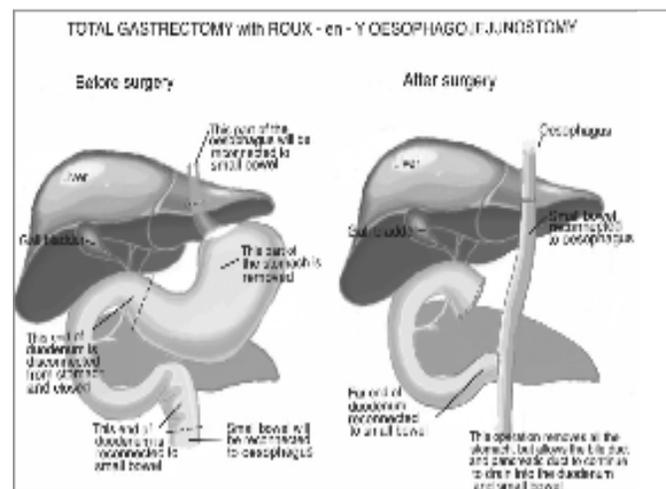
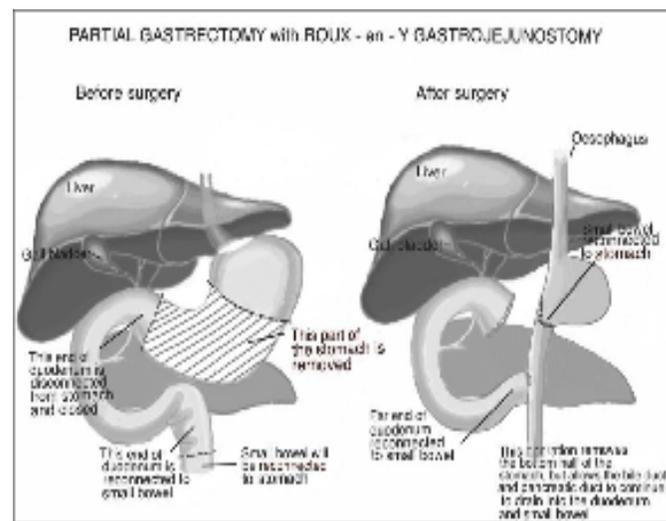
If you are a smoker, it is vital to stop smoking as soon as possible; help is available from your GP and most pharmacies.

At one of your clinic appointments a Physiotherapist or ANP will teach you how to use an inspiratory muscle training device; this device will build up the strength in your breathing muscles so that they are fitter and more able to cope with your operation.

## A Gastrectomy

This operation involves the total removal (**total gastrectomy**) or the partial removal (**partial gastrectomy**) of the stomach. Which operation you will be offered depends on the size and position of the tumor. If you have a total gastrectomy, the top part of the small bowel (the jejunum) is joined on to the bottom of the oesophagus. If only part of the stomach has been removed the small bowel is joined to the remaining part of the stomach. This means that the food you eat will pass almost immediately from the stomach into the small bowel.

Ask your clinical team for more details if you need to better understand your condition. You may find that a clearer understanding will help you cope.



## Keyhole surgery

Some patients are offered keyhole surgery or laparoscopic surgery to have all or part of their stomach removed. Doing the operation in this way means you will only have a small opening or openings instead of one larger cut. Consequently your recovery may be quicker but you should not underestimate the

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seriousness of your operation.

## After your operation

If you have an oesophagectomy performed, you will be looked after on an intensive care unit (ICU) usually for a day or two or on the overnight recovery unit. This does not mean you have complications, it is standard procedure. A ventilator may be used to help you to breathe. Patients who have a gastrectomy do not routinely go to ICU.

## Pain

It is very important that pain is controlled adequately:–

- for comfort;
- to enable effective breathing and to minimize the risk of chest problems;
- to enable better mobility – vital for breathing, increasing muscle strength and stamina and to avoid deep vein thrombosis.

It is possible that you will experience some pain and/or discomfort after the operation. Most patients will have pain controlled using an epidural. This is a fine plastic tube that is inserted into the space around your spinal cord so that a drug can be given to numb the nerves. Your doctor or nurse will explain this procedure to you. Pain killing drugs can also be given through the feeding tube or by mouth or intravenously (through a vein). The Acute Pain Team monitors pain control after surgery. It is vital to let your nurse or doctor know if your pain is not under control.

## Drips, drains and tubes

A drip will be used to give you fluids until you are able to eat and drink again. You may also have a naso-gastric (NG) tube, as total gastrectomies usually don't have a NG tube. This is a fine tube that passes down your nose into your stomach and allows any fluids to be removed so that you don't feel sick. This helps the area of the operation to recover. You will have chest drains in place for a few days – this always applies to an oesophagectomy, not always for a gastrectomy. These tubes are inserted into your chest during the operation to drain away any fluid that may have collected around the lungs. The fluid drains into a bottle beside your bed.

A Jejunostomy tube (Jej tube) is normally inserted during an oesophagectomy. This is the tube through which you will be fed while you cannot eat and drink or as a top-up to your nutrition in the early weeks following surgery. Patients who undergo a gastrectomy will not have a Jej tube inserted as they are likely to get back to eating and drinking more quickly.

## Breathing after your operation

In the post-operative period, a Physiotherapist will teach you exercises to re-expand your lungs to enable you to clear any

mucus that has built up in your lungs during the operation. They will also show you how to cough effectively with your wound supported. They will also assist you to walk from the first day after your operation as this promotes lung re-expansion.

## Enhanced Recovery after Surgery (ERAS)

Enhanced Recovery is a new way of improving the experience and well-being of people who need major surgery. It helps the patient recover sooner so that life can return to normal as quickly as possible.

The programme focuses on making sure that patients are actively involved in their recovery, with daily goals and targets to achieve to help keep the patient focused and motivated in their recovery.

The Oxford University Hospitals NHS Trust has enhanced recovery programmes for oesophagectomy, total gastrectomy and partial gastrectomy.

## Mobility

After your operation you will be encouraged to start moving around on the first day after your operation and then regularly from then until your discharge. This is an essential part of your recovery. If you have to stay in bed it is important to do regular leg movements to prevent blood clots forming in your legs. The physiotherapist and ward nurses will help you until you are able to walk independently. To enable you to monitor your progress the ward has a walking track with distances clearly marked every 10 metres.

## Eating and drinking

At first you may be allowed sips of liquid, and the usual progression is to clear fluid, free fluids, soups and smooth puddings, to fork mashable, until your doctor is satisfied that the join (anastomosis) in the oesophagus/stomach is healing. Mouthwashes can help freshen the mouth. During an oesophagectomy, the surgeons put a small feeding tube (Jej tube) into the middle part of the small bowel (jejunum) through a small cut made in the wall of the abdomen (tummy) and this will be held in place with three stitches. This is used for feeding and medications until you are able to eat and drink enough. You will be discharged with the feeding tube in place.

You will be shown by ward nurses, how to flush Jej tube daily. It is important to inform your Advanced Nurse Practitioner (ANP) if one or more of the stitches come out. If this happens, put a dressing over the tube until you get it stitched back in place. If you are eating and drinking well enough at your first follow-up appointment – and you are not going to have further treatment, then the tube can be removed.

You may feel afraid to swallow for a short while and you may be able to feel the upper join when you swallow. Eating and drinking and using the oesophageal muscles will help reduce this feeling. For the first 2–3 weeks you should choose a soft, moist diet. It is important to eat 'little and often' as you will not be able

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to cope with a large meal. You may lose some weight in the first few weeks after your operation. Weight loss is common after surgery and should slow down once your eating improves. Inform your dietitian or ANP if you are not eating or you continue to lose weight.

Many people find they have a poor appetite during the early stages of recovery. Initially your sense of taste may be affected with food and drink not tasting of much. You may prefer more sweet or savoury foods than you did before. You may also find that your sense of taste changes during the first few weeks. You may find that one week you like something and the next you don't.

Relax, avoid rushing meals and chew your food well before swallowing. Try using a smaller plate and serve meals which are attractive and colourful. If you are too tired to prepare a meal, have a ready meal instead. You may find food has no taste, so try highly seasoned or marinated food. If you find cooking smells are a problem, avoid the kitchen or use cold or microwaved foods. Perhaps someone else can prepare your food for you. However, for some people, the smell of food will tempt the appetite.

In time, most patients will work out a best routine for meals. Every patient is different.

## ***'Little and often'***

The key to eating well after surgery is not to eat large meals, but to eat smaller amounts regularly. You may find this difficult at first, but try to eat **SIX** times a day; three small meals with 3 nourishing snacks in-between. Eat slowly and chew your food well. This will help you digest your food and prevent you feeling full too quickly. You will feel uncomfortable if you eat too much at one time. A good guide would be to eat half of a normal portion size. You will gradually get to know what is the right amount for you. Try to have your last meal at least 2 hours before going to bed or lying down.

While eating is important, so is the intake of fluids to maintain hydration. However, it is a good idea not to drink for an hour before your meal or for one hour after your meal as it will fill you up and reduce your capacity for food.

## ***Gaining weight***

People may have lost weight prior to surgery and may continue losing weight after leaving hospital. However, it is beneficial to aim to maintain your weight to aid recovery. Some people never return to the weight they were prior to their illness. It may take anything between a few months to a year or longer – but by eating little and often you should be able to maintain a good calorie intake. However, there are ways to increase your calorie intake (see appendix). If you become in any way concerned about your on-going weight loss, contact your dietitian.

## ***Vitamin B12 and stomach surgery***

Your body may experience difficulty in absorbing certain vitamins and minerals. Vitamin B<sub>12</sub> plays an important role in making red blood cells. So if you have had your stomach removed, you will need an injection of B<sub>12</sub> at your GP surgery, usually every 3 months. If you have only had a part of your stomach removed, ask your doctor to check your levels of B<sub>12</sub>.

## ***Vitamin and Mineral Supplements***

After all types of stomach and oesophageal surgery it can be difficult to take in the right amount of vitamins and minerals. Talk to your dietitian about vitamin and mineral supplements that may be recommended.

## ***Unexpected symptoms***

Following your operation it will take your body some time to settle down and find how to work with your new body. This may cause you unexpected symptoms. Most of these will subside with time.

## ***Dumping Syndrome***

Normally, the stomach controls the release of food into the bowel. After an operation to remove part or all of your stomach, the loss of this slow and steady release can result in a number of symptoms known as Dumping Syndrome. The symptoms occur when the food you have eaten passes rapidly through the digestive system and into the bowel. It can be unpleasant and distressing, or the symptoms may be mild, but it is not serious and generally the frequency of episodes becomes less. The effects normally disappear in half an hour or so. In most cases, Dumping Syndrome symptoms can be avoided or managed. Speak to your dietitian if you suspect you may have it.

There are two types of Dumping Syndrome: Early and Late:–

### ***Early Dumping Syndrome***

This can occur within 30 minutes of eating. It is due to a high concentration of undigested food moving too quickly into the bowel from the stomach, stomach tube or oesophagus.

The stomach usually acts as a reservoir to store food while it is mixed with digestive juices, churned and broken into smaller particles.

When food is delivered too quickly into the bowel either due to the loss of the stomach or loss of its reservoir function, water will follow causing a drop in blood pressure. This can cause bloating, nausea and diarrhoea.

### ***Late Dumping Syndrome***

Late dumping occurs 1–3 hours after eating. This happens

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when the food delivered into the bowel is absorbed more quickly than usual. In response, the body releases insulin, a hormone which causes blood sugar levels to drop. This can make you feel weak, faint, sweaty and dizzy and cause palpitations. Lie down and rest until you feel better. Then continue to eat and drink as you would normally.

Your bowels may be slow to get going in the first days post operation due to the constipating effect of some pain medications. You may require laxatives to encourage a normal bowel function. You may also have some diarrhoea for a while after the operation, this is not unusual and can be controlled with medicine if it continues.

## ***Gastric retention and sickness***

Food can sometimes remain in the stomach rather too long, causing you to feel sick and bloated, with, sometimes persistent, burping. This may occur as you begin to eat slightly bigger meals. It is common and your GP will be able to give you a medicine (for example, metoclopramide or domperidone) which you should take half an hour before each main meal to improve the movement of food through the system. You will not need it forever – just until the body gets used to the new arrangements.

If you have had an oesophagectomy and there are repeated episodes of regurgitation or feeling of fullness, discuss this with your ANP or surgeon – major nerves are severed during the operation and this may be the cause of the problem. Sometimes an antacid is prescribed, occasionally an endoscopy is required to stretch the exit of the stomach (pylorus).

## ***Food sticking***

If food gets stuck, try having a fizzy drink. If the blockage occurs for more than a couple of hours, ring the ANP, surgeon, dietitian or hospital ward for advice. Remember, choose soft, moist foods for 2–3 weeks and chew it well.

Post-surgery scar tissue at the join in the oesophagus may restrict the flow of food or cause it to stick and cause problems with swallowing. This can be a worrying reminder of the original issue, however, an endoscopy can be performed to stretch the join. Some patients need this performed more than once. Please do not let this situation go on for too long, consult your ANP or surgeon.

## ***Acid regurgitation (reflux)***

Sometimes an extremely unpleasant feeling in the stomach may come over you for a short while, particularly first thing in the morning or at night. Although there may be no acid burning in the throat the trouble appears to be caused by acid in an empty stomach.

Some food in the stomach or gut helps to absorb the acid and there are also medicines which can help to prevent its regurgitation (prokinetics) or reduce its formation (proton pump

inhibitors – PPIs). If you continue to experience reflux, please contact a member of your clinical team.

Extra pillows or raising the bed head by about 10–15 cms (4–6 inches) with blocks of wood or a house brick can be very beneficial and a pillow under the knees may prevent slipping down during the night. If you have had an oesophagectomy, whether you sleep flat or propped up, may be affected by the position of the join between the remainder of the oesophagus and the smaller stomach. The higher the join is, the less reflux may be experienced.

If you feel reflux is about to happen, drink some water to dilute the effect and encourage it to go downwards. It should become less frequent in time, but there may always be a possibility of it occurring. You may also find a reduction in reflux by avoiding eating late into the evening.

## ***Wind***

Burping more than usual is not unusual. In the early days, this can cause embarrassment, but with some practice this can be controlled. It also happens that wind gets trapped in the stomach area which can be painful and worrying, however it does improve fairly quickly.

## ***Diarrhoea***

Patients may suffer from diarrhoea, particularly in the first few months after the operation. It may be accompanied by colicky pain.

This problem does ease over time (maybe also with the help of medicine prescribed by your GP), but it often happens for no apparent reason, that is to say that it cannot be related to any food that has been taken. It will not harm to keep a food diary, but also to reduce the amount of intake of high fibre foods, *i.e.* less fruit, green vegetables, pulses (beans and lentils), high fibre cereals and wholemeal bread. While the condition may be a nuisance, don't be over concerned and consult your GP if it persists. If you are having loose stools, pale in colour and difficult to flush, sometimes accompanied by increase in wind, please contact dietitian or ANP as you may not be absorbing fat well.

## ***Speed of recovery***

Your GP will be informed when you are leaving hospital. It is possible that the district nurse will also be informed, if you need specific care, e.g. if a wound needs dressing.

Recovery from a major operation involving digestive organs is not fast. It can take months for the digestive system to adapt after surgery although some patients recover quicker than others. It will be some months before you are at your peak again and you will have good and off days along the way. Try not to be impatient.

Initially you will feel very tired, possibly exhausted at times and plenty of rest is needed. Sometimes the tiredness may come on

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very quickly; don't feel you have to fight it. An afternoon nap in bed is helpful for the first 5–6 weeks to prevent you getting overtired, or you may find you need to go to bed for several hours during the day and still need to go to bed early in the evening. Take some gentle exercise as soon as you can – walking to start with for just a little further each day – it will help stimulate the appetite. It will also stimulate your breathing, helping the chest to expand and restore its suppleness, and helps to build up strength and stamina.

## **Lifestyle after surgery**

Your aim after getting over your operation may be to become fitter than you were before. Muscles, bones and organs have all been affected in the chest, abdomen and often, the throat. Recovery takes some time; if you were working you are going to be off for some months and it could be more than 12 months or so before you are really at your best, although hopefully you will feel pretty well long before that.

## **Exercise**

You will be helped to start exercising very quickly after the operation; the physiotherapist has to get your lungs going again, expelling fluid that can gather as a result of the operation and anaesthetic. This may feel hard work at the time but effort put in at this time is well worthwhile. As you get out of bed and feel so weak you see the challenge. Walking is about all you can do at this stage. Any effort exhausts you and going up stairs is like climbing Mount Everest, but try walking a little further each day and it will get easier.

Progressive exercise during this early period should be taken by increasing speed or distance – **not** both. Bear in mind that outdoor walking is more difficult – there may be slopes, a wind and heavier clothing to wear – and don't forget you have to get back again!

Look after yourself at this stage, not the house work! Continue the breathing exercises the physiotherapist taught you in hospital – six deep breaths each held for a count of 3 and gently exhaled. Do this 5 or 6 times a day. It can be done sitting up straight or standing. (If there is still phlegm coming up you may have been given extra exercises to do – don't neglect them!)

## **Back home**

Progress may seem slow, but pushing it too hard will possibly do more harm than good. Don't try to prove anything; it's not worth it, the body will take its own time. During this early stage, coughing, perhaps occasional sickness and movement generally will be painful and you may feel that things will come apart inside. Be assured – they will not. If you have had an open oesophagectomy the ribs do take time to repair and it will be a month or two before you can sleep on the side affected. Muscles too have been stitched together but these heal well in about two months; bones and cartilage take rather longer. Nerves, which are necessarily severed in any operation, repair very slowly indeed

and some areas around the wound may remain numb.

Surface pain at the wound may occasionally occur for years. Nothing to worry about – it's the raw nerve endings. However, if you experience continued pain, you should request a medical review by your surgeon.

You may feel able to tackle the odd bit of housework after a few weeks but don't aim to complete it all in one go.

You may find that your ability to concentrate has been affected. This can be very frustrating, but it will gradually return. It may help to take up a new hobby that is not so demanding while you have got time on your hands.

## **Driving**

The real test with regard to going back to driving is that you must be capable of making an emergency stop. Have a couple of practice runs first! Equally important is that you must be in a frame of mind that makes you feel safe and in control.

## **Eating and eating out**

There is absolutely no reason why you cannot return to a full social life including dining out with family and friends, so long as they understand that you can only eat small portions and need to eat and drink separately. You should have been given a card, the size of a credit card, which you can carry in your wallet or purse which can be shown in a restaurant explaining that for medical reasons you require a child's portion. They are available in English only or English backed with Dutch, French, German, Greek, Italian, Portuguese and Spanish. (If you did not receive one, please call OOSO and ask for one – contact details are at the end of this booklet.)

Some patients may shy away from eating tough meat and bread as it can be difficult to swallow. However, you should be able to manage mince, soft meats, such as corned beef, and slow roasted meats in the first few weeks and move to normal textures after this.

## **Sleep**

It may take a while to get back into a normal sleeping pattern. In order to ensure a good night's rest, taking a painkiller just before going to sleep would be a good idea. In the early days, an afternoon nap is common, however, it is advisable not to sleep much beyond 4:00 pm as it may otherwise interfere with your night sleep.

Because of medication that is given, some patients experience hallucinations or dreams, but these will tail off after a while. If they persist, please consult your GP.

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## ***Psychological effects and support***

For some, it is an overwhelming experience, from diagnosis to treatment and adjusting to the effects of the surgery. If you find the emotional reaction to what you have been through is a problem, try talking to family and friends or your GP, or a member of OOSO, each of whom has been through a similar experience and can relate to your experience. If you are struggling with your emotions and adjustment, it is important to speak to your ANP.

## ***Relationships and sex***

The invasiveness and enormity of either an oesophagectomy or gastrectomy cannot be overstated and inevitably it can alter our relationships with others. Feelings for our closest family may be enhanced and the patient may need extra love and reassurance. It is normal to feel anxious about having sex, but give the patient plenty of time if they feel uneasy about resuming sex. There is no reason why sex cannot be possible and as enjoyable as before.

## ***Review with your surgeon***

You should be seen by your surgeon within a few weeks of your discharge from hospital. If you experience any concerns, please contact your ANP – it is natural for you to worry about cancer recurring but in time your confidence will grow. If you have any concerns see your GP or contact your ANP. If there are problems in between appointments, then contact your ANP or surgeon. They will always be pleased to see you earlier.

## ***Three to six months after surgery***

We are all individuals but somewhere within this period you should be able to tackle more exercise. Perhaps swimming, as it is very good exercise for all ages. Take someone with you to give you confidence and the benefits will soon show.

For the non-swimmer (though it's never too late to learn) walking is good all-round exercise as long as you walk far enough and at a fair pace. Cycling and dancing are also suitable as they need not be too strenuous, and as you become stronger any sport that you enjoy can be added, but don't start with competitive games like squash and badminton and avoid lifting weights. Sports like running can be added later (up to marathon standard if you are really determined).

Activities which involve bending down may cause acid regurgitation. This would apply to some yoga exercises and to gardening (usually weeding) where it can be avoided by squatting or kneeling and using long-handled tools.

## ***Back to work***

When you go back to work is entirely up to you and depends on a number of factors: your age, type of work, effort put into regaining fitness. In any event, it may be some months before you go back to work. Heavy work makes more demands and might in

fact not be suitable if much bending and lifting is involved. It is always helpful if you and your employer discuss your immediate future with the company and how you can use alternative skills until you are fully fit again. Maybe you could discuss a slightly shorter working day initially, thereby avoiding rush hour traffic. Also, if you ordinarily drive or work with machinery, you could tire too easily so this should be avoided. Finally, always remember to plan your snacks when you need them – **little and often**.

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## Appendix

### *The art of eating*

Following an oesophagectomy or gastrectomy, it is important that you change your eating habits of a life-time. Rather than having three large meals per day, you need to eat at least SIX times per day; three small main meals interspersed with nourishing snacks.

It is important to remember to drink **between** meals so that you are able to eat food at meal times. You will need to follow a soft, moist diet for 2–3 weeks following surgery. After these 2–3 weeks there is no need for a special diet, unless you follow one for other reasons.

If the smell of cooking makes you feel sick, use convenience foods – supermarkets have a range of frozen, chilled or packet ready meals and home delivered frozen meals are also available. You won't need to rely on these sources of foods for any great length of time. Alternatively ask friends and family to cook at their houses and bring cooked food to you.

Another way to avoid eating difficulties is to cook enough food for two meals and freeze one for a different day.

Following are some meal ideas for when you have progressed beyond a soft, moist diet:

### **Breakfast**

Instead of plain egg and bacon, fry the egg and add a slice of buttered toast.

Stewed fruit with full fat yoghurt.

Muffin or crumpet with honey or jam.

Full fat yoghurt with nuts, seeds and dried fruit.

Ready Brek or Weetabix with fortified milk\* and a sprinkle of sugar.

Porridge with fortified milk and added sugar or honey.

\* fortified milk is full cream milk with 4 tablespoons of milk powder added.

### **Mid-morning**

Try having one of the following with your mid-morning cup of coffee or tea: biscuits; a slice of your favourite cake; a couple of squares of your favourite chocolate; fromage frais, full fat yoghurt, milky pudding or plain custard. Or for those of you with a more savoury tooth, try having crackers and cheese; bread sticks; a savoury dip, or crisps.

### **Lunch**

Jacket potato, mash the centre of the potato with extra butter and add a filling such as, cheese, baked beans, chicken or tuna and mayonnaise.

Beans or cheese on toast or tinned, oily fish on toast.

Steamed fish with vegetables, remembering to add butter to the

vegetables.

Your choice of soup with added cream or cheese.

### **Mid-afternoon**

Experiment with a variety of fresh or stewed fruit, well chopped, served with either custard, cream, yoghurt or ice cream.

### **Dinner**

Wherever possible and when suitable, serve the main meal with a sauce or gravy.

Pasta with a sauce – bolognese, cheese, tomato, macaroni cheese or lasagne with a side salad with added dressing.

Moussaka.

Grilled fish (with a sauce – cheese, parsley, white) and buttered vegetables or rice.

Chicken (either thinly sliced or casseroled) with roast potatoes and buttered vegetables.

Shepherds or cottage pie with buttered vegetables.

### **Adding nourishment to your meals**

Use full cream milk/cream in drinks, foods and cooking.

Add extra butter to vegetables and crackers.

Add extra cheese to potatoes, soups, scrambled egg or omelettes.

Add sauces to vegetables and fish.

# Life after an Oesophagectomy or Gastrectomy

## GLOSSARY

Following are some of the words you may come across when cancer is diagnosed and while you are being treated. It is not a complete dictionary of medical terms, and there may be medical terms you hear used which are not listed here. You can always ask your doctor or nurse what a word means if you don't understand it.

### **Ablation**

The removal or destruction of a body part or tissue or its function. Ablation may be performed by surgery, hormones, drugs, radiofrequency, heat or other methods.

### **Adenocarcinoma (AC)**

The most common type of cancer which occurs at or near the junction of the oesophagus and the stomach.

### **Adjuvant treatment**

Additional treatment, such as chemotherapy or radiotherapy given after surgery.

### **Advanced cancer**

When cancer cells spread from where they first grew to other parts of the body. Also known as metastasis or secondary cancer. This can also be when the cancer attaches itself to adjacent organs.

### **Advanced Nurse Practitioner (ANP)**

Nurses trained to an exceptionally high level specialising in particular illnesses.

### **Anaesthesia, anaesthetics**

Drugs or gases given before and during surgery so that the patient will not feel pain. The patient may be awake (local anaesthetic) or asleep (general anaesthetic).

### **Anastomosis**

A connection made surgically between adjacent blood vessels, parts of the intestine, or other channels of the body, or the operation in which this is constructed.

### **Barrett's Oesophagus**

A condition in which the cells lining the lower part of the oesophagus have changed or been replaced with abnormal cells that could lead to cancer of the oesophagus. The backing up of stomach contents (reflux) may irritate the oesophagus and over time, cause Barrett's oesophagus.

### **Benign**

Tumour that is not malignant or condition that does not produce harmful effects. It is usually not life-threatening.

### **Biopsy**

One of the main tests used to diagnose cancer. A piece of body tissue is removed from the area where there might be cancer, and the cells are examined under a microscope. This is one of the tests used to decide whether or not a person has cancer, and what type of cancer it is.

### **Blood cells**

Cells that make up the blood. There are three main types – red blood cells (which carry oxygen around the body), white blood cells (which fight invading germs), and platelets (which help the blood to clot).

### **Brachytherapy**

The placement of a radioactive source on or inside a tumor.

### **Cancer**

1. Cancer is present when the normal division of cells gets out of control and invades healthy tissue.
2. Cancer – general term to describe a collection of diseases.

### **Carcinoma**

A type of cancer which begins in the lining or covering of an organ.

### **Chemotherapy**

A drug treatment usually with anticancer drugs. A course of treatment usually takes several months.

### **Consultant**

Most senior doctor.

### **CT Scan (CAT Scan)**

Computer Aided Tomography scan. X-ray scan using a computer to construct pictures of the body in cross section and 3D body images..

### **Diagnosis**

Identifying a disease in a person's body, or deciding what is wrong with them.

### **Dietitian**

A specialist in nutrition in the field of oncology and specialist surgery.

### **Dumping syndrome**

A condition that occurs when food or liquid moves too fast into the small intestine. Symptoms include cramps, nausea, diarrhoea, sweating, weakness and dizziness. Dumping syndrome sometimes occurs in people who have had part of their stomach removed.

### **Dysphagia, Dysplasia**

Difficulty or discomfort when swallowing. Cells that look abnormal under a microscope but are not yet cancerous. Abnormal cells which if left untreated could develop into cancer.

### **Endoscopy**

A procedure that uses an endoscope to examine the inside of the body. An endoscope is a thin, tube-like instrument with a light and a lens for viewing. It may also have a tool to remove tissue to be checked under a microscope for signs of disease.

### **Hepatobiliary (HPB)**

"Hepato-" refers to the liver and "-biliary" refers to the gallbladder, bile ducts, or bile.

### **Hickman Line**

A special tube put in under anaesthetic through the chest wall into a large vein, so that chemotherapy drugs can go directly into the bloodstream.

### **HPB Dietitian**

Hepatobiliary dietitian.

### **ICU**

Intensive Care Unit.

### **In situ**

The earliest stage of cancer, when it has not spread to any other organ or area of the body.

### **Jejunostomy tube, (Jej tube)**

A feeding tube normally inserted during an oesophagectomy, into the small bowel. This is the tube which you will be fed through while you cannot eat or drink. Patients who undergo a gastrectomy will not have a Jej tube inserted as they are likely to get back to eating and drinking more quickly.

### **Laparoscopy**

Procedure using a flexible tube of optic fibres to look inside the body and to collect sample tissues.

### **Lymph nodes**

Lymph nodes are small masses of tissue found in clusters which purify the lymph fluid and form lymphocytes (white blood cells) Small bean-shaped organs, sometimes called lymph glands, which are part of the lymphatic system. The nodes are part of the lymphatic system, which is the body's natural defence against infection.

# Life after an Oesophagectomy or Gastrectomy

## **Metastasis, Metastasis, Metastatic**

The spread of cancer cells from one part of the body to another through the bloodstream or lymphatic system. Cells that have metastasised are like those in the original tumor.

## **MRI**

**Magnetic Resonance Imaging.** Scan using magnetism to build up a picture of the organs inside the body.

## **NMR**

**Nuclear Magnetic Resonance.**

## **Nausea**

Feeling sick.

## **Nutrition**

A healthy diet and the correct intake of vitamins and minerals. This can be difficult to achieve for some people with cancer and they may need advice from health professionals/dietitians.

## **Nutritional supplements**

Specially formulated drinks, powders and foods to increase calorie intake and help weight gain.

## **Oesophagus**

The tube that runs from the mouth to the stomach.

## **Oncologist**

Specialist doctor treating cancer. A consultant clinical oncologist usually treats patients with radiotherapy, chemotherapy and hormone therapy. A consultant medical oncologist normally specialises in chemotherapy and hormone therapy.

## **Oncology**

Study and practice of treating cancers. Can be divided into medical, surgical and radiation oncology.

## **Palliative care**

Palliative care is designed to manage symptoms rather than cure. It can be used at any stage of the illness if there are symptoms such as pain or sickness. Palliative care may help someone to live longer and to live comfortably, even if they cannot be cured.

## **Pathology**

The study of diseased tissues.

## **PET Scan**

**Positron Emission Tomography.** A scanner which uses a radioactive drug (tracer) which shows how the body tissues are working as well as what they look like.

## **Physiotherapist**

A person who has specialised in exercises required to help patients to regain fitness following surgery.

## **PICC Line**

**Percutaneous Intravenous Central Catheter** – a long intravenous line going into your arm, to give antibiotics or chemotherapy.

## **Primary Cancer/ Tumour**

Site where the cancer started. The type of cell that has become cancerous will be the primary cancer. For example, if a biopsy from a liver, lung or breast contains cancerous cells, then the primary cancer is where these cells originate.

## **Prognosis**

The predicted or likely outcome of what might happen in a specific case of cancer.

## **Pylorus/Pyloric Sphincter**

The sphincter is at the bottom of your stomach (pylorus). This sometimes needs to be stretched after an oesophagectomy.

## **Radiotherapy**

Cancer treatment using high-energy rays. It can take the form of 'external beam radiation', which is aimed to destroy the tumor and surrounding tissue or 'conformal' radiotherapy, which is a more targeted approach to minimise radiation to the surrounding area or 'intraluminal radiation' which places a radioactive source close to the cancer. 'Rad' stands for radiation absorbed dose. Gy (Gray) is a measurement unit of absorbed radiation.

## **Radiographer**

Person qualified to operate radiotherapy machines and take X-rays. Radiographers specialise in either diagnostic or therapeutic functions.

## **Radiologist**

A doctor who specialises in reading X-rays and scans and carries out scans and other X-ray techniques.

## **Squamous**

Consisting of a single layer of plate-like cells. A covering resembling scales.

## **Squamous Cell, Carcinoma (SCC)**

Squamous cell carcinoma usually occurs higher up in the gullet than adenocarcinoma.

## **Staging**

The extent of a cancer in the body. Staging is usually based on the size of the tumor, whether lymph nodes contain cancer, and whether the cancer has spread from the original site to other parts of the body. Each cancer type has its own staging, often from 0 to 4 or A to D.

## **Surgeons**

They perform operations and other surgical procedures (including biopsies) to diagnose and treat cancer. There are many different kinds of surgeon and they have different areas of interest or expertise. They may specialise in a type of cancer, such as oesophageal or gastric cancer, or in operating on a particular part of the body. Sometimes several surgeons work together.

## **Thoracotomy**

An operation to open the chest.

## **Tumour**

A growth or enlargement that causes a swelling. It is also called a neoplasm. A tumor can be localised or spreading, harmless or cancerous. It is named after its location, or its cellular make-up or for the person who identified it.

## **Tylosis**

A very rare skin disorder which is associated with oesophageal cancer.

## **Upper gastrointestinal**

The upper part of the digestive system, including the oesophagus, stomach, liver, pancreas, gall bladder and bile ducts. Often shortened to Upper GI.

## **Ultrasound**

Scan using sound waves to build up a picture of the inside of the body. The resulting picture of body tissues is called a sonogram.