Oxfordshire Oesophageal and Stomach Organisation

Registered Charity No: 1152733

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

We are grateful to the following people from the Oxford University Hospitals NHS Foundation Trust Churchill Hospital, for reviewing and contributing to it:

— Nick Maynard, Consultant Upper GI Surgeon
— Anne Phillips, Upper GI Senior Specialist Nurse
— Liz Ward, Upper GI Specialist Dietitian
— Hamira Ghafoor, Enhanced Recovery Programme Facilitator
— Nathan Robbins, Surgical Specialist Physiotherapist

Illustrations by Julian King

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 keeping ourselves as fit as possible.

Contents

Introduction 1

The oesophagus 1
- Causes 1
- Symptoms 2
- Breathing before your operation 2
- Nutrition before your operation 2
- An oesophagectomy 3
- Keyhole surgery 3

The stomach 4
- Causes 4
- Symptoms 4
- Breathing before your operation 4
- A gastrectomy 5

Life after an oesophagectomy or gastrectomy 6
- After your operation 6
- Pain 6
- Drips, drains and tubes 6
- Breathing after your operation 6
- Enhanced Recovery After Surgery (ERAS) 7
- Mobility 7
- Eating and drinking 7
- 'Little and often' 8
- Gaining weight 8
- Vitamin B_{12} and stomach surgery 9
- Vitamin and Mineral Supplements 9
- Unexpected symptoms 9
- Dumping Syndrome 9
- Gastric retention and sickness 10
- Food sticking 10
- Acid regurgitation (reflux) 10
- Wind 11
- Loose Stools 11
- Speed of recovery 11
- Lifestyle after surgery 12
- Exercise 12
- Back home 12
- Driving 13
- Eating and eating out 13
- Sleep 13

Psychological effects and support 13
Relationships and sex 14
Review with your surgeon 14
Three to six months after surgery 14
Back to work 14

Appendix 15
The art of eating 15
Breakfast 15
Mid-morning 15
Lunch 15
Mid-afternoon 16
Dinner 16
Adding nourishment to your meals 16

Glossary 17

For your own notes 21

Former patients have gone on to …

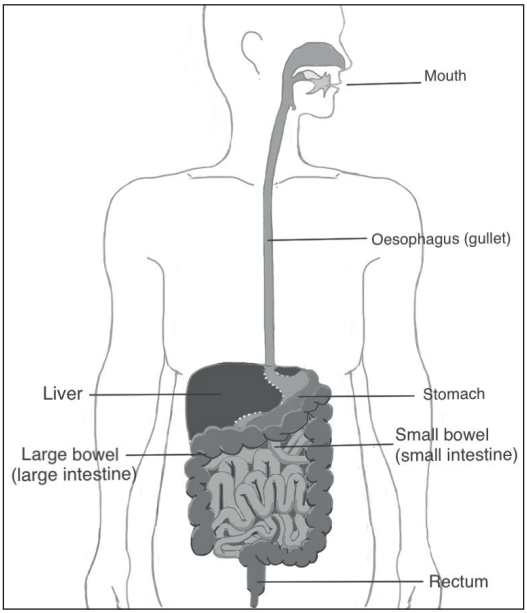
… perfect "sploshing" with her 2-year-old grandson;
… take a photographic holiday around India;
… enjoy a cruise in the Mediterranean;
… go on safari in South Africa;
… get married!

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 people 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 tumour 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 patients with Barretts) 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. We also signpost individuals looking to stop smoking to the National Smoking Helpline: Tel: 0300 123 1044 www.nhs.uk/smokefree

Prior to your surgery a Surgical Specialist Physiotherapist will teach you how to use an inspiratory muscle training device; this device will help build up the strength in your breathing muscles so that they are fitter and more able to cope with your operation. Your fitness levels will also be assessed and advice around exercise before your surgery will be provided by the Physiotherapist. Current pre-operative service is awaiting confirmation of ongoing funding - March 2020.

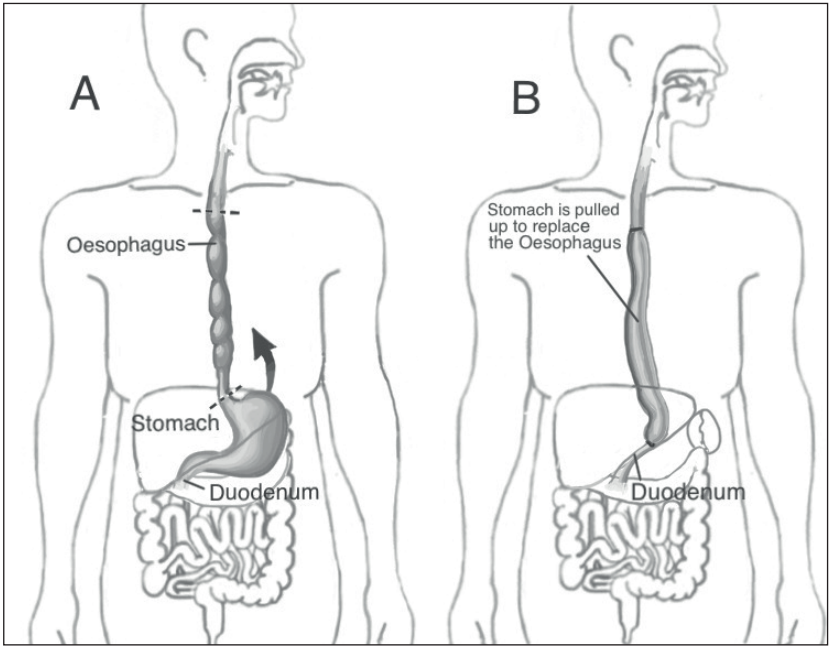
Nutrition before your operation

It is very important to remain well nourished before your operation. You may be advised to choose high calorie and high protein foods, fortify foods to add extra calories and protein and/or modify food textures. You will be guided by your

Specialist UGI Dietitian on a one to one basis when you attend clinic and you may be offered nutritional supplement drinks in the out patients clinic or by your GP. If swallowing becomes increasingly difficult, you may require a feeding tube **(Jejunostomy tube)** to be inserted into your small bowel for extra nutrition. Your Dietitian will discuss this further with you.

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 tumour. 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 but usually most of the stomach will be in the chest. Very occasionally the bowel is used to replace the oesophagus instead of the stomach.



A: Before surgery

B: Following an oesophagectomy

Keyhole Surgery

Some patients are offered keyhole (laparoscopic) surgery for part of their operation – either the abdominal part only, or both the abdominal and chest parts. Doing the operation in this way means you will only have a small opening or openings instead of one larger cut. Despite the smaller cuts, you should not underestimate the seriousness of your operation.

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 stomach starts the digestive process, but the rest of the digestive system can adapt well if the stomach is removed.

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 rare reasons why you might need a gastrectomy.

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 anaemia; feeling very full after eating.

Breathing before your operation

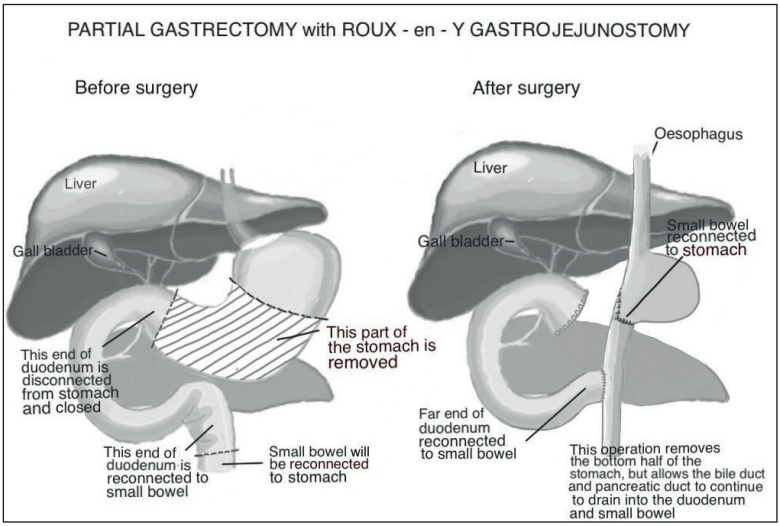
If you are a smoker, it is vital to stop smoking as soon as possible; help is available from your GP and most pharmacies.

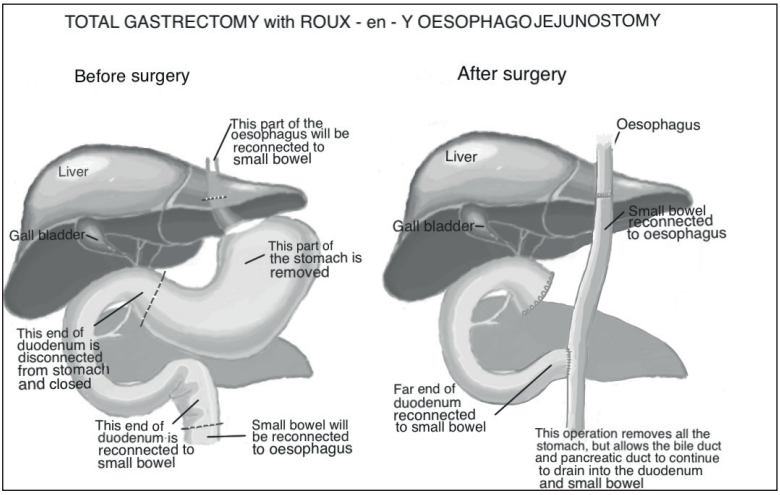
Prior to your surgery, a Physiotherapist will teach you how to use an inspiratory muscle training device; this device will help build up the strength in your breathing muscles so that they are fitter and more able to cope with your operation. Your fitness levels will also be assessed and advice around exercise before your surgery will be provided by the Physiotherapist. Current pre-op service is awaiting confirmation of ongoing funding - March 2020.

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 tumour. If you have a total gastrectomy, 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.





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. 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, but will go to the overnight recovery unit.

Pain

It is very important that pain is controlled adequately:–

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

You may 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, 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. 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 into the abdomen 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

During your post-operative recovery 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 you 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. Daily goals and targets for mobilising (walking) and nutrition (eating and drinking) help to keep you focused and motivated in your recovery.

The Oxford University Hospitals NHS Foundation Trust has Enhanced Recovery Programmes for oesophagectomy and gastrectomy.

Mobility
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 you will be provided with a diary to keep track of your progress and the ward has a walking track with distances clearly marked every 10 metres. You will be discharged with a supply of blood-thinning injections (to last 28 days after your operation) to reduce the risk of blood clots. In addition, you will be encouraged to complete a prescribed exercise programme to help with strengthening and recovery after surgery. You will also have access to a gym space where you can complete supervised exercise with specialist equipment.

Eating and drinking
At first you will be allowed sips of water, and the usual progression is to clear fluid; free fluids (drinks including tea/coffee with milk); soups and smooth puddings and then onto a puréed diet for home. Mouthwashes can help freshen the mouth. During an oesophagectomy, a feeding tube will be placed into the small bowel (jejenum)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, extra water and medications until you are able to eat and drink enough. You will be discharged with the feeding tube in place and all of the equipment needed to use it at home for top-up feeding.

You will be shown by the ward nurses how to the flush the Jej tube daily and a Nutrition Nurse will visit you on the ward to show you how to feed at home and use the equipment for home feeding. You can also receive further assistance once you are at home if you need more help or a refresher session. It is important to inform your Nurse Specialist or Specialist Dietitian 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. The tube is usually kept in place until you are able to meet your nutritional needs again by mouth and your weight has stabilised. You will be encouraged to use your jej tube for additional fluids until you are able to drink enough.

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 weeks you should choose a puréed diet, followed by a diet of soft and bite sized foods. You will receive detailed information regarding this. It is important to eat 'little and often' as you will not be able 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 Nurse Specialist 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 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** small meals per day. 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. It is a good idea to use a small tea/side plate so you are not tempted to serve yourself too much. 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 30 minutes before your meal or for one hour after your meal as it will fill you up and reduce your capacity for food. If you struggle to drink enough after surgery and you have a jej tube in place, speak to your Dietitian about using it for extra water.

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 and protein intake. However, there are ways to increase your intake (see appendix). If you become in any way concerned about your on-going weight loss, contact your Dietitian.

Vitamin B_{12} and stomach surgery

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

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. Therefore, we strongly recommend that you take a daily A–Z complete multi-vitamin and mineral supplement. Look for one with at least 12mg of iron.

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 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 by reducing your portion sizes, reducing the amount of refined carbohydrate or sugary foods. Speak to your Dietitian if you suspect you may have it. It is important to try to limit the frequency of Dumping Syndrome to ensure that you are absorbing enough energy, protein and viatamins and minerals to support recovery.

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 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 be given laxatives to encourage a normal bowel function. You may also have some diarrhoea for a while, 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 Nurse Specialist 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 sipping a warm drink and walking around. If the blockage occurs for more than a couple of hours, ring the Nurse Specialist, Surgeon, Dietitian or hospital ward for advice. Remember, choose puréed foods for 2 weeks and eat slowly.

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 Nurse Specialist 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 oeosophagus 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 for at least 2 hours before going to bed.

Wind

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

Loose Stools

Patients may suffer from loose stools, 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. If you are having loose stools, pale in colour and difficult to flush, sometimes accompanied by an increase in wind, please contact the Dietitian as you may not be absorbing all of the fat from your food.

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 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 helps to get you taking deeper breaths which will help to move any mucus 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. Activity that includes gentle upper limb and lower limb exercises are encouraged.

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. 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 recommendation is not to drive until 6–8 weeks after the operation. 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.)

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.

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 Nurse Specialist.

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 Nurse Specialist – it is natural for you to worry about cancer recurring but in time your confidence will grow. If there are problems in between appointments, then contact your Nurse Specialist 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 a 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 phased return to work, 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 meals when you need them – **little and often**.

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.

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 and bite sized 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 butter.
- 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 or semi-skinned milk with 4 tablespoons of skimmed 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 and a protein based dip, such as hummus, ideally try to eat something that provides you with protein such as crackers with pate or cheese rather than just biscuits or cake.

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 or tinned oily fish.

- Beans or cheese on toast or tinned, oily fish on toast.
- Steamed fish with vegetables, remembering to add butter to the vegetables (if you feel you have enough capacity for vegetables). Speak to your Dietitian if you are unsure.
- 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 or an olive spread to vegetables and crackers.
- Add extra cheese to potatoes, soups, scrambled egg or omelettes.
- Add sauces to vegetables and fish.

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.

Adenocarcinoma (AC) The most common type of cancer which occurs within the oesophagus, gastro oesophageal junction and the stomach.

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

Specialist Nurse 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).

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 glandular cells, often the lining of an organ.

Chemotherapy A drug treatment usually with anti-cancer drugs. A course of treatment usually takes several months.

Consultant Most senior doctor.

CT Scan (CAT Scan) **C**omputer **A**ided **T**omography 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.
Dysphagia	Difficulty or discomfort when swallowing.
Dysplasia	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.
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 usually have a Jej tube inserted as they are likely to get back to eating and drinking more quickly.
Laparoscopy	Procedure using a rigid tube connected to a camera which is usually inserted through an incision next to your umbilicus, 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.
Metastasis, metastasise, 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 tumour.
MRI	**M**agnetic **R**esonance **I**maging. Scan using magnetism to build up a picture of the organs inside the body.
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	**P**ositron **E**mission **T**omography. 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	**P**ercutaneous **I**ntravenous **C**entral **C**atheter – 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 tumour 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. 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 oesophagus than adenocarcinoma.

Staging	The extent of a cancer in the body. Staging is usually based on the size of the tumour, 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	Doctors who 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 tumour 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.

For your own notes

For your own notes

If you feel you would like to support the Oxfordshire Oesophageal and Stomach Organisation (OOSO), please visit our website, www.ooso.org.uk or tick below and return this form to us at:

OOSO
12 The Glebe
Aynho
Oxfordshire
OX17 3AZ

☐ Membership of OOSO

☐ Making regular donations

☐ Making a donation via *Charity Checkout*

☐ Giving via my payroll (Give As You Earn)

☐ Fundraising for OOSO

☐ How my company can help

☐ Leaving a gift in my will

Please complete your name and address alongside.

Our services are available free of charge to people who have had either an oesophagectomy or gastrectomy, their families and friends.

To make a donation online to support our work please visit www.ooso.org.uk.

This form allows you to make a donation by post.

I would like to donate £

Please enclose a cheque made payable to OOSO. (Please see address in first column.)

Signature: _____

Date: _____

Name: _____

Address: _____

Postcode: _____

Gift Aid

I am a UK taxpayer and would like OOSO to treat this and any subsequent donations as eligible for tax relief under the Gift Aid scheme. ☐

To qualify for Gift Aid, you must pay UK income tax and/or capital gains tax at least equal to the tax that the charity claims on your donations in the appropriate tax year. Tax year is 6 April one year to 5 April the next.

I do not require an acknowledgement of my donation. ☐

The OOSO help line is open from 8 am to 10 pm, seven days a week.

07711 160 766

www.ooso.org.uk

First Edition: January 2013
First Revision: December 2014
Second Revision: December 2016
Third Revision: December 2018
Fourth Revision: February 2020