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Cancer Support Helpline: 0121 704 9860

The OPA Guide to Life After Oesophageal/ Gastric Surgery

Oesophageal and Gastric Cancer Support

Registered Charity No. 1194327

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1. INTRODUCTION

You have had a major operation and might be feeling that life can never be the same again. It can, with slight modifications, and it can in fact be a very good life.

Your objective now must be to learn to live with the changes in your system so that they affect your quality of life as little as possible.

There is no need for a special diet: you can eat and drink anything you like, but some guidelines may influence the way you eat. For example, for the first 4–6 weeks, you should eat food that is soft and well-cooked and adopt a regime of eating little and often. Almost certainly, you will soon develop a greater interest in healthy eating, that will be better for you

The recovery process is slow, but slow, steady improvement is best. It is possible for people to return to their former fitness level over time, and they can even run marathons!

In the UK, the most common reason for undergoing the operation you have had is cancer, but it can also be due to a rupture of the oesophagus, a long-term hiatus hernia, the development of Barrett's oesophagus, a congenital condition. Research has been continuously carried out on both the causes and treatment.

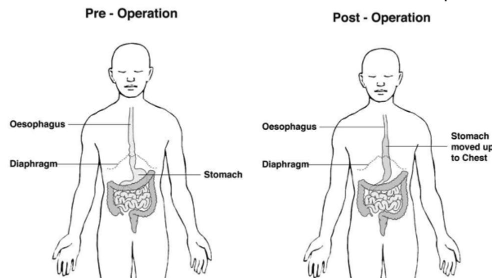
You may initially wonder, if you will ever recover from this operation has left you feeling as if you have been under a steam-roller. At first, you may feel exhausted by the slightest exertion, and will thus need a lot of rest but you will soon notice a gradual improvement. Your recovery will occur over a number of months.
And some people will take longer than others.

This booklet will help you as it is based on the experiences of those who have had the same operation as you, and it offers valuable input from health professionals.

2. THE OPERATION

Oesophagectomy

This operation involves removing part of or most of the oesophagus (gullet) and part of the stomach, with the degree of removal for each varying according to the position of the tumour. The stomach is subsequently moved into the chest and joined to the remainder of the oesophagus. The position of the joint may be near the neck or slightly lower, and part of or the whole stomach may be in the chest. To help heal the join, at the hospital, you may have been fed through a tube inserted up the nose and into the stomach, or perhaps directly into the small intestine (the jejunum) where most of our digestion takes place.

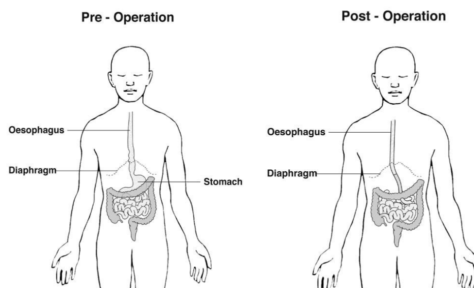


Gastrectomy

In this operation, the whole stomach has been removed (total gastrectomy), the upper part of the small bowel (the jejunum) is joined to the lower part of the gullet (oesophagus).

If only part of the stomach has been removed, the small bowel is joined to the remaining part of the stomach (distal or subtotal gastrectomy).
This means that the food you eat will pass almost immediately from the stomach into the small bowel.

After oesophagectomy, to help heal the join, you may have been fed through a tube inserted up the nose and into the stomach or perhaps directly into the small intestine (the jejunum) where most of our digestion occurs. In the future, you will need to get regular injections of vitamin B12 from your General Practioner (GP).



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

Keyhole surgery (laparoscopic or minimal access surgery)

Some people undergo a partial or full surgery, performed using keyhole surgery. This means that although the same operation is performed, you would not end up with a large wound. You may therefore recover faster, but remember that although there is little to notice on the surface, your body still has to recover and this will take time.

Keyhole surgery has some crucial advantages and disadvantages that should be discussed in detail with your surgeon. Bear in mind that all surgeons or units are trained in keyhole techniques.

What do I need to know about vitamin B12?

If a large part of or the whole stomach has been removed, you are likely to develop a type of anaemia resulting from a vitamin B12 deficiency. This is because the stomach produces a protein called the intrinsic factor that the body requires to be able to absorb vitamin B12 from food.

This type of anaemia does not present immediately as your body may have a store of vitamins and may take six months or more to manifest. If you underwent a total gastrectomy, then you will require injections of vitamin B12 every three months.

Your GP should be informed of the need for these injections to organise their administration.

Enteral (tube) feeding

As part of your operation, a small feeding tube may be inserted into your bowel; this is called a jejunostomy or JEJ tube. It is routine in some Upper gastrointestinal units, whereas in other units, a tube is used only in select patients. Please contact your surgeon for more clarity about this.

A liquid feed may be used to ensure that you receive the nutrition you need whilst your ability for oral intake is re-established. By the time people are ready to go home, most people have nutritional intake orally (via mouth), although enteral (tube) feeding may be used following discharge from hospital. If this is required, you will be taught how to use the pump and take care of the tube before being discharged

The extent of time you will need the enteral feed for varies from person to person, but it usually ranges from a few weeks up to three months. You need to continue taking enteral feeds until your complete nutritional intake can be carried out orally. Please refer to individualised instructions on your feed plan and care instructions.

What to ask your surgeon?

Most surgeons treating oesophageal and gastric cancer work in large hospitals that have all the specialists to look after patients undergoing the operation. These include critical care facilities (intensive care or high-dependency units), interventional radiology unit and other specialists to help care for you. It is important that your case is discussed at a multidisciplinary team (MDT) meeting so that you get the best possible treatment.

All surgeons who have treated this cancer have their outcome data published online.
This can be found here:

- https://www.augis.org/Guidelines/NOGCA-Audit/Outcomes-Data-2021

The routinely collected outcome data for this operation includes the risk of dying after surgery within 30 or 90 days and the average length of stay. This can be compared between surgeons and hospitals treating this cancer. However, as with any performance data, this needs to be interpreted with some caution.

Some suggested questions to ask your surgeon include the following:

- Has my case been discussed at a specialist Upper GI cancer MDT?
- Are you a member of the Association of Upper GI Surgeons (AUGIS)?
- How many similar operations have you performed?
- What is your published outcome data like?
- Which operative technique would you advise in my case?
- Would you advise traditional open surgery or keyhole surgery?
- Where will I be cared for after my surgery?
- Do you have a local patient support group?
- Is there an option to speak to previous patients who have undergone my operation?
- Could you have any local literature patient information on post-operative recovery?

3. SPEED OF RECOVERY

Your GP will be informed your time of discharge from the hospital. Most likely, the district nurse will also be informed, especially if you are still using a feeding tube. If your feeding tube is still in place when you are discharged, you will be taught how to take care of it.

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 months before you are at your peak again, and you will have off-days along the way. Try not to be impatient – enjoy the new lease of life.

Initially, you will feel, possibly on occasion, and plenty of rest is needed. Sometimes, the tiredness may set in very quickly; don't feel like you have to fight it. An afternoon nap in bed is helpful for the first 5-6 weeks to prevent fatigue, or you may need to go to bed for several hours during the day and still need to early in the evening. Do some gentle exercise as soon as you can – start with walking and go just a little further each day. This will help develop an appetite. It will also improve your breathing, helping the chest expand and restore its suppleness.

Diarrhoea can be a problem in the early days (see the section on this below). You may also have dry cough, perhaps when talking too much or too loudly. This can be remedied by sipping on a cold drink or sucking a boiled sweet. It goes away over time, but this may take a year or more.

4. EATING AND DRINKING

Depending on the type of surgery you underwent, you may now have a much smaller stomach or no stomach at all. This means that you no longer have the capacity to ingest large amounts of food, but this capacity may gradually increase. The digestion process will be different, and it will take a while for you to become used to this. You will feel "full" more quickly, but the sensation will probably be different. At first, it will be easy to overeat, and it will take you a while before you can judge when you have had enough. You will also find that your sense of taste keeps changing during the initial weeks; one week, you may like something, and the next, you won't. Regardless eating a wide variety of foods.

Swallowing

The act of swallowing should not be impaired, but trepidation about food entering the "new arrangements" can make it feel a little difficult and lumpy at first. Staying on a liquid diet should not be necessary, and gradually move onto a normal diet as you feel able. Avoid hard or sharp food pieces during the first six weeks, but well-cooked meat (white in particular) can be eaten as well as fish without bones. You should be able to manage a normal diet within about six weeks to three months. Crispy foods such as crispbread and toast may be easier to manage than soft bread since they don't absorb as much saliva and become a doughy mass. Do not be alarmed if in the early weeks you experience problems with swallowing. This often occurs due to the join being swollen and tender. See the section titled "Food sticking".

Appetite

Many people have poor appetite during the early stages of recovery, so have foods you like. Initially, your sense of taste may be affected, with food and drink not tasting of much and possibly a bit unpleasant. You may prefer more sweet or savoury foods than you did before. As said previously, an operation on the digestive system does have major effects, but these vary person to person, thus requiring different solutions. Foods that are not easily digested or liked in the early days may continue to be so after a while. There may have been certain foods or drinks that did not agree with you in the past for whatever reason, and this is not likely to change following surgery.

<u>Developing an appetite</u>

- Relax and avoid rushing meals.
- Try using a smaller plate and serve meals that are attractive and colourful.
- If you are too tired to prepare a meal, have a ready meal instead.
- If you have lost your sense of taste, try highly seasoned or marinated food.
- If hot food upsets you, eat food that is at room temperature or cold.
- A small drink of sherry or other aperitif, or even a small beer, before a meal may help stimulate your appetite and improve taste.

- If you find cooking smells a problem, avoid the kitchen or use cold or microwaved foods.
  Perhaps someone else can prepare you food; however, for some, the smell of food will increase the appetite.
- If you do not feel like eating, you may supplement a snack with a milky drink; you can fortify the milk by adding dried milk powder to it.
- Alternatively, have a food supplement or try one of the nutritious drinks listed in the appendix.

Mealtimes
In the early days, talking during meals may affect the ease of swallowing. You may like to sit at the table to eat, or prefer to be in an armchair with a tray on your lap. Some people find it easier to eat with a distraction such as reading or watching TV. Sitting upright helps avoid any tendency to choke on food.

Consider using a microwave oven for reheating food that has gone cold, as may happen if you are eating slowly.

Sit for a while after a meal.

Little & often

The key to eating well after surgery is not eating big meals, but eating smaller amounts regularly. This may feel difficult at first, but try to eat SIX times a day; three small meals and nourishing snacks in-between. Eat slowly and chew your food well. This will help you digest your food and prevent you from feeling full too quickly. You will feel uncomfortable if you eat too much at one time. However, will gradually get to know what is the right amount for you. Eating more frequently can be a pleasure – biscuits with coffee in the morning; a scone or cake with tea in the afternoon; during gaps between the main meals of the day, be it midday or evening, one is always eating! Try to make it an enjoyable activity – you now have time for conversation, and there's no need to complain about slow service when you are eating out!

Drinking

Drinking is important, and you should make sure that you have plenty of fluids. However, be careful not to fill yourself up before or during a meal as you will no longer want to eat your food. When eating, just take from sips your drink.

There is no reason why alcohol should not be consumed, but the effect may be felt a little earlier than hitherto – so beware!

Observe moderation in all things! (Be wary of the effect of alcohol on certain medicines – look at the label).

Gaining weight

People often lose weight prior to surgery, and it is quite common to continue losing weight after leaving the hospital, maybe for months. In fact, many people never return to their weight prior to their illness. Nonetheless, you will reach a new "fighting weight" in due course.

It may take a long time – a year or longer, and by eating little but often, you should be able to maintain a good calorie intake. However, if you feel that you need to gain weight, there are ways of adding calories to your diet. See page 12.

5. POSSIBLE REPERCUSSIONS

Following your operation, your body will take a while to settle down, and you may initially encounter some unexpected experiences. Most of these will subside with time. For instance, if milk seems to be making you ill, you can switch to soya milk, but consult your dietician as you may need to take a food supplement to maintain your nutrition levels. Keep trying to have a little milk as the problem should not last more than a few months when the enzyme required to digest milk is produced again.

Dumping

A condition known as dumping syndrome occurs when the food you have eaten passes rapidly through the system and may give rise to some of the following symptoms: dizziness, possibly fainting, feeling very hot, sickness and pain in the abdomen. Diarrhoea or frequent bowel movements may follow. It can be unpleasant and distressing, but it is not serious and generally the frequency of the attacks decreases. The effects normally disappear in half an hour or so. For oesophagectomy patients, it generally occurs for an hour or more after eating (late dumping). Those who have had a gastrectomy may be more prone to dumping, and this may happen sooner after eating (early dumping).

In late dumping, the sugar content in the food or drink causes insulin to be released by the pancreas. A slight excess of this secretion gives rise to aforementioned feelings, and some patients have found that quickly having a glucose tablet or sweet can relieve the symptoms.

Dumping is a fairly complex subject, and we have other factsheets available that give more details.

Gastric retention & sickness

Conversely, food can sometimes remain in the stomach rather too long, causing you to feel sick and bloated, in addition to burping. This may occur as you begin to eat slightly bigger meals. It is very common, and your hospital team or 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 motility of the system. You will not need it forever and are in fact generally prescribed in short courses – but it can help until the body gets used to the new arrangements.

Major nerves are severed when performing the operation, and this is the cause of the problem. Sometimes endoscopy procedures using a balloon to stretch the muscle at the end of the stomach (after oesophagectomy) can also be effective. Remember to stay in touch with your surgical team as they can offer help with this.

If you suffer more persistent sickness that is not relieved by the above medicines, mint or ginger products, the traditional remedies for nausea and sickness, may be beneficial.

Food - sticking

If you feel that a little food is stuck, try a fizzy drink, which may help loosen it. If food remains stuck for more than a couple of hours, ring for advice from the hospital ward where you were treated. Normal intake of solids should not be a problem, given that they are well chewed and obviously not too large. After surgery, scar tissue at the join along the oesophagus may restrict the passage of food or even cause it to stick. This can be worrying and a reminder of the original trouble, but it can be alleviated fairly easily by slightly dilating it at the hospital.
This is a routine endoscopy procedure using a balloon to stretch the oesophagus under sedation, and may only have to be carried out once. A few patients however need to have it performed several times in the early months. Do not wait too long for the problem to subside; it is better to treat it early. Consult your doctor/surgeon if you feel this procedure could result in improvements.

Acid regurgitation (reflux)

Sometimes, you may experience an extremely unpleasant feeling in the stomach for a short while, particularly first thing in the morning. There may not be any acid burning in the throat and could be caused by the accumulation of acid in an empty stomach. The remedy is to spit out as much fluid as you can, or if identified in time, drink some water to dilute the gastric acid and encourage it to go downwards. It should become less frequent over time, but there may always be a possibility of it reoccuring.

Having some food in the system may help prevent acid or bile from the stomach area from reaching the throat and even the mouth, which is very unpleasant. It occurs most commonly at night or in the early morning. The presence of food in the stomach or gut helps absorb the acid, and there are also medicines that can help prevent its regurgitation (prokinetics) or reduce acid production (proton pump inhibitors – PPIs). Mints or ginger biscuits may also make you feel more comfortable.

Using extra pillows or raising the bedhead by about 4–6 inches with wooden blocks or bricks can be very beneficial, and placing a pillow under the knee area may prevent slipping down during the night. Electric beds are now available much more cheaply than in the past. If you have had an oesphagectomy, your sleeping posture may be affected by the position of the join between the remainder of the oesophagus and the stomach. The higher this is, the lesser the reflux may be experienced.

Flatulence

You will probably experience a tendency to burp more than before. Sometimes, it can almost be involuntary, but with practice, some control can be gained. Discomfort can be relieved, but it has to be tolerated since it may remain a long-term effect. You may also find that wind gets trapped in the stomach area. This can be painful and worrying, but it does subside fairly quickly.

Diarrhoea

Due to the surgery, you may suffer from diarrhoea, particularly in the first few months post operation. It may be accompanied by a rather severe colicky pain.

This problem generally eases with time, and medicine prescribed by your GP can help; however, it often seems to occur for no apparent reason, i.e, it cannot be related to anything you have eaten.

You could take note of what you have eaten on the day of occurrence/sickness, just to see if it is food-related. It may be advisable to reduce the intake of high-fibre foods and milk for a day or two when affected, i.e, cut down on fruit, green vegetables, pulses (beans and lentils), high-fibre cereals and wholemeal bread. A diet with more meat, fish, eggs and potatoes is likely to be useful in controlling the condition. It’s a nuisance, but don’t worry about it; learn the method of control that suits you best. Diarrhoea can have other causes of course. Hence, see your doctor if it persists.

6. A SUMMARY OF NUTRITIONAL GUIDANCE

Try to eat often – graze throughout the day.

Sit upright, eat slowly and chew your food well; this will help you digest your food and prevent you feeling full too quickly.

Eat soft foods (not liquidised) for 4 – 6 weeks following surgery. Thereafter, a normal consistency should be suitable. Ordinary bread can lead to problems for a while – try toast, crackers or crisp-breads.

Sip on a drink while eating if you like, but don't drink much before meals – it will fill you up. Having a small aperitif, or whatever you like, may help as it stimulates the gastric juices.

After eating, sit still for half an hour, and make sure you don't bend down soon (you may regurgitate your food). Your last snack of the day should be timed at least an hour before bed – this can help absorb stomach acid.

Food supplements (on prescription) can be useful – they provide good nutrition in small volumes you like. There are many, so you could also ask your dietician.

Do not put too much emphasis on weight gain – it will come with time. Weight loss is normal after surgery as you will be able to eat much for a few weeks. Then it should stablilise and gradually increase, but not usually up to your previous weight. If you are still losing weight after two months or if food sticks while swallowing, speak to your specialist nurse or consultant.

If you have no appetite, consult your doctor – a short course of steroids may help resolve the issue.

Some patients find probiotics (e.g, Yakult, Actimel, etc.) beneficial with reflux and digestive problems.

Adding nutritious drinks to the diet can be very valuable. Have milky drinks (e.g coffee, cocoa, hot chocolate, Horlicks, etc.) with full fat milk. You can also drink Complan, Build-Up or any other nutritional drinks, which are available in sweet and savoury flavours.

7. LIFESTYLE AFTER SURGERY

Your aim post operation may be to become fitter than you were before. However, in the immediate post-operative period, exercise is the last thing you feel capable of doing as the muscles, bones and organs in the chest, abdomen and often the throat would all be affected. Recovery takes some time; if you were working, you are going to be on leave 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 great long before that.

The first few weeks

You start exercising very soon after the operation; the physiotherapist attempts to make your lungs fully functional again, expelling fluid that can gather as a result of the operation and anaesthetic. This is a rather painful process, but putting in effort at this time is well worthwhile. It is when you feel so weak after getting out of bed realise the challenge. Walking (or staggering) is about all you can do at this stage. Any effort exhausts you, and climbing stairs feels like scaling the Everest, but try walking a little further each day, and it will eventually get easier.

Progressive exercise should be done during this early period by increasing speed or distance – not both. Bear in mind that outdoor walking is more difficult – navigating slopes and strong winds in heavy clothing - and don't forget, the return journey!

Look after yourself at this stage, not the housework. Continue the breathing exercises given at the hospital six deep breaths held for a count of three each and gently exhale. Do this five or six times a day. It can be done sitting up straight or standing. (If there is still sputum coming up you may have been given extra exercises to do – don't neglect them.)

At 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; let the body take its own time. During this early stage, coughing, perhaps occasional sickness, and movement generally will be painful, and you may feel that your insides will come apart. 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, and while they heal well in about two months, bones and cartilage take longer. Nerves, which are inevitably severed in any operation, repair very slowly indeed, and some areas around the wound may remain numb.

Surface pain may occasionally be experienced on the wound for years. However, there's nothing to worry about – it's the raw nerve endings.

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

It is probably wise to inform your motor insurance company that you have undergone a major surgery before you start driving again. When driving, must be capable of making an emergency stop. Have a practice run first. There are mental as well as physical aspects to consider, and you must feel to be driving. You can expect some pulling on healing muscles, depending on the size of car and ease of handling.

Eating out

Eating with others represents a very social occasion, and there is no reason why you should stop doing this. However, Friends and family should be aware that you only eat small portions, and in a restaurant, ask for a child's portion or have a starter as a main course. Do not worry about leaving food on your plate. If you wish, you may explain to a member of staff that it does not reflect their cooking but that you can only eat a little. The Oesophageal Patients Association has issued a card that states that because of medical reasons, one can only eat small portions.

Sleep

It may take you several weeks to fall back into your normal sleeping pattern. To avoid waking up to pain, it may help to take a painkiller before going to bed.

As already stated, you may feel worn out, which can be relieved by taking an afternoon nap for the first 5/6 weeks. Some people like to go to bed, while others nap in a chair.

Hallucinations and dreams

Some patients may "see" or dream about things they know cannot be happening. This may be related to their medication and should gradually happen less. If you find this disturbing, talking to your family or GP can prove useful.

Psychological effects and support

Now that you are recovering, you may find yourself having an emotional reaction to the events that have taken place. If this is a problem for you, try talking to your family and friends or your GP. Many patients find it very helpful to talk to somebody who has also had the surgery, and the Oesophageal Patients Association will be able to put you in touch with a knowledgeable former patient. There are support groups around the country, and you can consider joining the one nearest to you.

Relationships and sex

The trauma of being diagnosed with cancer and undergoing surgery often alters our relationships with others. Feelings for our closest family are enhanced, and couples may need extra love and reassurance.

Both partners may be worried about having sex after surgery. It is normal to feel anxious, but sex should be possible and could be as enjoyable as it was before. It may although be best to wait 4 – 6 weeks, but allow yourself plenty of time if you feel uneasy about resuming sex. Treat it like any other activity; if you are tired and tense, wait until you are ready.

Smoking

If you are a smoker, you will have stopped smoking at the hospital, so try not to start again. If you need help quitting contact your GP. For further information, visit www.givingupsmoking.co.uk and www.nhs.uk/smokefree

Getting back to normal

You should be seen by your surgeon within two months of your surgery. Further appointments may then be made, but some hospitals leave it to the patient to make contact if they feel the need. Clinic procedures also vary; some doctors will always examine you, but others only do so if there is a problem. It is natural for you to worry about the cancer recurring, but over time, your confidence will grow. If you have any concerns, see your GP or contact your specialist nurse.

Three to six months post surgery

Somewhere within this period, you should be able to do exercises.This could include wimming, which is a very good exercise for all ages and generally something you enjoy doing.

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 steady pace.

Cycling and dancing are also suitable as long as they are not too strenuous, and as you become stronger any sport that you enjoy can be tried. Nonetheless, be sure not to start with competitive games like squash and badminton, and avoid lifting weights. These and sports like running can be taken up later (up to marathon standard if you are really determined – one of our former patients has in fact run several). If you were previously overweight, now is your chance to get that new slim figure by taking up a sport that you used to find too exhaustive.

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

The most important things to keep in mind regarding exercising are that it should be done regularly, be strenuous enough to make you puff, and be enjoyable.

Returning to work

The timing of one's return to work depends on many factors: age, type of work, the effort put into regaining fitness, etc. In any event, it may be months before you start working, but we are all individuals. Heavy work is more demanding and might in fact not be suitable if it involves much bending and lifting. Hopefully, your employer may be able to help you by utlising your skills and knowledge for lighter work. Initially, travelling in rush-hour traffic may be stressful, and shorter hours for a few weeks will enable you to "run in". Remember to plan so that you can take nourishment when you need it – little and often. Remember too that for some time, you may tire more quickly, so if work entails driving or working with machinery, extra care and planning may be necessary.

8. HEALTHY EATING

The following are suggestions only and do not necessarily have to be followed. If you have to follow a special diet for medical reasons, you should not change it without consulting your health professional.

Adding calories

- Melt butter on vegetables, meat and fish and add it to sauces and milk puddings.
- Add grated cheese to mashed potato, vegetables and soup.
- Have mayonnaise with salads and in sandwiches, cream in soups, sauces and desserts, and cream cheese on bread and biscuits.
- Put minced meat or flaked fish into soups.
- Make fortified milk (4 tablespoons of milk powder mixed into a pint of milk), and use in your drinks and in cooking in porridge, sauces, soup and milk puddings.

Snacks and small meals

Keep snacks at hand so you can nibble throughout the day. These may include nuts, Bombay mix, pasteurised cheese, pâté, peanut butter, biscuits, crackers, breadsticks, dips – such as hummus or tarasamalata, crisps, nachos, tortilla chips, pepperoni, cheese dippers. Fresh and canned fruit, popcorn, yoghurt, muesli bars, chocolate, sweets, dried fruit, breakfast cereal, e.g., crunchy nut cornflakes, teacakes, muffins, crumpets and croissants

Sandwiches

These can be made with sliced bread, toast, bagels, baguette, chapatti or pitta bread. Fillings could include cold meats, tinned fish, pâté, dhal, hummus, egg, bacon, cheese or peanut butter. Add mayonnaise, pickles, chutneys, salad or avocado to make them more interesting.

On Toast

Baked beans, cheese, sardines, and eggs – poached, scrambled or fried can be had on toast. Add plenty of butter or margarine and top with grated cheese.

French toast (eggy bread) or omelette

Add cheese, mushrooms or ham.

Jacket potatoes

Have jacket potatoes with butter and fillings such as cheese, beans, tuna mayonnaise, chilli con carne, coleslaw, bolognaise sauce, hummus or sour cream.

Ready made meals

They can be frozen, chilled, tinned or boil-in-bags.

Nutritious soups

When having soup as a meal, choose one that contains meat, fish, cheese, lentils peas or beans. Make soup with milk or cream and serve with a roll.

Pasta

You can have instant or microwaved pasta with added cheese or ham.

Puddings

- Milk puddings made with rice or semolina. Add jam, fresh or tinned fruit or cinnamon and sultanas and brown sugar.
- Thick and creamy or custard-style yoghurt, fromage frais, fruit mousse or fool or trifle.
- Tinned sponge pudding, jelly with tinned fruit and ice cream or cream. Add raspberry or chocolate sauce.
- Hot/cold pie or crumble with cream, ice cream or custard. Waffles or pancake with maple syrup and cream or ice cream.
- Cheesecake or sweet pastries with cream.
- Baked apple or banana with brown sugar and sultanas. Serve with custard, cream or ice cream.
- Milk jelly made by whisking a small tin of evaporated milk into a cooled jelly made with 1/2pt water.
- Fruit fool made using custard and stewed or pureed fruit.
- Angel Delight made with banana and chocolate or other confectionery.
- Full fat Greek yoghurt with honey and soft fruit. This can be topped with brown sugar and grilled to make crème brulee.
- Pudding with added cream will boost the energy content. For convenience, try aerosol creams. These keep well in the fridge. Long life cream is also useful.

Nutritious drinks

To tempt the appetite, serve drinks chilled in a tall glass or tumbler with a straw.

Milkshake

- 1 cup milk
- 1 packet Build-Up or Complan – flavour of your choice
- 1 scoop ice cream
- Blend all the ingredients together and serve.

Fruit milkshake

- 1 cup milk
- 1 cup tinned fruit (drained) or fresh fruit
- 1 packet vanilla Build-Up, Complan or full cream milk
- 1 teaspoon sugar (optional)
- Liquidise the fruit.
- Add other ingredients.
- Blend and serve.

Coffee Calypso

- 1 cup milk
- 1 packet Build-Up, Complan or full cream milk
- 1 teaspoon instant coffee (amount could vary according to your taste)
- 1 scoop ice cream
- Dissolve coffee in a little hot water.
- Add it to the other ingredients.
- Blend and serve.

Choco-mint surprise

- 1 cup milk
- 1 packet chocolate Build-Up, or Complan
- 2 table spoons single cream
- Few drops peppermint essence (varies to taste)
- 1 scoop ice cream
- Blend or whisk all ingredients together except the ice cream.
- Pour it into glass, add ice cream and serve.

Yoghurt smoothie

- 1 pot full fat yoghurt – flavour of your choice
- 1 banana
- 1 packet Build-Up or Complan
- 1 cup milk
- 1 teaspoon sugar (optional)
- Blend all ingredients together.

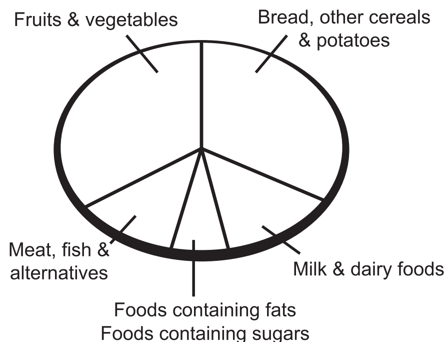
Sherbet fizz

- 1 packet vanilla Build up, Complan or full cream milk
- 1 scoop ice cream
- 150ml lemonade
- Blend all ingredients together and serve immediately.

After recovery

It can take up to six months for the digestive system to adapt after surgery. When you feel fully recovered from your operation and are more fit and active, you may want to return to a lower-fat diet and include more fibre, fruit and vegetables.
If you are still losing weight or experiencing difficulties with eating at this point, contact your dietician or GP.

The balance of good health



Patient support groups
Please ask your surgeon or specialist nurses about the times and locations of the local patient support group meetings. Most large centres treating this condition have these groups. These groups comprise previous patients who have undergone treatment for oesophageal and gastric cancer. They meet and discuss ways of coping with the after-effects of surgery and share helpful tips and tricks. Often, members of the multi-disciplinary team (such as dieticians, specialist nurses, surgeons, oncologists, gastroenterologists, etc.) are invited to these meetings to update patients on the latest developments.

In addition, other charities may be able to offer you support along your journey.

These include the following:

Oesophageal Patients Association
www.opa.org.uk

Macmillan Cancer Support
www.macmillan.org.uk

Cancer Research UK
www.cancerresearchuk.org

Notes

This space is left for you to write notes, comments or any questions you need to ask.

ABOUT US

The Oesophageal Patients Association (OPA) is an independent registered charity formed in 1985 when a few former oesophageal cancer patients met and found tremendous reassurance in sharing experiences. Since then, we have helped thousands of patients, carers and their families. The friends and users of the OPA are primarily patients who have experienced oesophageal or gastric difficulties, not forgetting the hard work of their carers, of course, and the support of their families, friends and our excellent health care professionals. We produce many thousands of our booklets and leaflets, as a valuable reference for many organisations, patients, carers and their families.

The Charity is represented on various committees involved with the management of upper GI cancers and research into new treatments. Patient involvement is increasingly recognised as a valuable input to the thinking and documentation on such matters.

WHAT WE OFFER

Our objectives are to help patients, carers and their families to cope with any difficulties arising as a result of treatment and giving support, encouraging them to achieve a good quality of life. This is done by providing information booklets and leaflets on matters of concern, a telephone support line, and arranging patient support meetings around the UK.

We make no charge to patients or their families for any support and advice provided. The OPA can only maintain its vital service through trust donations and other fundraising activities generated by the community it serves.

It costs the OPA substantial funds to keep vital services running, providing advice, support and practical help.

We produce many thousands of our booklets and leaflets as a valuable reference for patients, carers and their families, as well as many organisations, and all of this is supplied free of charge and paid for by the OPA. We would be grateful for any donations you could make so we can continue to help those who need it – https://opa.org.uk/donations/

Support Nationwide

The OPA has led the fight against oesophageal and gastric cancers for over 30 years. Our purpose is to support patients, their families and carers and raise awareness of these cancers and their prevention. Whatever stage you’re at, the OPA is here to help you.

Group Support
By sharing experiences and discussing our issues and problems, we are often able to help each other overcome areas of common concern.

Support meetings: These are held online and in person around the UK throughout the year and inevitably, most patients attending these meetings have had, or will be having surgery. The OPA's aim is to help new patients, families and carers to cope with difficulties arising as a result of treatment, giving support and encouraging patients to achieve a good quality of life.

Our patient support meetings provide the opportunity for patients to meet former patients and carers, some of whom are leading relatively normal lives.

One to One Support
From personal experience, we know that the first few weeks and months before and after the treatment can be challenging.

Most patients find it helpful and encouraging to talk to someone who has experienced similar symptoms and has undergone the same course(s) of treatment. Our volunteers (all of whom are current or former patients themselves) are on hand and willing to offer you support, encouragement and reassurance.

Whilst the OPA does not offer counselling or medical advice, based on our own experiences, we offer general guidance and suggestions, from questions to ask your GP to tips on what to eat, and a lot more.'

We will be happy to put you in touch with someone local to talk to via a Zoom appointment or over the telephone. Please contact our Cancer Support Helpline via phone: – 0121 704 9860 or by email: enquiries@opa.org.uk

Newsletters
Sign up for our twice yearly newsletter with articles of interest and latest news of treatments. https://opa.org.uk/register/

MEDICAL SUPPORT

The OPA is an independent registered charity that works with specialist hospitals and medical teams around the UK where oesophageal and gastric problems are regularly treated. The teams involving upper gastrointestinal surgeons, thoracic surgeons, gastroenterologists, oncologists, dieticians and physiotherapists have extensive experience of treatments and provide continual support and advice to the OPA.

Cancer Support Helpline: 0121 704 9860

HOW YOU CAN HELP

We receive no government funding, and we do not make any charge to patients, carers' or their families for any support and advice provided. The OPA can only maintain its vital service through donations and other fundraising activities among the community it serves.

If you can support the work of the OPA at this time, we would be indebted to you.

Cheques should be made payable to The OPA and sent to:
Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF.

YOUR LEGACY COULD MAKE A DIFFERENCE

A message from our patron Fiona Wade:

"Your legacy will help to save the lives of future generations. Please consider making a gift in your Will to The OPA and help us to continue our fight against oesophageal and gastric cancers.

I lost my father to oesophageal cancer. He was such an amazing person, the best father I could ever wish for, and it was so sad and shocking when he was diagnosed. I had never heard of his type of cancer before and I always feel to this day that if we had been more aware of oesophageal cancer or reflux disease then, for sure, earlier diagnosis would have made a huge difference and maybe saved his life.

Early diagnosis by spreading awareness is absolutely key in saving lives from this cancer. So please help us carry on doing all we can to make people more aware and help us to save lives and to support every single patient who needs our help.
Thank you."

You can support The OPA by making a gift in your Will; one of the most effective ways to help ensure that our fight against oesophageal and gastric cancers continues and saves the lives of future generations. Scan the QR code below to view the legacy leaflet.

HOW YOUR GIFT WILL HELP

Your gift will help the Oesophageal Patients Association (OPA) to encourage seeking early diagnosis and will assist patients who are facing or recovering from an operation for one of the most unpleasant, life-changing and rapidly increasing cancers.

Early symptoms may only show as heartburn or indigestion, often resulting in late referral and diagnosis. Treatment by surgery is extremely complex with long operations that often involve restructuring the digestive organs in the chest, which is a traumatic procedure.

We can continue to give medically informed support to patients, carers and families through:

- Our cancer support helpline
- Online information and support
- Medically approved high quality information booklets & leaflets
- UK wide network of patient support groups & OPA buddies
- Zoom Meetings

Your gift will also help us to continue to work with the NHS to improve cancer treatment and outcomes and to continue our support across the UK.

Making your Gift

The OPA is an independent registered charity. We receive no government support and depend entirely on public support.

The Chairman and Trustees of The OPA will ensure that your legacies' are used to the greatest advantage and your gift will not be used for administration costs.

Name..

Postal Address ....

Email Address ....

Phone Number...

If you would like further information, please complete your details below and return to this address: The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF.

☐ I am considering leaving a legacy to The Oesophageal Patients Association – please send me more information about your work

☐ I have made a gift in my Will to The Oesophageal Patients Association – please keep me informed about news and events

I would love to make a donation

I am pleased to send a donation of £ ___________ Please tick here ☐ if this is to be treated as a Gift Aid donation.
Title: (Mr/Mrs/Dr etc.)________________ Name:____
Address: ____
____
Tel: ________________________ Email:____
Signature: ____ Date: ____ /____/ ____
For online donations – Account number: 51354981 Sort Code: 40-42-12

For Standing Order Donations

By bank transfer
Recipient bank: HSBC Bank
Sort Code: 40 – 42 – 12
Account Number: 02301636

To make an online donation visit:
https://www.opa.org.uk/donations.html

By regular Standing Order payment – Sort Code: 40-42-12 Account Number: 51354981
I wish to make regular donations to the Oesophageal Patients Association of *(tick appropriate box)*
☐£2 ☐£5 ☐£10 ☐£25 ☐£100, or other amount: ☐
Please state amount in words:
every *(tick appropriate box)* ☐Week ☐Month ☐Year starting on ___ /___ /___ until further notice.

Your bank details
To: (insert name and address of your bank) ____
____
____
Sort Code: ____-____-____ Account Number:________________________

Boost your donation by 25p of Gift Aid for every £1 you donate

Gift Aid is reclaimed by the charity from the tax you pay for the current tax year. Your address is needed to identify you as a current UK taxpayer.

In order to Gift Aid your donation you must tick the box below:
☐ I want to Gift Aid my donation of £_____________ and any donations I make in the future or have made in the past 4 years to the OPA.

I am a UK taxpayer and understand that if I pay less income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay.

Your Details
Title: (Mr/Mrs/Dr etc.)______________ Name: ____
Address: ____
____
Tel: ________________________ Email: ____
Signature: ______________________ Date: ____ /____ /____

Please send this form to: Fundraising Dept. The OPA, 6 & 7 Umberslade Business Centre, Pound House Lane, Hockley Heath, Solihull B94 5DF, or email to; enquiries@opa.org.uk Charity Number: 1194327
For further information, please contact The OPA on 0121 704 9860 or send an email to charity@opa.org.uk.

Ways You Can **Donate**

Online Donations

Online donations make things really simple, there is no need for you to collect money in person or worry about banking cheques, etc. Online donations are becoming more popular; many donation portals also allow you to log in and check how your fundraising is going and check your progress.

The OPA accepts payments via Paypal, bank transfer, Just Giving, debit or credit card or donations via mobile.

Text Donations

One-off Text Giving

Text **HELPOPA 3** to 70450 to donate £3.
Simply change the amount, e.g. **5, 10 or 20 to donate more.**

Regular Text Giving

Text **DONATEOPA 3** to 70450 to donate £3 a month.
Simply change the amount, e.g. **5, 10 or 20 to donate more.**

Postal Donations

You can now make a single donation by cheque or set up a regular payment via standing order. Please make cheques payable to the **"Oesophageal Patients Association" (or "OPA")** or download our Standing Order form (PDF).
https://opa.org.uk/wp-content/uploads/2022/05/Standing-Order-Form-2022.pdf

Please address your donation to:
6 & 7, Umberslade Business Centre, Pound House Lane,
Hockley Heath, Solihull B94 5DF
Gift Aid form: **https://opa.org.uk/wp-content/uploads/2021/02/Gift-Aid-Declaration-for-a-single-donation.pdf**

PayPal

You can make a donation to the OPA via our PayPal page –
see **https://www.paypal.com/donate/?cmd=_s-xclick&hosted_button_id=X2FRXGH7FTGCG**

Bank Transfer

Account Payee: OPA Bank: HSBC Bank.

Sort Code: 40-42-12. Account Number: 02301636

Just Giving

Visit the OPA's Just Giving page at
https://www.justgiving.com/oesophagealpatientsassociation

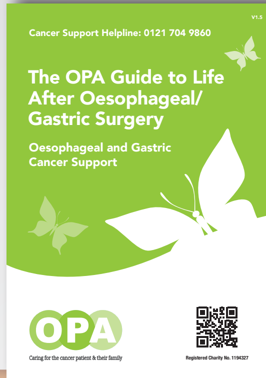
Legacy

OPA Legacy Leaflet –
https://www.opa.org.uk/edit/files/20200901_legacy_leaflet_dl_6pp_-_final.pdf

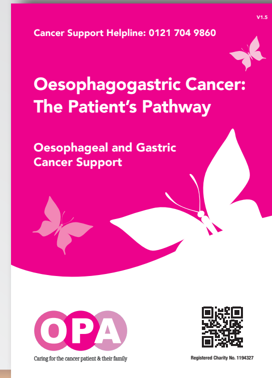
We accept all major credit and debit cards.

Publications from the OPA.

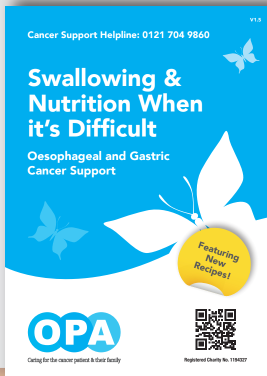
We are here to help those with or affected by Oesophageal and Gastric Cancer. Here are some of our helpful booklets; they are free and can be posted or downloaded from our website.



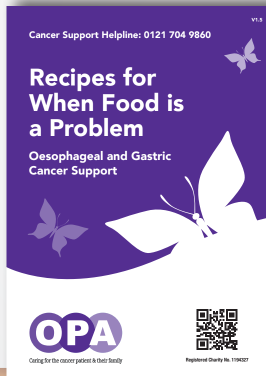
A Guide to Life After Oesophageal/Gastric Surgery – Oesophagectomy & Gastrectomy
(Informative guide for Oesophageal & Gastric patients following surgery)



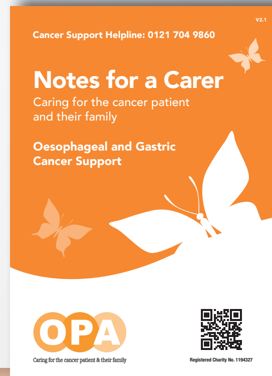
Oesophagogastric Cancer: The Patient's Pathway
(Patient's guide following diagnosis based on the St. Thomas' Hospital Pathway)



Swallowing & Nutrition – when it's difficult
(For those not having an operation but perhaps having a stent inserted or other treatments)



Recipes for When Food is a Problem
(Recipe book for patients post surgery/ treatment)



Notes for a Carer
(Informative guide for carers of Oesophageal & Gastric patients following diagnosis)

These publications are available to patients and medical staff on request. There is no charge to individuals and no membership subscription. The OPA is supported entirely by donations.

Reviewed by Philip Wright 2021, Ewen Griffiths, MD FRCS Consultant Upper GI Surgeon and Laura Nicholson, Upper GI Dietitian at University Hospitals Birmingham NHS & Professor Janusz Jankowski, MBChB MSc MD PhD PGCE PGCM AGAF FACG FRCP SFHEA 2019.

Cancer Support Helpline
Tel: 0121 704 9860

9.00am - 5.00pm Monday to Friday.
(Answerphone for out of hours callers)

Email: enquiries@opa.org.uk
Web: www.opa.org.uk

This booklet is published by the OPA relying solely on donations.
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