National helpline: 0121 704 9860

A Guide to Life After Oesophageal/Gastric Surgery

- Oesophagectomy & Gastrectomy

The Oesophageal Patients Association

Caring for the cancer patient and their family

Registered Charity No. 1062461

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1. INTRODUCTION

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

The 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 which is soft and well cooked, and adopt a little and often regime. Almost certainly you will develop a greater interest in healthy eating and that will be better for you too.

The recovery period is slow, but slow steady improvement is best. It is possible for people to return to their former fitness level in time, including running marathons!!

In the UK the most common reason for the operation you have had is cancer, but it can also be a result of a rupture of the oesophagus, a long-term hiatus hernia, a development from Barrett‟s oesophagus, or because of a congenital condition. Continuing research is being carried out on both the causes and treatment.

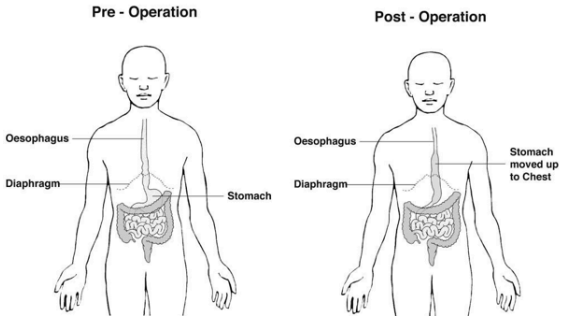
You may wonder, in the early days, if you will ever recover from this operation which has left you feeling as if you have been under a steam roller. Initially you will need a lot of rest and may feel exhausted by the slightest exertion, but you will notice a gradual improvement. Your recovery will take place over a number of months and some people will take longer than others.

This booklet will help you. It is based on the experiences of people who have had the same operation as you, with valuable input from health professionals.

2. THE OPERATION

Oesophagectomy

This operation involves removal of part, or most of the oesophagus (gullet) and part of the stomach, the amount of each varying according to the position 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 and all or only part of the stomach may be in the chest. To help healing of the join you may have been fed in hospital through a tube up the nose and into the stomach, or perhaps directly into the small intestine (the jejunum) where most of our digestion of food takes place.

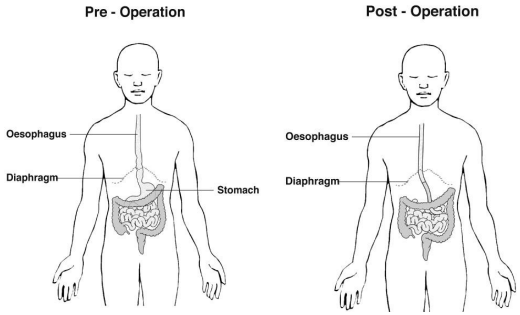


Gastrectomy

In this operation, if all of your stomach has been removed (total gastrectomy), the top part of the small bowel (the jejunum) is joined on to the bottom 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 (this is called a distal or subtotal gastrectomy). This means that the food you eat will pass almost immediately from the stomach into the small bowel.

As after oesophagectomy, to help healing of the join you may have been fed in hospital through a tube up the nose and into the stomach, or perhaps directly into the small intestine (the jejunum) where most of our digestion of food takes place. In the future you will need to have regular injections of vitamin B12 from your GP.



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

Keyhole surgery (also known as laparoscopic or minimal access surgery)

Some people have part or all of their surgery performed using keyhole surgery. This means that although the same operation is performed you do not have a large wound. You may therefore recover more quickly, but you should remember that although there is little to see on the surface your body still has to recover and heal and this will take time.

Keyhole surgery has some important advantages and disadvantages and this should be discussed in detail with your surgeon. Not all surgeons or units are trained in keyhole techniques.

What do I need to know about vitamin B12?

If all or a large portion of your stomach was removed, you are likely to develop a type of anaemia resulting from a deficiency in vitamin B12. This is because the stomach produces a protein 'intrinsic factor' that is required for the body 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 the vitamins, and may take 6 months or more to become apparent. If you have had 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 and will organise administration.

Enteral (tube) feeding

As part of your operation you may have a small feeding tube placed into your bowel; this is called a jejunostomy or JEJ tube. It is routine in some Upper GI units, whereas in other units they place a tube only in selected patients. Please ask your surgeon about this.

A liquid feed will be used to feed you liquids to ensure you receive the nutrition you need whilst your oral intake is re– established. When you are ready to go home, you will be feeding using a combination of both enteral (tube) and oral (via the mouth) intake when you are ready to go home. Enteral feeding begins the day after your operation and continues after you are discharged from hospital. You will be discharged home on enteral feed for a minimum of 1 month. You will be taught how to use the pump and care for the tube before you go home.

The amount of time you will need the enteral feed for varies from person to person, but usually ranges between 2 – 3 months. You need to continue taking enteral feeds until you are able to meet all your nutritional needs by mouth. Please see separate instructions on your feed plan and care instructions.

What to ask your surgeon?

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

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

- http://www.augis.org/outcomes-data-2016
- https://www.nhs.uk/service-search/performance/Search

The routinely collected outcome data for this operation includes the risk of dying after surgery with 30 or 90 days and the average length of stay. This can be compared between surgeon and hospitals treating this cancer.

Some suggested questions to ask your surgeon include:

- 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 operations like this have you performed?
- What are your published outcome data like?
- What operative technique would you advise in my case?
- Would you advise traditional open 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 a previous patients who has had my operation?
- Do you have any local literature / patient information on post-operative recovery from this operation?

3. SPEED OF RECOVERY

Your GP will be informed when you are leaving hospital. It is quite likely that the district nurse will also be informed especially if you still have a feeding tube in place. If your feeding tube is still in place when you are discharged you will be taught how to care for it before you leave.

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 are quicker than others. It will be some 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 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.

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

4. EATING AND DRINKING

Depending on exactly what surgery you have had, you may now have no stomach at all, or you may have a much smaller stomach. This means that you no longer have the capacity for large amounts of food, but this 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 up” more quickly, but the sensation will probably be different. At first it will be easy to over eat and it will take you a while to judge when you have had enough. You will also find that your sense of taste keeps changing during the initial weeks. You may find that one week you like something and the next you don’t. Keep eating a wide variety of foods.

Swallowing

The act of swallowing should not be impaired but some 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. 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 included as well as fish without bones. You should be able to manage a normal diet within about six weeks to three months. However, crispy foods such as crispbreads 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 have problems with swallowing. This often occurs due to the join being swollen and tender. See under “Food Sticking”.

Appetite

Many people find they have poor appetite during the early stages of recovery so concentrate on things 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 earlier an operation on the digestive system does have major effects, but these vary from one person to another so different solutions are needed. Something not easily digested or liked in the early days may become 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 these are not likely to change following surgery.

<u>Stimulating the appetite</u>

- A small drink of sherry or other aperitif, or even a small beer, before a meal may help to stimulate your appetite and improve taste.
- Relax and avoid rushing meals.
- 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.
- If food has no taste, try highly seasoned or marinated food.
- If hot food upsets you, eat it at room temperature or cold.
- If you find cooking smells a problem, avoid the kitchen or use cold or microwaved foods. Perhaps someone else can prepare your food for you, however, for some, the smell of food will tempt 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 ease of swallowing. You may like to sit at the table to eat, or prefer to sit 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 to avoid any tendency to choke on food.

A microwave oven is useful for reheating food which 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 to eat large meals, but to eat smaller amounts regularly. You may find this difficult at first, but try to eat SIX times a day; three small meals and nourishing snacks in-between. Eat slowly and chew your food well. This will help you digest your food and prevent you feeling full too quickly. You will feel uncomfortable if you eat too much at one time. You 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; a gap between courses of the main meal 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 grumble at slow service when you are eating out!

Drinking

Drinking is important and you should make sure that you drink plenty of fluids. However, you must be careful not to fill yourself up before or during a meal or you will not want to eat your food. When eating, just take sips of fluid.

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

Moderation in all things! (Remember certain medicines can react with alcohol - look at the label).

Gaining weight

Often people have lost weight prior to surgery and it is quite common to continue losing weight after leaving hospital, maybe for some months, and many people never return to the weight they were prior to their illness. You will establish a new "fighting weight" in due course.

It may take a long time - a year or longer - and by eating little and 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 food. See appendix.

5. SOME POSSIBLE PROBLEMS

Following your operation it will take your body 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 use soya milk instead but consult your dietician as you may need to add a food supplement to maintain your nutrition levels. Keep trying a little milk as the problem should not last more than a few months when the enzyme needed to digest milk starts being produced again.

Dumping

A sensation 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 is not serious and generally the frequency of attacks becomes less. The effects normally disappear in half an hour or so. For Oesophagectomy patients it generally occurs an hour or more after eating (late Dumping). Those who have had a gastrectomy may be more prone to dumping, and this may occur sooner after eating (early Dumping).

In late dumping the sugar content of the food or drink causes insulin to be released by the pancreas. A slight excess of this gives rise to the 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 which give more detail.

Gastric retention & sickness

Conversely, food can sometimes remain in the stomach rather too long, causing you to feel sick and bloated, with burping. This may occur as you begin to eat slightly bigger meals. It is very 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 motility of the system. You will not need it forever - just until the body gets used to the new arrangements.

Major nerves are severed in doing the operation and this is the cause of the problem.

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

Food sticking

If you feel that a little food is stuck, try a fizzy drink, which may help to loosen it. If food does become stuck for more than a couple of hours ring for advice from the ward at the hospital where you were treated. Normal eating 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 in the oesophagus may restrict the flow of food or even cause it to stick. This can be worrying and a reminder of the original trouble but it is

alleviated fairly easily by dilating it a little in hospital. It is a routine procedure and may only have to be carried out once but a few patients need to have it done several times in the early months. Do not persist with the problem too long; it is better to treat it early. Consult your doctor/ surgeon if you feel this aspect could be improved.

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. Although there may be no acid burning in the throat the trouble appears to be caused by acid in an empty stomach. The remedy is to spit out as much fluid as you can or, if caught in time, 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.

Keeping some food in the system may help to prevent acid or bile from the stomach area actually encroaching on the throat and even into the mouth, which is very unpleasant. It occurs most commonly at night or in the early morning. 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). Mints or ginger biscuits may make you feel more comfortable.

Extra pillows or raising the bed head by about 4 - 6 inches with blocks of wood or a house brick can be very beneficial, and 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, whether you sleep flat or propped up may be affected by the position of the join between the remainder of the oesophagus and the smaller stomach. The higher this is the less reflux may be experienced.

Flatulence

You will probably experience a tendency to burp rather more than before. Sometimes it can almost be involuntary but with practice some control is gained and embarrassment can be avoided. Discomfort is relieved and 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 improve fairly quickly.

Diarrhoea

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

This problem generally eases in time and medicine from your GP can help, but it often seems to occur for no apparent reason, i.e. it cannot be related to anything you have eaten.

You could take a note of what you have eaten that day, just to see if it is food related. It may be wise to reduce intake of high fibre foods and milk for a day or two while affected, i.e. less 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, and learn the method of control that suits you best. Diarrhoea can have other causes of course. 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 food (not liquidised) for 4-6 weeks following surgery. Then, normal consistency should be suitable. Ordinary bread can be a problem for a while - try toast, crackers or crisp breads.

Sip a drink with food if you like, but don't drink much before meals – it will fill you up. A small aperitif such as sherry may help.

What you like is best – it stimulates the gastric juices.

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

Food supplements (on prescription) can be useful – good nutrition in small volume – find ones you like. There are many – ask your dietician.

Do not put too much emphasis on weight gain – it will come in time. It is normal to lose weight after surgery, as you will not eat much for a few weeks. Then it should become stable and gradually increase, but not usually to your original weight. If you are still losing weight after two months or if food sticks on swallowing, speak to your specialist nurse or consultant.

If you have no appetite speak to your doctor – a short course of steroids may help.

Further ideas for food are in the appendix.

Some patients find probiotics (eg Yakult, Actimel, etc) helpful with reflux and digestive problems.

Nutritious drinks can be very valuable in the diet. Make milky drinks (eg coffee, cocoa, hot chocolate, Horlicks, etc) with full fat milk. You can also purchase Complan, Build-up or supermarket/chemist own brand nutritional drinks, which are available in sweet and savoury flavours.

The Oesophageal Patients Association

Caring for the cancer patient and their family

Oesophageal and Gastric Cancer Support

Reg Charity No. 1062461

Helpline number 0121 704 9860
www.opa.org.uk - enquiries@opa.org.uk

Telephone helpline service Mon-Fri 9am—3pm including access to former patients.

We can arrange guidance and support and put you in touch with a local group member who is recovering (or has recovered) from a similar condition.

Website: www.opa.org.uk

Email: enquiries@opa.org.uk

We are able to offer support in the following areas:-

Information literature which is medically approved and written by former patients who know how you are feeling

Newsletters with up to date information, with both patient and medical input

Regional support groups in many areas

Hospital visitors in some areas

We understand that its not just patients that need support. Carers, and their family members, friends and loved ones can also benefit from our support.

Ways you can Donate

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By regular Standing Order payment

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.

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Signature: _____ Date: ____ /____ /____

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I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax for the current tax year (6 April to 5 April) that is at least equal to the amount of tax that all the charities that I donate to will reclaim on my gifts for the current tax year. I understand that other taxes such as VAT and Council Tax do not qualify. I understand the charity will reclaim 25p of tax on every £1 that I have given.

All donations are gratefully recieved and can help us to give patients the support they need as well as raising awareness of Oesophageal Cancer.

The Oesophageal Patients Association
Caring for the cancer patient and their family

Please send this form to:
Fundraising Dept. The OPA, 50 High Street, Henley-in-Arden, Warwickshire, B95 5AN
Or email to: enquiries@opa.org.uk

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Name:.....

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Email address:.....

Age at Diagnosis:..... Occupation:.....

Additional Optional Information

Please tick/delete whichever is applicable

[ ] I am a patient
[ ] Please register my details with your Association
[ ] Please include me on your mailing list
[ ] I have / have not had surgery for oesophageal / gastric cancer

Date of surgery:.....

Name of hospital which is treating me / has treated me:.....

.....

Name of consultant:.....

Date of treatment:.....

Month & Year of diagnosis:.....

Treatments given [e.g. Chemotherapy / Radiotherapy / Stent (tube in oesophagus) / Laser / Photodynamic Therapy *(please specify)*]

.....

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NB Personal membership details supplied are confidential to the OPA and are not available to any other organisation without the prior written permission of the individual. Information is stored strictly in accordance with the Data Protection Act 1998

Please return this slip
in a sealed envelope to

Patient Support
OPA
50 High Street
Henley-in-Arden
Warwickshire
B95 5AN

7. LIFESTYLE AFTER SURGERY

Your aim after getting over your 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. 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.

The first few weeks

You start exercising very quickly after the operation; the physiotherapist has to get your lungs going again, expelling fluid that can gather as a result of the operation and anaesthetic. This is a rather painful process 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 (or staggering) is about all you can do at this stage. Any effort exhausts you and going up stairs is like climbing Everest, but try walking a little further each day and it will get easier.

Progressive exercise during this early period should be taken by increasing speed or distance - not both. Bear in mind that outdoor walking is more difficult - there may be slopes, a wind and heavier clothing to wear - and don‟t forget the return journey!

Look after yourself at this stage, not the housework. Continue the breathing exercises given in hospital - six deep breaths each held for a count of 3 and gently exhaled. Do this 5 or 6 times a day. It can be done sitting up straight or standing. (If there is still 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, 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.

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 major surgery before you start driving again. You must be capable of performing an emergency stop. Have a practice run first. There are mental as well as physical aspects to consider and you must feel safe. There will be some pulling on healing muscles, depending on the size of car and ease of steering.

Eating out

Eating with others is a very social occasion and there is no reason why you should not continue to do this. 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. If you wish you may explain to a member of staff that it is no reflection on their cooking, but you do not have to do this. The Oesophageal Patients Association has produced a card which states that for medical reasons you can only eat small portions.

Sleep

It may take several weeks to establish your normal sleeping pattern. To avoid pain waking you it may help to take a painkiller before you go to bed.

As already stated, you may feel totally exhausted and an afternoon nap for the first 5/6 weeks is helpful. Some people like to go to bed, others nap in the chair.

Hallucinations and dreams

Some patients may “see” or dream about things they know cannot be happening. This may be related to medication and should gradually happen less. If you find this disturbing it may help to talk to your family or GP.

Psychological effects and support

Now that you are recovering you may find that you have an emotional reaction to the events which have taken place. If this is a problem for you try talking to 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 groups around the country and you can be told about 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 as enjoyable as it was before. It may 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 in hospital, so try not to start again. If you need help to stop smoking 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 in time your confidence will grow. If you have any concerns see your GP or contact your specialist nurse.

Three to six months on

We are all individuals but somewhere within this period you should be able to tackle exercise. Perhaps swimming, which is a very good exercise for all ages.

Take someone with you to give you confidence and the benefits will soon show.

For the non-swimmer (though it's never too late to learn) walking is good all round exercise as long as you walk far enough and at a fair pace. Cycling and dancing are also suitable as they need not be too strenuous, and as you become stronger any sport that you enjoy can be added, but don't start with competitive games like squash and badminton and avoid lifting weights. These and sports like running can be added later (up to marathon standard if you are really determined - one of our former patients has run several). If you were previously overweight, now is your chance to keep that new slim figure by taking up a sport that you used to find too energetic.

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.

The most important things about exercise are that it should be taken regularly, be strenuous enough to make you puff, and be enjoyable.

Back to work

The timing of a return to work depends on many factors; age, type of work, effort put into regaining fitness. In any event it may be some months before you do, but we are all individuals. Heavy work makes more demands and might in fact not be suitable if much bending and lifting is involved. Hopefully your employer may be able to help by using 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 to be able to take nourishment when you need it - little and often. Remember too that for some time you may tire more quickly so if driving or working with machinery is involved extra care and planning may be necessary.

8. HEALTHY EATING

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

Adding calories

- Add extra sugar or glucose to drinks, cereals, desserts and fruit.
- Add honey, syrup or jam to porridge and desserts.
- Melt butter on vegetables, meat and fish and add to sauces and milk puddings.
- Add grated cheese to mashed potato, vegetables and soup.
- Have mayonnaise on 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 milk powder mixed into a pint of milk) and use this for your drinks and in cooking in porridge, sauces, soup and milk puddings.

Snacks and small meals

Keep snacks to hand so you can nibble throughout the day. Nuts, Bombay mix, pasteurised cheese, pate, 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, croissants

Sandwiches

These can be made from sliced bread, toast, bagels, baguette, chapatti or pitta bread. Fill with cold meats, tinned fish, pate, 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, eggs – poached, scrambled or fried. Add plenty of butter or margarine and top with grated cheese.

French toast (eggy bread) or omelette

Add cheese / mushrooms/ ham

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

Can be frozen, chilled, tinned or boil in bag

Nutritious soups

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

Pasta

Instant or microwaved pasta with added cheese or ham.

Puddings

- Milk puddings such as 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, trifle.
- Tinned sponge pudding, jelly with tinned fruit and ice cream or cream. Add raspberry or chocolate sauce.
- Hot or 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.
- Whisk a small tin of evaporated milk into a cooled jelly made with 1/2pt water to make a milk jelly.
- Use custard and stewed or pureed fruit to make a fruit fool.
- Banana and chocolate or other confectionery can be chopped into Angel Delight.
- Full fat Greek yoghurt with honey and soft fruit. This can be topped with brown sugar and grilled to make crème brulee.
- Adding cream to any pudding 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 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 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 (vary amount according to your taste)
- 1 scoop ice cream
- Dissolve coffee in a little hot water.
- Add to other ingredients.
- Blend and serve.

Choc-mint surprise

- 1 cup milk
- 1 packet chocolate Build up or Complan
- 2 table spoons single cream
- Few drops peppermint essence (vary to taste)
- 1 scoop ice cream
- Blend or whisk all ingredients together except the ice cream.
- Pour 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

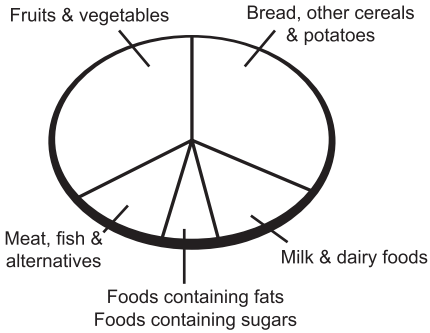
Sherbet fizz

1 packet vanilla Build up, Complan or full cream milk
1 scoop ice cream
150mls 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 you 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 time, 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. Most large centres treating this condition have these groups. These groups are formed by previous patients who have undergone treatment of oesophageal and gastric cancer. They meet and discuss ways of coping with the aftereffects of surgery and share 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 also be able to offer you support on your journey.

These include:

Oesophageal Patients Association
http://www.opa.org.uk/

Macmillan Cancer Support
https://www.macmillan.org.uk/

Cancer Research UK
http://www.cancerresearchuk.org/

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Notes

This space if left for you to make notes, comments or any questions you need to ask.

WHO WE ARE

The Oesophageal Patients Association is a national registered charity and was formed in 1985 when a few former oesophageal cancer patients met and found tremendous reassurance in sharing experiences. The members of the Association are all patients who have experienced oesophageal or gastric difficulties or are carers for patients. We have prepared medically approved booklets and fact sheets on the problems, which we can talk about at first hand, understanding the fears that can be generated, the pains that can be suffered and the effects on the digestive system that can be experienced.

WHAT WE DO

Our objectives are to help new patients and their families to cope with any difficulties arising as a result of treatment, giving support and encouraging them to achieve a good quality of life. This is done by providing information leaflets on matters of concern, a telephone support line, arranging patient support meetings around the UK and, where possible, visiting patients in hospital or making contact during their convalescence.

Patients may be referred by other agencies, such as Macmillan, doctors or specialist nurses anywhere in the UK and can by helped by telephone on the National Helpline or put in touch with a trained former patient where possible. Talking about the problems with someone who knows what they are like (perhaps rather better than the doctor) can be a great relief and there is time to deal with all the questions that seemed too trivial to mention to the doctor or were forgotten at the time.

The Association 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.

MEDICAL SUPPORT

The Association is an independent registered charity with links to 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 Association.

MEETINGS

Informal meetings for patients and carers (family or friends) are regularly held in regional centres around the UK. Problems are aired and suggestions for overcoming them are exchanged. The essential aim is to enable new patients to meet and talk to former patients who have recovered, are back to work if not retired, and lead relatively normal lives. If you have not already met a former patient member of the Association and would like to talk and meet with others, please telephone our Helpline number below.

OPA Patient Helpline: 0121 704 9860

Ways you can help

We receive no government funding, nor do we make any charge to patients or their families for any support and advice provided. The OPA can only maintain its vital service through donations and other fundraising activities generated by the community it serves.

It costs the Oesophageal Patients Association several hundred pounds per day to run the national telephone helpline, provide regional meetings, train volunteers and produce our support literature.

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, 50 High Street, Henley-in-Arden, Warwickshire, B95 5AN.

Your Legacy

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 our mission to save the lives of future generations.

The OPA has supported thousands of patients since it started over thirty years ago. By remembering The Oesophageal Patients Association (OPA) in your Will you can help us continue and to save the lives of future generations of family and friends. Your legacy will help to fight oesophageal and gastric cancers and support patients, families and carers to cope with this devastating disease.

The OPA supports people with life threatening cancers and works to save lives through our national campaign to create public awareness and early diagnosis. However, people of all ages should be made be aware regular heartburn or indigestion could be early symptoms of oesophageal or gastric cancers which can be dealt with through a straight forward procedure long before developing into cancer.

How your Gift will Help

Your gift will help the OPA to promote 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, families and carers through:

- Our national telephone helpline
- Online information and support
- Medically approved high quality information booklets
- UK wide network of patient support groups

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

Information

OPA Publications

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

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

• Oesophagogastric Cancer - The Patients Pathway
(Patients guide following diagnosis based on the St. Thomas Hospital Pathway)

• 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 Association is supported entirely by donations.

The Oesophageal Patients Association

Caring for the cancer patient and their family

Helpline Tel: 0121 704 9860

9.00am - 3.00pm Monday to Friday.
(Answerphone for out of hours callers)

Email: enquiries@opa.org.uk

www.opa.org.uk

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