

**Living well after your
Oesophagectomy
(Removal of part or all
of the gullet)**

**Information for you
and your family**

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Contents

Introduction.....	Page 2
Recovery at Home	Page 3
Potential problems	Page 11
Follow up.....	Page 17
Contact numbers.....	Page 19

Introduction

You have recently undergone an operation to remove part of your oesophagus and stomach.

We appreciate that life may feel like an emotional roller coaster at the moment as you begin to recover from your surgery. You may feel like life will never be the same again and have many questions and anxieties.

The aim of this booklet is to answer many of these questions, help you learn how to adapt to the new changes your body is going through and help you get back to a more normal life. It will supplement the information given to you by your doctors, Dietitian, ward nurses and specialist nurses. It may not cover all your concerns so if you, your relatives or friends have any other questions after reading this booklet, please don't hesitate to contact one of the staff listed on the last page.

We recommend you read this booklet in conjunction with the booklet you will have been given about your operation. It includes specific information about work up for your surgery, giving consent, and details about the operation itself.

Recovery at home

After your discharge from hospital, your body needs time to recover and to adjust to its new condition. Many people are surprised how long this can take

You may feel impatient that you are not recovering as quickly as you would like. This is normal; it can take many months, even a year, before you feel back to full fitness particularly if there have been complications after surgery.

During your first 2 weeks following discharge you may also feel quite vulnerable, so it is an advantage to have someone at home with you to guide and support you with your nutrition, medication, exercise and personal care.

Medication

When you are discharged from hospital, you will be given a two week supply of tablets to go home with. These may include acid reducing tablets, anti-sickness tablets and some painkilling tablets. Please take these regularly as directed to allow you to eat more comfortably, cough and breathe deeply without discomfort.

Consult your GP or specialist nurse if your painkillers or medication are not working. As your pain lessens try taking one tablet instead of two i.e. reducing the dose of medication before reducing the frequency.

Wound healing

Healing of your wound will take place over a period of time as all wounds progress through stages of natural healing.

- **Do not** pull off scabs as these protect new tissue underneath.
- **Seek advice** if the wound becomes very painful, if it starts to discharge or becomes red or inflamed.
- **It is normal** for the wound to tingle, itch, or feel slightly numb.
- **It is normal** for the wound to feel slightly hard and lumpy.
- **It is normal** to experience a slight pulling around the wound.

Eating and drinking after your operation

After this operation people are not able to eat as large a meal as they did before, they can feel full more quickly. It is also common to lose some weight after you get home. This is all normal in the early stages of recovery. In addition **People may not feel as hungry and food may not taste the same for a long time post operatively.** The following advice is to help you slowly build up to a high calorie and high protein diet. This will build up your strength and help you recover.

- You will be advised by your dietitian to only eat pureed diet for the first 2 weeks after you go home. After this period of time you can start to increase the texture and volume of food eaten. You should not need to liquidise food after

completing the puree diet unless swallowing has become difficult again.

- Do not try to eat large meals. Start off with a small amount of food and stop as soon as you begin to feel full or uncomfortable.
- Take your time eating and chew your food well.
- Try to have 5-6 small meals or snacks each day rather than 2-3 larger meals. If you do not feel like a cooked meal have a nourishing snack instead.

Helpful tip:

The Oesophageal patients association has produced a card for eating out which states that ‘for medical reasons you can only eat small portions’. This is available from your specialist nurses or at www.opa.org.uk

- Try not to eat and drink at the same time, this can make you feel full very quickly, and lessen the amount of food you eat. Try and leave drinking to 20 minutes either side of meals and snacks.
- It is important to drink enough. Try to have 6-8 cups of fluid each day. Ideally choose nourishing drinks e.g. milky drinks, drinking chocolate, a nutritional supplement drink instead of water, tea or low calorie squash.
- There should be no reason why you cannot drink alcohol but the volume you can tolerate will be reduced and the effect maybe felt a little earlier than before. Remember that certain medications can react with alcohol.

- Check your weight weekly and aim to keep your weight steady.

Eating a balanced diet

- Have three helpings of the following protein food daily e.g. meat, fish, chicken, eggs, milk, cheese, yoghurt, beans, lentils or nuts.
- Try and include a bread or cereal food at every meal e.g. breakfast cereals, crackers, rice, pasta or potatoes.
- Try to have at least 3 portions of dairy a day eg milk, cheese, yogurt to help meet your calcium requirements.

Fruit and vegetables

Fruit and vegetables provide fibre and vitamins however they may cause you to feel full quickly. Try to have 2-3 small portions each day. Try serving a small portion of fruit with ice cream, cream or yoghurt to increase your energy intake.

How to fortify your diet

- You may need extra calories if you have a poor appetite or are losing weight.
- Extra sugar or glucose can be added to drinks, cereals and desserts **only if you do not have problems with your blood sugars e.g. diabetes.**
- To fortify milk add 4 tablespoons skimmed milk powder to one pint of milk and mix well.
- Serve cream, custard or full fat yoghurt with puddings and cakes.
- Add butter and cheese to potatoes and vegetables.

Nutritional supplements

They are available if you are unable to get everything you need from your dietary intake:

Milk shake powder and soups e.g. Complan (Nutricia) and Meritene (Nestle) are available from chemists and supermarkets.

Your GP or Dietitian can prescribe other powders and ready made drinks if required e.g. Fresubin 2kcal, Fortisip Compact Protein and Food Link Complete. These come in a variety of flavours.

Please contact your Dietitian if you are struggling. They will be happy to discuss this and other dietary issues. Contact details at end of booklet.

Helpful reading:

A guide to life after Oesophagectomy/gastric surgery available from Oesophageal Patients Association www.opa.org.uk

The importance of exercise

After surgery many people do not feel like they 'return to normal' for 6- 12 months, with initial progress being slow and frustrating. There's good evidence however that physical exercise can boost your appetite, lift your mood, give you more energy, help reduce stiffness, and help you get over your operation more quickly.

Your physiotherapist will have given you information before you left the ward about breathing exercises and how to build exercise into your daily routines.

- Start with walks around the garden or up the street. Don't be afraid to go out, gradually increasing the amount of exercise week by week.

- You may become quite tired at times, so continue to have a rest after lunch. A small nap should not affect your sleep at night.
- You should aim to be able to walk at least 1-2 miles a day after 6-8 weeks.
- If it is raining or too cold to go out using your stairs to exercise can be a good way to build stamina.
- When you start walking around you may notice stiffness around your shoulders. Check your posture in the mirror, and do not allow your shoulders to stoop towards the side of your operation. This is the natural consequence of having a surgical wound in the side of your rib cage.

The Mustard Tree Cancer Support Centre in Plymouth offers a range of **free supervised exercise programmes** across Plymouth city for people recovering from cancer treatments. Your specialist nurse can help you access these recovery packages.

Helpful reading:

Macmillan cancer support “life after cancer treatment” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Showering and bathing

Bathing is not harmful to your wound, it is quite safe to get it wet as long as it's healing well and you have not been advised against it. Do not soak in the bath for too long and pat your wound dry with a clean towel afterwards. It is sensible to have someone else in the

house when you take your first shower/bath, even if no help is needed.

Housework

Light work (e.g. dusting or drying up) can be introduced into your regime when you feel fit and able, usually within the first 1-2 weeks you are at home. Avoid any heavy lifting, pushing or pulling for the first 8 weeks.

Gardening

Light gardening such as weeding may be done 2 weeks after discharge. Mowing the lawn and heavy digging should not be done for at least 8 weeks.

Driving

Everybody recovers differently. In general you should be able to safely resume driving 6 weeks after discharge. If you drive as part of your work it could be considerably longer. When you feel able to resume driving we advise you speak with your employers (if appropriate) car insurers and DVLA for individual guidance.

Travel

Once you feel well enough there are no restrictions to travel, however you are recommended to always wear anti embolism socks for long haul flights. Holiday Insurance after this surgery can be expensive, the Cancer support centre at Plymouth hospitals have a list of insurance companies that are more competitive.

Helpful reading:

Macmillan cancer support “Travel and Cancer” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Sexual Activity

Whenever you feel ready you can start to return to your normal routines. But it is common after major surgery to have a drop in libido. This is often due to lack of strength and weakness. Remember closeness and sexual pleasure can be shown in a number of ways.

Helpful reading:

Macmillan cancer support “sex and relationships” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Back to Work

This depends on your job and on the speed of your own recovery. A time frame of 3 to 6 months after you have returned home is reasonable, but it is very individual. Some people prefer to go back to work part time building slowly up to full time work.

When you have returned to work it's important to remember to stick to your usual diet routine of “little and often”. If you require advice regarding work and benefits ask your specialist nurse who can arrange for you to meet a benefits advisor in the cancer support centre.

Helpful reading:

Macmillan cancer support “work and cancer” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Potential problems

Dumping Syndrome

If too much is eaten at once you may feel discomfort, nausea (feeling sick) and perhaps dizzy and sweaty.

This is known as 'Dumping Syndrome'. There are two main reasons for this:

- After a meal, food passes more quickly than before through the stomach into the small bowel (gut), by doing so it draws more water into the gut, which can cause a drop in blood pressure and make you feel uncomfortable and faint. Eat slowly and in small amounts until you know what you can manage. Avoid eating and drinking at the same time.
- Dumping syndrome can also occur within a couple hours after eating. Especially after eating sweet foods or drinks. Again foods pass quickly into the gut, sugar is absorbed rapidly causing the body to release a large amount of insulin. The insulin then causes the blood sugar to drop below normal levels and you can feel faint and dizzy. A sugar rich drink or dextrose sweet will help return your sugar levels back to normal.

Helpful reading:

“Dietary advice for dumping syndrome ” booklet available from your local Specialist nurse or Dietitian (see contact numbers at end of booklet).

Reflux and dry cough

This is very common problem as the valve (doorway) between your stomach and gullet has been removed at the operation. This makes it very easy for stomach

contents (food, acid and green bile) to travel back up your gullet. This can happen commonly at night waking you up with a burning at the back of your throat and through to your back making you feel sickly. As a result of reflux its possible for a small amount of stomach contents to go the 'wrong way' into your airways this can give you an **irritating dry cough**. There are a number of things you can do to reduce this problem occurring:

- Avoid eating or drinking within two hours of going to bed. If you are troubled by reflux at night, you may find sleeping with extra pillows or raising the bed head by 4 inches using blocks bricks or books.
- You may find lying on your left side makes reflux worse, so try to lie on your back or on your right side
- Try not to eat fatty foods in the evening
- Your surgeon may suggest a course of ant acid tablets to reduce the burning effect and/or anti sickness tablets that encourage your stomach to empty so lessening amount of reflux experienced.

Wind problems

This may be a long-term effect. You may have a tendency to “burp” rather more than before as the throat and stomach are closer together. This may be involuntary but with time some control will be gained. A fizzy drink or peppermint oil may help release the trapped air.

Swallowing difficulties

Occasionally the new join in the gullet narrows due to the natural healing process, which can result in

difficulty in swallowing. This narrowing can be easily stretched by doing an endoscopy. You can call any of the numbers on the back page for help if you develop swallowing difficulties.

Breathing difficulties

If the incision was made in your side of the chest your rib cage will have had a hard time. Breathing and coughing initially maybe painful. This can remain sore for several months. You can make deep breathing and coughing easier by supporting your rib cage with a cushion.

Losing Weight

It is quite common to continue losing weight after leaving hospital. Try not to worry about it. You may have a feeding tube deliberately left in place, if so it can be used to give you nourishment via overnight feeds while you are asleep.

You will probably find that you will not return to the weight you were before you became unwell. You will establish a new weight. This can take a long time, maybe 6 months or a year. The 'little and often' eating routine will be a good way to achieve this. When you do not feel like eating much, supplementary drinks such as Fresubin or Complan can help.

Some of these supplements are available on prescription from your GP. Your dietitian will be pleased to advise you about what is suitable for your needs.

Diarrhoea

You may experience some changes in bowel habit. Diarrhoea or constipation is common. If you have

severe diarrhoea it can cause you to lose weight quickly and make you lose confidence about going outdoors or being too far away from a toilet. Please tell your specialist nurses as this can be treated with anti diarrhoeal tablets and with diet adjustment.

Helpful tip:

The Oesophageal Patients Association has produced a card which states that for medical reasons you require urgent access to toilet facilities at www.opa.org.uk

Vitamin B12 and iron deficiency anaemia

As a result of your operation you will lose part of your stomach. As a result it's possible to develop a type of anaemia resulting from a deficiency in Vitamin B12. Removing part of your stomach removes special cells, which absorb vitamin B12 from your diet. Without absorption of this vitamin you will slowly become anaemic. Therefore, once all your treatment is complete we will monitor your blood regularly and if you become anaemic we will ask your GP to arrange a Vitamin B12 injections (sometimes needed every 3 months). We will also recommend you start a multi-vitamin and mineral tablet that contains iron, to take daily ongoing.

Malabsorption of fats

A small number of people may have problems absorbing their fat in their diet. The stomach normally produces hormones which stimulate the pancreas to release enzymes to break fat down. When you have undergone surgery on your stomach this can be reduced. You could notice that your stools are light in colour, smelly, oily and difficult to flush away. You may

be prescribed a course of pancreatic enzymes called Creon to help ease this symptom.

Tiredness and emotional impact

Many people underestimate how severe this operation is and how slow progress can be, especially if you have had other treatments as well as the surgery. It's common to have good days and bad days. Low mood anxiety and depression are also possible if progress slows and you have set backs.

Everyone needs support through difficult periods in their life. Taking through how you feel and what is worrying you can be helpful to understand what is normal and how to aid progress.

Tiredness (fatigue) and feelings of exhaustion can continue for for several weeks or months after treatment is completed. There are many ways of reducing the amount of tiredness you feel each day, eg maximising your diet, building exercise into your daily routines, and by drinking plenty of fluids.

Helpful reading:

Macmillan cancer support “coping with fatigue” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Buddy List

Some people find it helpful to talk to other people who have gone through the same treatment. A 'buddy' list has been compiled with names of patients who have undergone the operation and who are willing to talk to new patients.

If you would like to take advantage of this or to be a buddy, please contact your Specialist nurses (see contact numbers at end of booklet).

Support Groups

Local support groups are available in North Devon Exeter and Treliske. These groups are supported by the national Oesophago-gastric Patients Association and provide a focal point for patients and their carers, to talk and exchange experiences, and hopefully to feel less isolated. There is also a regional meeting held once a year in May for everyone. Your Specialist Nurses and other Health care professionals attend the meetings for advice and support. If you are interested in going to one of these meetings please contact your Specialist nurses (see contact numbers at end of booklet)

Oesophageal Patients Association (0121 7049860)
www.opa.org.uk

Cancer Support Centres

If you would value the opportunity to talk to someone about how you feel, take advantage of the complimentary therapies, or would like some practical help, Several hospitals have Cancer Support Centres available to anyone affected by cancer at any stage of the illness and offers a comfortable space where you can share your concerns, ask questions and receive support. It is staffed by professionals and trained volunteers many of whom have a personal experience of cancer.

Plymouth: The Mustard Tree Macmillan Support Centre (mon-fri) 01752 763672

Tavistock: Triangle Centre (Fridays) 01822 615935

Kingsbridge Triangle Centre: (Tuesdays) 01548
852349

Liskeard: Triangle Centre (Thursdays) 01579 335600

Exeter: The Force Centre (Mon-Fri) 01392 402875

Truro: The Cove Macmillan Support Centre
(Mon-Fri) 01872 256363

Follow up

Approximately 2 weeks after your operation the surgeon will see you in clinic as an outpatient (If you don't receive this please call your consultant secretary, or your specialist nurse for advice). It may be useful to write down anything that you wish to talk about at this appointment and you are welcome to bring someone with you.

Treatment summary

At this first appointment after your operation your surgeon will have the report from the histopathologist which will give a clearer picture of how the operation went and may enable the surgeon to tell you more about the stage of the disease removed. He will then give you a written Treatment Summary explaining what treatment you have had and how well it has worked.

A few patients may need further cancer treatments, if this is felt to be in your interest the surgeon will let you know and refer you to an oncologist for an opinion.

Ongoing follow up /reviews

Your specialist nurses and surgeons will continue to follow you up regularly in clinic for 5 years. There will be no need for regular scanning through this period unless you have a specific problem that requires investigation.

Worries and uncertainties

You will probably feel relieved when you have finally completed treatment to get rid of the cancer. But you may find yourself worrying about whether it has worked and what might happen in the future. It's natural to feel like this. Even when your doctor is reassuring it's normal to still worry.

Helpful reading:

Macmillan cancer support “Worrying about cancer coming back” booklet available in the Cancer Support Centre at Plymouth Hospitals or online at www.Macmillan.org.uk

Knowing if you need more help

Sometimes loss of appetite, weight loss, new pains after the operation, or renewed difficulty swallowing can make you think the cancer is coming back when actually these can be common problems after surgery. Please don't wait for the next clinic appointment, do call your specialist nurse at any time to talk about your worries or concerns.

How to contact the hospital team

Within office hours

Your specialist nurses (key workers) are available to you, your family and close friends for any questions, concerns or worries. All the surgical and oncology teams can be contacted via them.

Plymouth Nurse Specialists & Dietetic team

Marilyn Bolter	☎01752 431528
Jen O'Reilly	☎01752 431528
Lizzie Bevan	☎01752 431528
Support Worker Angela Bleasdale	☎01752 431528
Dietetic team	☎01752 432243

Exeter Nurse Specialists & Dietetic team

Specialist nurses	☎01392 402775
Dietetic team	☎01392 406237

North Devon Nurse Specialists & Dietetic team

Specialist nurses	☎01271 314147
Dietetic team	☎01271 322306

Torbay Nurse Specialists & Dietetic team

Specialist Nurses	☎01803 655890
Dietetic team	☎01803 654385

Truro Nurse Specialists & Dietetic team

Specialist nurses	☎01872 252177
Dietetic team	☎01872 258326

Out of hours

Help is available by contacting Wolf Ward directly

Wolf Ward (open 24hrs/day) ☎01752 439678

This booklet and other local patient

information can be found on:
www.plymouthhospitals.nhs.uk

Your notes:

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This booklet and other local patient information can be found on:
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**This leaflet is available in large print
and other formats and languages.
Contact: Oncology Department
Tel. 01752 431344**

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