


Oxford Upper Gastrointestinal Centre

Discharge after an oesophagectomy or an oesophagogastrrectomy

Information for patients

A decorative graphic consisting of a grid of overlapping squares in various shades of grey, creating a stepped or staircase effect. The squares are arranged in a pattern that descends from left to right, with some squares overlapping others.

Introduction

This information leaflet gives you information about the “do’s and don’ts” after major surgery on the oesophagus. Some of the facts are based on information collected from other people’s experiences at various stages after the same type of surgery. This information is to help you and your carer(s) to recognise some of the problems you might encounter once you are back at home.

If you have any concerns about your condition once you have returned home, please contact your Advanced Nurse Practitioner, consultant surgeon or your GP.

If you would like to speak with someone who has had surgery on the oesophagus, either before or after your operation, please contact:

Oxfordshire Oesophageal and Stomach Organisation (OOSO)

www.ooso.org.uk

Tel: 07711 160 766

Follow-up appointment

This appointment will normally take place **around two weeks** after your discharge from hospital. If you have not received an appointment date after one week, it is important that you contact the consultant’s secretary or your Advanced Nurse Practitioner. We are of course happy to see you earlier if you have any particular concerns or problems.

At home

You have just been through a major operation. Your body needs time to recover from the trauma and to adjust to its new condition.

Many people are surprised at the length of time it takes to get over an operation. When you first get home, you may feel impatient or feel that you are not recovering as fast as you would like.

Try to be patient; it takes a while to recover, particularly if there have been complications after surgery.

Pain and pain relief

You may experience pain of one sort or another for quite some time. You do not have to put up with great pain. Whilst in hospital, the nursing and medical staff will work with you to control and minimise any discomfort you may experience. The pain generally improves over time. A small supply of painkillers will be arranged for you to take home and a copy of the prescription will be sent to your GP. Once you are at home, please talk to your Advanced Nurse Practitioner or GP about the type and level of pain relief which is best for you. Please do tell them if the pain gets worse.

Nutrition and eating

You will be seen by a specialist dietitian before you are discharged home. The dietitian will give you dietary advice and useful information leaflets.

For the first few weeks after surgery you will be advised to have a “fork-mashable” diet before going onto a ‘normal diet’. Eventually, you will find a pattern of eating and drinking that suits you, although this may take some time.

Eating and drinking

Many people find that they may not be able to eat as large a meal as before, will feel full more quickly after meals and will need to eat small amounts **“little and often”**. It is a good idea to have several smaller meals and additional snacks during the day, rather than a few large meals. It is also best to take drinks separately from meals.

These are some of the things you may experience:

- **Not feeling hungry**

In the early weeks after surgery you may not feel as hungry as you did before, but it is important to try to build up to a high calorie and protein diet. This will build up your strength and help you to recover.

- **Weight loss**

It is not uncommon to lose some weight after discharge from hospital. It can be regained slowly by following the instructions given by the dietitian. You may find you don't return to the weight you were before the operation.

If you are continuing to lose weight, it is important to contact the Advanced Nurse Practitioner or the specialist dietitian for assessment and advice (contact numbers are at the end of the leaflet).

- **Difficulty swallowing**

Occasionally, soon after the operation, the area that was joined during the surgery (anastomosis) can narrow. This is usually due to scar tissue. This narrowing can result in difficulties with swallowing.

The narrowed join can be gently stretched during an endoscopy. Please contact the Advanced Nurse Practitioner or surgeon if you have any difficulty swallowing.

- **Reflux or acid regurgitation, particularly at night**

This is very common because the part of your body which stopped stomach contents (food, acid and possibly green bile) from coming back up into your oesophagus is no longer there. This usually settles after a while, but in the early days there are a number of things you can do which may help reduce the problem:

- Don't eat late at night. Try to eat your last meal of the day around 6 o'clock. If you are hungry after that, eat a water biscuit, rye crisp bread or a dry biscuit – anything without fat in it. Try not to eat fatty foods in the evening.
- Prop yourself up in bed with several pillows or a V-shaped pillow (it may still not be comfortable for you to sleep on your back) and try to raise the head of your bed on blocks, bricks or books.
- Your surgeon may suggest a course of antacid tablets. If you have continued regurgitation or reflux, an endoscopy with a gentle stretch of the exit from your stomach tube may be recommended. Sometimes the exit of the stomach tube can become slow to function and empty into the small bowel as a result of damage to nerves in this area.
- **Nausea** It is quite common for people to experience nausea from time to time. This may be because you may have eaten too fast or too much, or it may be that you are in need of food but not actually feeling hungry. Eating a dry biscuit can help. It is best to contact your Advanced Nurse Practitioner or surgeon if the nausea is constant or continues for a long period of time.
- **Wind** Some people find that they have a lot of air in their stomach which may cause burping. This can be very uncomfortable but it should get better fairly quickly. A fizzy drink will help to release the trapped air.

- **“Dumping syndrome”** Dumping syndrome happens in a small number of people after surgery on the oesophagus. The symptoms may occur immediately or within a couple of hours after eating. They may include:
 - diarrhoea
 - a feeling of faintness or dizziness
 - sweating
 - nausea
 - occasional abdominal cramps.

There are two main reasons for this.

1. After a meal, food moves rapidly into the small bowel and, by doing so, draws water into the gut. This can cause a drop in blood pressure.
2. Dumping syndrome can also occur within a couple of hours after eating. Again, it is due to food passing quickly into the small bowel. Sugar is absorbed very rapidly and as a result the body reacts to this by releasing a large amount of the hormone insulin. This insulin then causes your blood sugar to drop below normal levels. A sugar-rich drink or sweet can be used to raise your blood sugar levels if you feel faint after eating.

Most symptoms settle with time and are usually helped by introducing simple changes to your diet. Some people find that sucking a dextrose tablet will very quickly improve how they feel. Some people carry a packet around with them just in case; they are available from most chemists.

Please let your dietitian or Advanced Nurse Practitioner know if you have any of these symptoms or suspect you are suffering from dumping syndrome.

Malabsorption

A small number of people may have problems absorbing fat after surgery involving their stomach. The stomach normally produces hormones to stimulate pancreatic function. This function may be reduced by the surgery and therefore the pancreas may not release the pancreatic enzymes as efficiently to break down the fats in food. You may experience episodes of diarrhoea regularly, with stools that are smelly, fatty, oily, floating or difficult to flush away. You may be prescribed a course of pancreatic enzyme supplements to ease the symptoms.

Your surgery, a change in diet, a change in activity and the use of some drugs can all lead to irregular bowel habits. This usually corrects itself with time, as you adapt to your new condition.

If you have any concerns about bowel function, please speak to the specialist dietitian or Advanced Nurse Practitioner for advice.

Wound healing

All wounds progress through several stages of healing. You will be able to see changes in your wound over time. Most people frequently experience:

- Unusual sensations, such as numbness, tingling, or itching.
- Slight pulling around the stitches or staples as the wound heals.
- A slight hard lumpy feeling as new tissue forms.

Remember, please do not pull off any scabs as they protect the new tissue underneath and act as nature's dressing. They will fall off without any help when ready.

Occasionally, **an infection might** develop in the wound. This may just show as an increased reddening of the skin or can progress to oozing of a pus-like fluid from the wound.

Sometimes, the wound may open up. If this happens, the wound will need to be checked and dressed by a district nurse/practice nurse. If you develop an infection it will take longer for your wound to heal. You may also need antibiotics to treat the infection.

Bathing and showering

It is quite safe to get your wound wet after you have gone home, as long as it is healing well (or unless you are advised not to). Try to avoid soaking in the bath for too long and make sure that the wound is carefully patted dry. If your wound requires a dressing, please speak to the district nurse or practice nurse for advice about bathing or showering.

Exercise and activity

Most people feel very tired when they first go home from hospital and are frustrated by not feeling able to do all the things they want to do. Do not worry, this is normal and will improve as the weeks and months go by. Many people do not feel they have “returned to normal” for around 6-12 months after the operation. It may take longer if there have been complications.

Please follow the advice about breathing and exercises given to you by the physiotherapist in hospital. These exercises will help you to gain strength and stamina when you return home.

It is useful to make a plan for yourself of gradually increasing your normal activities over the next few weeks and months. Progress may feel slow and frustrating, but pushing it too hard at an early stage may do more harm than good. Gentle exercise will help to stimulate your appetite and your energy levels. A gradual increase in the amount of exercise you take is helpful, perhaps starting with short walks and increasing the distance over the next few weeks. Climbing stairs can be surprisingly tiring, but is a useful way of getting exercise and judging your progress.

Remember to avoid any heavy lifting of weights (including small children or shopping) or pushing or pulling (including mowing

the lawn) for the first 8 weeks after surgery or after the wound has completely healed. Make use of any help available in these first weeks. Trying to go back to doing usual household jobs is important, but you should balance your increased activity with suitable rest.

Take care not to overdo it on one day as you may feel it the next day. You may feel more tired, feel stiff and ache more, or feel lower in mood or more irritable.

Rest

At first, you may feel exhausted and may want to sleep a lot. Your body needs all its energy to mend and heal itself. It is helpful to plan a 'rest time' during the day, when you cannot be disturbed. This is a time to have a sleep or to simply rest without interruption. On the whole, resting on your bed rather than a chair is more relaxing. An afternoon nap before 4pm should not affect your sleep at night.

It is a matter of balancing periods of rest with periods of activity to encourage recovery from surgery and to build up stamina again.

Be assured that your sleep patterns will improve over time.

Visitors

When you first get home, all your caring and well-meaning friends may want to visit or telephone and wish you well. You will need to make sure that you are not subjected to 'visitor overload'. Visitors can be very exhausting and may need you to tell them if you get too tired and need to rest quietly.

Breathing

If the incision (cut) was made through your side, your rib cage will have had a really hard time. Breathing and coughing may be extremely painful and the area where the rib cage was opened up may go into spasm (tensed muscles) or be sore for several months. You can make deep breathing and coughing easier by

supporting your rib cage with a cushion, as demonstrated by the physiotherapist on the ward.

Your scar may develop adhesions (the scar feels stuck to the rib cage). Your GP may be able to get you some physiotherapy, which will help with your movement and break down the adhesions.

Depression, anxiety or irritability

Some people go through short periods of low mood, depression, anxiety or irritability. This is usually when they feel they are not making any progress, when they are in pain, or when they suffer a setback of some sort.

Many people underestimate how severe this type of operation is. It is normal to want to see immediate improvement, but the reality is that it takes time to get over the surgery. It may be helpful to set yourself small goals to achieve in the first few weeks after the operation rather than expecting to go back to your normal daily activities immediately – which will only lead to disappointment and frustration.

Flashbacks and poor sleep are not uncommon and may be related to a stay in the intensive care unit.

It can be difficult to talk to loved ones and to explain how you feel, or to assume that they understand how you feel. By sharing how you feel you and your family and friends are more likely to be able to support each other during this time in your recovery.

Please do contact the Advanced Nurse Practitioner if you are feeling low, anxious or depressed.

Some people find it helpful to speak to someone else who has already had similar surgery. Please ask if you would like to speak with someone who has been through the same experience as you.

Sex

It is common after major surgery to experience a temporary drop in libido. This is often due to lack of energy and physical strength. Try to talk openly with your partner about your feelings. Remember, closeness and sexual pleasure can be shown in a number of ways and not just by the act of sex.

You should be able to resume sexual activity as soon as you feel ready.

Work

The time at which you return to work depends on the type of job you have. You can expect to be off work for at least 3-6 months and it could be 6-12 months before you feel back at your best. Some people start off by going back to work part-time and then increase to full-time work.

Driving

We recommend that you don't return to driving until 6-8 weeks after the operation, as long as you are feeling well and are not taking any medication which can cause drowsiness. Remember, for your own safety and that of others, you must have the strength and movement to do an emergency stop.

It is advisable to contact your insurance company to make sure you are covered when you decide to drive again.

Other symptoms

People experience a wide variety of different symptoms and responses to their new condition. If you are worried about any symptoms not listed above, contact your Advanced Nurse Practitioner or surgeon. They will be able to offer you advice and support.

When will I be discharged home?

You will normally be discharged from hospital when you have met specific targets with your recovery. Some examples of these are:

- being assessed as medically fit (well enough) for discharge
- controlling your pain with painkillers
- managing a soft/moist diet and fluids
- being able to open your bowels
- being independently mobile (able to get out of bed and on/off the toilet without help).

Once you are eating enough, moving well, and feel reasonably well, then we can plan for your discharge from hospital. The Advanced Nurse Practitioner will give you written advice about discharge and will discuss any specific issues with you. The dietitian and the physiotherapist will give you written information about diet and exercises too.

The ward nurses will teach you (or your carer) how to give yourself a short course of blood-thinning injections before you go home.

Most people will be discharged with their feeding tube in place. To keep the tube clear it simply needs flushing through with water once a day. We will show you how to do this on the ward before you go home. The ward will also organise a district nurse to visit you at home. Provided that you are eating well and maintaining a stable weight at your first out-patient appointment, we will remove the feeding tube in clinic.

You will need to make your own arrangements for discharge, including transport and making sure that you have adequate support at home. If you have any questions or concerns about leaving hospital, please speak to your ward nurse.

Further information can be found in the following patient information booklets, which are available from the Oxford Upper Gastrointestinal Centre at the Churchill Hospital, Oxford:

- Leaving Hospital: information for patients leaving hospital
- A guide to life after surgery (Oesophageal Patients Association (OPA))
- Life after an oesophagectomy or gastrectomy (Oxfordshire Oesophageal and Stomach Organisation (OOSO))
- Eating and drinking following oesophageal or stomach surgery
- Life after discharge from intensive care

How often will I need check-ups?

We usually see you in clinic two weeks after discharge from hospital. After this, your routine follow-up appointments will take place at three to four monthly intervals during the first year and then usually on a six monthly basis after this. We will of course see you earlier if you have problems or concerns.

Please do not hesitate to contact the Advanced Nurse Practitioner or the medical staff in the event of any concerns or problems.

Please also contact the Advanced Nurse Practitioner if you have not received any outpatient appointments.

Will I need further treatment?

All your scans/X-rays and tissue samples (histology) are discussed at specialist multidisciplinary team (MDT) meetings at different times during your treatment programme. After the operation we will review the tissue removed at the time of surgery. We will discuss the results of the operation with you either on the ward or in the clinic.

Occasionally, further treatment with chemotherapy or radiotherapy will be needed. If we feel that this treatment would be suitable for you it will be discussed in more detail with you, either on the ward or in clinic.

How to contact the hospital team

In office hours, please contact the Advanced Nurse Practitioner, the surgeon or specialist dietitian on the telephone numbers listed below. If you are unable to contact a member of the team please contact your GP or the Oxford Upper GI Centre.

Consultant Oesophagogastric Surgeons

- **Mr Nick Maynard** 01865 235 673
- **Mr Bob Marshall** 01865 235 158
- **Mr Bruno Sgromo** 01865 235 158
- **Mr Richard Gillies** 01865 235 673

Upper Gastrointestinal Advanced Nurse Practitioner:

Telephone: 01865 235 706

Telephone: 01865 741 841 Please ask for
Bleep 1977 or 5928

Specialist Dietitian:

Telephone: 01865 235 421

Telephone: 01865 741 841 Please ask for
Bleep 4176

In an emergency:

In an emergency or life-threatening situation, you must go to your local emergency department for appropriate treatment.

Outside of office hours

After 4.30pm, during the night, at weekends and bank holidays, please contact either your GP Surgery or the Oxford Upper GI Centre to speak to an experienced ward nurse.

Oxford Upper GI Centre:

Telephone: 01865 235 061

If you would like to talk to someone who has been through the same operation, please contact:

Oxfordshire Oesophageal and Stomach Organisation (OOSO)

www.ooso.org.uk

Tel: 07711 160 766

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALSJR@ouh.nhs.uk**

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