

## Upper Gastrointestinal Surgery

# Going home after your surgery for cancer of the oesophagus

## Information for patients, relatives and carers

### Introduction

This leaflet is designed to give you some general advice about what to expect and what to look out for when you leave hospital after your surgery. We hope it will answer some of the questions that you or those important to you may have. It is not meant to replace the consultation between you and your medical team, but aims to help you understand more about what is discussed. If you have concerns about any issue to do with your recovery, please speak to a member of the medical team.

Before you are discharged, there are a few things that the team will want to be sure of:

- your wounds are healing properly
- you can swallow properly
- you are tolerating food and fluids
- you can care for your jejunostomy feeding tube (if you have one)
- you have been seen by a dietitian

On the day of discharge, you will be given a letter from the ward nurses.

A copy of this letter will be sent to your GP. This letter has information about your discharge, your treatment in hospital, your tablets, your future outpatient appointments and may have a section about referrals that have been made for you (for example, district nurses).

### Medication

You will be given a one-week supply of medication before leaving hospital. The ward nurse will explain to you what they are and how you should take them.

For further medication you will need to contact your GP. Please contact your GP as quickly as possible after discharge from hospital and make sure you take the pink sheet from your hospital prescription with you to your GP appointment.

Cancer patients are entitled to free prescriptions. Please discuss this with your clinical nurse specialist/key worker.

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## When you are at home:

### Caring for your wound

Your wound will need care. The ward nurses will arrange for a district nurse to visit you at home or arrange for you to attend your GP surgery. We would ask you to keep an eye on your wounds every day.

### Bathing and showering

You can get the wound wet, but this might make it feel sensitive.

Make sure that you dry your wounds carefully.

When having a bath or shower, do not put perfumed/scented soap, sprays, or cream on or near the wounds until they are fully healed, as this may cause irritation.

If you have a jejunostomy feeding tube, we recommend you have a shower for the first two weeks after this was inserted. After that time, you may have a shallow bath this to prevent your surgical wounds from getting wet.

**If you notice any redness or inflammation at your wound sites or if they become sore, contact your GP or district nurse immediately.**

An infection in the wound may be developing and you may need antibiotics. If you have a high temperature and need immediate help please attend A&E. If this is out-of-hours, please contact NHS 111 to find out the best place to get the right help.

## Nutrition

You may go home with a feeding jejunostomy tube. Your progress will be reviewed at your clinic appointment with the dietitian. The tube will be removed in the clinic when it is no longer needed. You will not need an anaesthetic to remove it.

The dietitian will provide you with information and guidance on how to gradually develop your diet.

## Emotional support at home

You may feel anxious because you have been separated from the hospital team. It is quite common for people who have had this surgery to feel a bit down when they first get home. It may feel like a frightening and unsettling time.

You may find it helpful to talk about your feelings and concerns with someone with specialist knowledge of your cancer, such as your clinical nurse specialist (CNS) or key worker. They will be able to offer support, advice, and guidance about how to cope with your illness.

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## Side effects and what you can do to help

Below is a list of possible side effects that may follow this type of surgery and some advice on what may help:

### **Tiredness and fatigue**

You will feel very tired at first when you leave the hospital, but this is normal. Try to get up and dressed in the morning and keep active around the house. You should take gentle exercise (see below), but you may need a rest in the middle of the day.

### **Eating**

As the stomach is now a narrow tube, you will not be able to eat large meals and will feel full quite rapidly. Therefore, you must have small and frequent meals. Your capacity for eating larger meals may slowly return, to some extent, over 9 to 12 months. Remember 'little and often'. Try not to eat late at night as this will give you indigestion.

### **Voice**

If your voice has continued to be weak and hoarse after your surgery, this will be monitored when you return to clinic. If necessary you may be referred to a speech and language therapist for voice therapy when you leave hospital.

### **Dumping syndrome**

This side effect is due to food entering parts of the bowel too quickly. This can lead to either a drop in blood pressure or a reduced blood sugar level.

This can make you:

- feel light-headed
- feel sweaty
- have an urge to open your bowels

It can be improved by:

- eating small amounts at regular intervals (every 1 to 2 hours)
- reducing the sugar in your diet
- eating slowly
- avoiding drinks or liquids around mealtimes

### **Taste changes**

Many patients say their taste changes after their operation. Food may have no taste or taste very different to what you expect. This can last for a few weeks after the surgery. Many people prefer savoury foods at this time. Try experimenting with different types of food and condiments.

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## Loss of appetite

You are likely to have a small appetite after surgery. It is important to keep going and eat little and often to try and minimise your weight loss even if you do not feel hungry.

## Weight loss

You may lose about 10% of your weight post-surgery. This is very common and is due to a combination of factors. It is important it does not happen too quickly as it can make you very weak.

If you find yourself losing weight too rapidly and struggling to eat **you must** call your CNS/key worker or dietitian for advice.

## Swallowing difficulties

In rare cases, scar tissue may have formed where the gullet and bowel are joined. This may result in food sticking in your gullet when you swallow. This is very simple to treat under sedation by stretching the gullet. This is done as a day case in the endoscopy department and is called a dilatation.

If this does occur, you must contact your CNS or key worker so that they can arrange treatment.

If you have had an oesophagectomy, which involved a neck incision, you may experience some difficulties with swallowing in the neck region. A speech and language therapist may visit you at home to advise you on how to eat and drink safely and comfortably.

## Acid regurgitation (reflux)

You might have 'heartburn' or acid reflux post-surgery. This can happen as a result of the operation, because:

- the valve between the gullet and stomach is removed
- the stomach is moved up into the chest

Acid reflux can be treated with antacid medications.

Many patients need to sleep more upright after surgery to avoid acid reflux.

There are several wedges (fixed and inflatable) and special beds available to make this easier. These devices can be bought VAT free if you need them for medical reasons. Please discuss this with your CNS/key worker.

## Diarrhoea

This is quite common due to the changes in the shape of your digestive tract. The diarrhoea can usually be controlled with changes in eating behaviour as well as medication and improves in time.

## When can I return to normal activities such as driving and work?

### Exercise

We encourage light physical activity to begin with. You should plan to take short walks for about 10 minutes three times a day. Gradually increase the distance during the first four weeks after your operation, until you are back to your normal level of activity.

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Do not lift heavy items such as bags of shopping or vacuum cleaners (anything heavier than 2 to 4 kg) for at least 10 to 12 weeks after the operation, as this can put pressure on the wound.

Please ask for advice on this at your first follow-up appointment after leaving hospital and before resuming any physical activity.

### **Driving**

Do not drive until your strength and speed of movement are back to normal, as you must be able to do an emergency stop. It usually takes about 6 weeks after discharge. It is important to inform your insurance company that you have had an operation to ensure that you are covered in the event of an accident. You should also make sure that you are not drowsy from any painkillers and that your concentration is good.

### **Work**

There is no set recommended time for returning to work. It will depend on your recovery and the type of work you do.

As you become stronger and the discomfort in your wound settles you will be able to do more. It can take between 6 to 12 months to feel back to normal again, but many patients start back with part-time work 3 to 4 months after their operation.

Please discuss with your surgeon, CNS or key worker about fit notes and returning to work.

## **Follow-up after surgery**

You will be seen by your surgeon two weeks after surgery.

Following that, you will be seen as required or every three months for the first two years and then every six months from years three to five. After that you will be seen every year.

## **Further treatment after surgery**

Depending on the laboratory results of the cancer removed during surgery, you may or may not need further chemotherapy or radiotherapy. The oncologist will discuss this with you.

## **Oesophago-gastric support**

Speaking to a patient who has been through this operation can help you get a feel for things, from someone who has been in your situation.

This can be arranged for you. Please tell your CNS/key worker if you would like to get in touch with a fellow patient.

There is a post-operative support group held at Maggie's Centre, Charing Cross Hospital, for patients who have had oesophago-gastric surgery and their carers. For sessions information, please contact Maggie's Centre on 020 3312 8753.

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## Further sources of support and information

### **Macmillan cancer navigator service at Imperial College Healthcare NHS Trust (ICHT)**

This is a single point of contact for ICHT cancer patients and their families, helping you to navigate your care and resolve queries that you may have. Our Navigators can access information about your appointments, connect you to appropriate services and signpost you on to further support. They can additionally book you in for a telephone call back from your Clinical Nurse Specialist (CNS) if you have a query that requires clinical input.

The service is open Monday to Friday 8:30 to 16.30 (excluding bank holidays).

Call: **020 3313 0303**

### **Macmillan cancer information and support service at Imperial College Healthcare NHS Trust (ICHT)**

The Macmillan information and support service provides free, confidential support and information to anyone affected by cancer. Our service offers the opportunity to talk to one of our team one-on-one about whatever matters most to you, as well as a range of weekly virtual groups that provide the opportunity to connect with other patients in a relaxed environment.

Our Macmillan welfare and benefits adviser can offer ICHT patients tailored advice on additional financial support.

We have physical centres at Charing Cross and Hammersmith Hospitals and also offer virtual and telephone support.

The service is open Monday-Thursday (excluding bank holidays), with various drop-ins available within our physical centres. For more information please call us on 020 3313 5170 or email [imperial.macmillansupportservice@nhs.net](mailto:imperial.macmillansupportservice@nhs.net)

### **Maggie's west London**

Maggie's is a cancer charity that provides the emotional, practical and social support to people with cancer and their family and friends. The centre combines beautiful architecture, calming spaces, a professional team of support staff and the ability to talk and share experiences with a community of people who have been through similar experiences. Maggie's centres are warm, friendly and informal places full of light and open space with a big kitchen table at the heart of the building. Maggie's west London is located in the grounds of Charing Cross Hospital but is independent of our hospital. The centre is open Monday to Friday, 09.00-17.00. For more information please call **020 7386 1750**.

### **Macmillan Support Line**

The Macmillan Support Line offers confidential support to people living with cancer and their loved ones. This support line is a national line provided by Macmillan and is independent of our

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Hospital.

Call: **0808 808 000** (Every day, 08.00-20.00) or visit [www.macmillan.org.uk](http://www.macmillan.org.uk)

## How do I make a comment about my visit?

We aim to provide the best possible service and staff will be happy to answer any of the questions you may have. If you have any **suggestions** or **comments** about your visit, please either speak to a member of staff or contact the patient advice and liaison service (**PALS**) on **020 3312 7777** (10.00 – 16.00, Monday to Friday). You can also email PALS at [imperial.pals@nhs.net](mailto:imperial.pals@nhs.net) The PALS team will listen to your concerns, suggestions or queries and is often able to help solve problems on your behalf.

Alternatively, you may wish to complain by contacting our complaints department:

Complaints department, fourth floor, Salton House, St Mary's Hospital, Praed Street  
London W2 1NY

Email: [ICHC-tr.Complaints@nhs.net](mailto:ICHC-tr.Complaints@nhs.net)

Telephone: **020 3312 1337 / 1349**

## Alternative formats

This leaflet can be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:  
[imperial.communications@nhs.net](mailto:imperial.communications@nhs.net)

## Wi-fi

Wi-fi is available at our Trust. For more information visit our website: [www.imperial.nhs.uk](http://www.imperial.nhs.uk)

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