

## Upper gastrointestinal surgery

# Going home after your surgery for cancer of the stomach

## Information for patients, relatives and carers

### Introduction

When you leave hospital after your surgery, you want to know what to expect and what to look out for. We hope this leaflet answers some questions for you and your loved ones. It is not meant to replace conversations between you and your medical team. Our aim is to help you understand more about your condition. If you have concerns or questions, please speak to your surgeon or clinical nurse specialist (CNS) team.

### What happens before I am discharged?

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
- treatment in hospital
- tablets
- future outpatient appointments

It may also have a section about referrals that have been made for you (for example, district nurses).

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## What if I need medication?

If you need medication, you will be given one week's supply before leaving hospital. The ward nurse will explain to you what they are and how you should take them.

If you need further medication, please contact your GP. As a cancer patient, you are entitled to free prescriptions. Please discuss this with your clinical nurse specialist (CNS)/key worker.

## How do I care for my wound?

If you still have a wound that needs care, the ward nurses will arrange for a district nurse to visit you at home or arrange for you to attend your GP surgery.

You should try and check your wounds every day. If you notice that your wounds are red or inflamed, or they become sore, please contact your GP. An infection in the wound may be developing and you may need antibiotics.

## Can I have a shower or a bath?

- you can get the wounds wet, but this might make them feel sensitive
- make sure that you dry your wounds gently (pat it dry)
- when having a bath or shower, do not put perfumed or scented soap, sprays or cream on or near the wound 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

## Will I get help with eating and drinking?

You may go home with a feeding jejunostomy tube.

Your progress with your eating and drinking will be reviewed at your clinic appointment with the dietitian.

The tube will usually be removed in an outpatient surgical clinic when you no longer need it. This will not need an anaesthetic.

The dietitian will give you information and guidance on how to progress your eating and drinking.

## Can I get support once I'm home?

You may feel worried or anxious because you have been separated from the hospital team.

These feelings are normal.

Your CNS or key worker will be able to give you advice and support during this time. It's important you contact them if you have any questions or worries.

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## What are the possible side effects?

### Possible side effects

You may have some or all these side effects. They are listed here in alphabetical order.

**Acid reflux** – because of the changes in your digestive system, stomach acid can travel up towards the throat (reflux). This causes heartburn, a burning pain in the chest. This can be treated with antacid medications. Many patients need to sleep more upright after surgery to avoid acid reflux. You can buy wedges (fixed and inflatable) and adjustable beds that make this easier. These are VAT free if they are needed for medical reasons. Please discuss this with your CNS/key worker.

**B12 absorption** – it will not be possible to absorb vitamin B12 after the removal of the whole stomach. You will need vitamin B12 injections every three months after a total gastrectomy. This is not usually needed after a sub-total gastrectomy.

**Diarrhoea** – this 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. It improves over time.

**Dumping syndrome** – this is due to food entering parts of the bowel too quickly. It leads to either a drop in blood pressure or a reduced blood sugar level. This can make you feel light-headed, sweaty or having an urge to have a poo. It can be improved by:

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

**Low mood** – it is quite common for people who have had this surgery to feel a bit down when they first get home. It may be a frightening and unsettling time. You may find it helpful to talk about your feelings and concerns with someone who specialises in dealing with your condition, such as your CNS/key worker. They will be able to offer support, advice and guidance.

**Reduced appetite** – You are likely to have a small appetite after surgery. You will have a narrow tube replacing your stomach. This means you will not be able to eat large meals and you will feel full quite quickly. So, you must have small and frequent meals. It is important to keep trying to eat a bit throughout the day, even if you do not feel hungry. Your recovery will benefit if you maintain your weight.

So, remember 'little and often'. Though avoid eating late at night as this will give you indigestion.

Your capacity to eat larger meals may return slowly over 9 to 12 months.

**Taste changes** – many patients say their taste changes after their operation. Your food may have no taste or taste very different from what you expect. This can last for a few weeks after

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the surgery. Many people prefer savoury foods at this time. Try experimenting with different types of food and condiments.

**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 may need a rest in the middle of the day.

**Weight loss** – you may lose up about 10% of your weight before surgery. For example, if you weighed 10st before surgery, your weight might drop to 9st. This is very common. It is due to a combination of factors. However, it is important it does not happen too quickly as it can make you very weak. If you find yourself losing weight too fast and struggling to eat you must call your CNS or key worker or dietitian for advice.

## When can I return to normal activities?

**Exercise** – we encourage light physical activity to begin with. Start by trying to take short walks for about 10 minutes, three times a day. Then try to increase this distance across the first four weeks after your operation, until you are back to your normal level of activity

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. This can put pressure on the wound.

Please ask for advice about 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. You **must** be able to do an emergency stop. It usually takes about 6 weeks after discharge.

Tell your insurance company about your operation. This is important to ensure that you are covered in the event of an accident.

Also, make sure 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 and 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 this with your surgeon or CNS/key worker.

## Will I have follow-up after surgery?

You will be seen by your surgeon two weeks after surgery in an outpatient clinic.

Following that, you will be seen as required or:

- every three months for the first two years
- every six months from years three to five

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After that you will be seen every year.

## Will I need further treatment after surgery?

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

## Oesophago-gastric support

It may be arranged for you to speak with another patient who has been through this operation so that you can get a feel for things from someone who has been in your situation. Please discuss with your CNS/key worker if you think this would be helpful.

There is a post-operative support group held at the 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 7386 1750).

## 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 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 to Thursday (excluding bank holidays), with various drop-ins available within our physical centres. For more information, please call us on 020 3313 5170 or

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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 in the grounds of Charing Cross Hospital but is independent of our hospital. The centre is open Monday to Friday, 09.00 to 17.00.

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 hospital

Call: **0808 808 000** (everyday, 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)