

Oesophago-gastric service

# My treatment plan booklet

Information for patients, relatives  
and carers

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## Details about me

**Name:**

**Address:**

**Date of birth:**

**Telephone number:**

**NHS Number:**

## Emergency contact details

**Name:**

**Relationship to me:**

**Contact telephone number:**

## Introduction

This booklet is designed to give you information about your treatment. Its aim is to improve communication between hospital staff, your GP, district nurses, community staff and out-of-hours services. It provides a record of your appointments, tests and treatments that you can carry with you.

It also contains space for you and others involved in your care to make notes and to record other aspects of your care.

Further specific information about your cancer is available through Macmillan ([www.macmillan.org.uk](http://www.macmillan.org.uk)) via their booklets and factsheets.

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**It is important that you take this booklet with you whenever you go to see your medical team, nurses, GP, etc.**

**It is also important to show this booklet to any health or social care professionals visiting you at home so they can update it and can complete any relevant sections.**

**This is your personal record, so please feel free to write in the notes/questions and other sections at the back.**

## **What is the oesophago-gastric multi-disciplinary team?**

Following your recent diagnosis of oesophageal (gullet) or stomach cancer, you will receive support and treatment from different clinicians who form the multi-disciplinary team (MDT).

The MDT consists of doctors, nurses and other professionals who meet together to assess your condition and plan treatment and care that is appropriate for you. In order to do this, the members of the MDT meet each Wednesday to discuss people who have a new diagnosis of cancer, and to review those who have previously been diagnosed with cancer.

Due to the nature of the disease, there may be a number of investigations and treatment options available. More than one specialist is likely to be involved in your care. It is essential that everyone involved can share their expertise and understanding about your case, even though you will not personally meet all the members of this team.

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## Our weekly clinic

Your consultant and the medical team will discuss any decisions with you and your family in the clinic at your next visit. They will answer any questions you have on the benefits and risks of your treatment options. Your GP will be sent a summary of your agreed treatment plan.

This is a very busy clinic and will usually involve some waiting. We do apologise for any delays. You are welcome to bring a friend or relative to these appointments to give support, or help you ask questions. Following your treatment you will continue to be seen in clinic regularly for follow-up appointments. This is to check your progress and allow you to discuss any concerns you may have or symptoms you may be worried about.

## Who does what?

### **Key worker**

One member of the MDT will be your key worker. Your key worker is your point of contact during your care. It will usually be one of the oesophago-gastric clinical nurse specialists (CNSs). This may change during your care, either to another CNS in the team or to a different member of the MDT (see below for further details). Should you have any concerns between your appointments you can contact your key worker via the navigator service (see page 7).

### **Oesophago-gastric clinical nurse specialist**

Your CNS will be able to help you by:

- explaining your treatment, giving you information and answering any questions you may have

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- providing emotional support and advice throughout your illness to you and your family or friends
  - arranging additional support at home if applicable, and maintaining links with community services, such as district nurses and GPs
  - giving advice about the best way to manage pain and other symptoms
  - assisting with financial issues
  - telephoning you at home to provide necessary support

Your CNS will also be your link with the other healthcare professionals in the team. One of the CNSs in the team will usually be your key worker.

**Gastroenterologists** specialise in endoscopy (camera investigations) to assess your gullet and stomach.

**Radiologists** specialise in interpreting x-rays and scans from which a diagnosis is made. Radiologists also specialise in fitting oesophageal stents (flexible tubes that allow patients to swallow and eat).

**Upper gastrointestinal surgeons** have expertise in performing operations on the upper gastrointestinal system (which includes the oesophagus, stomach, pancreas, liver and gallbladder).

**Medical oncologists** specialise in using chemotherapy and other drugs for the treatment of cancer.

**Clinical oncologists** may also prescribe the use of radiation, either separate from (or in addition to), chemotherapy and other drugs.

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**Histopathologists** examine the tissues removed during a procedure. They can detect features of cell structure which reveal abnormalities.

**Dietitians** specialise in nutrition. They provide advice on what and how to eat, as well as on different feeding methods, taking into account each individual's needs and condition.

**Speech and language therapists** help with managing swallowing, voice, speech, language and communication problems.

**Physiotherapists** focus on your breathing and mobility after surgery. They will create an exercise program for you, including deep breathing and coughing exercises. Their aim is to get you walking as soon as possible after your operation, help prevent chest infections, increase your independence and optimise recovery.

**Palliative care consultants and nurse specialists** focus on the relief of pain and other symptoms and problems experienced in serious illness. The goal of palliative care is to improve quality of life. The palliative care nurse may become your key worker depending on your needs.

**Clinical trial co-ordinators** specialise in screening patients for possible inclusion into clinical trials on the basis of their eligibility. Once a patient has been approached and given their consent to enter into a trial, clinical trial co-ordinators are also responsible for assisting clinicians in co-ordinating trial-related assessments and patient follow up.

**MDT coordinators** provide administrative support and prepare information for the weekly MDT meetings

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## Useful contact numbers

Below is a list of useful contact details:

**Patient transport:** 020 3311 5353

**Endoscopy unit:** 020 3312 7932

**CT scan department:** 020 3312 6241

**Charles Pannet ward:** (St. Mary's Hospital): 020 3312 6118

**6 north ward:** (Charing Cross Hospital): 020 3313 0917

**6 south ward:** (Charing Cross Hospital): 020 3311 1918/20

**Dietitian:** 020 3311 1445

**Speech and language therapy department:** 020 3311 1761

Imperial College Healthcare NHS Trust has a Macmillan navigator service for access to your CNS (and other members of the clinical team if required). Navigators can also help with queries and provide a range of other information, help and support relating to your care. The service is available Monday to Friday 08.00–18.00 and 09.00–17.00 at weekends. Telephone: **020 3313 0303**

## Emergency contact numbers

**Chemotherapy day unit:** 020 3311 7872 or 020 3311 7871

**Out-of-hours helpline:** 020 3311 7866

Please use the space below to add any other useful contact details.

Name and role: \_\_\_\_\_

Telephone: \_\_\_\_\_

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Name and role: \_\_\_\_\_

Telephone: \_\_\_\_\_

Name and role: \_\_\_\_\_

Telephone: \_\_\_\_\_

## About my illness

### Diagram of oesophagus and stomach

Ask your doctor to indicate your tumour site and/or radiation field location on this diagram, as well as any other areas of relevance.



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## Holistic needs assessments

People with cancer often require support as well as management of their condition. They may also need information about those who can help with issues that can affect them at any given time.

Often, patients do not raise issues that are important to them with their doctors or nurses.

Such issues might include:

- difficulties with relationships - these might be connected to the relationships you have with your friends, the role you have within your family or intimacy issues you have with your partner
- symptoms and physical concerns - you may feel anxious about your illness and recovery, or about the changes in your body
- feelings and emotions - you may feel low or worried
- money worries - you may want to know more about the financial help available to you
- other concerns

Your doctor or nurse will give you time to talk about your concerns. You will have an arranged appointment at which this will happen, or you can ask for a discussion at any time that suits you. This discussion may be called a holistic needs assessment (HNA).

My HNA appointment date:	
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## Treatment options

Your treatment depends on where your cancer is and what type of cancer you have. Treatments include radiotherapy, chemotherapy and surgery. Some patients need only one form of treatment and others need a combination of different treatments, such as surgery and chemotherapy, just surgery, or chemotherapy and radiotherapy.

## My care plan

**This plan gives you a quick overview of what treatment you are going to have. This can change throughout treatment.**

**Ask your healthcare team to write down your diagnosis and initial treatment plan here:**

Diagnosis:

Treatment plan:

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Treatment plan (continued)

## Information about diagnostic tests

<b>Investigation/ description</b>	<b>Reason for investigation</b>	<b>Hospital</b>	<b>Location</b>
<b>Blood tests</b> (phlebotomy)	In preparation for treatment	All hospitals	Outpatient departments
<b>CT scan</b> (a means of producing images of the body using x-rays and a computer)	To see exactly where the cancer is and whether it has spread to other parts of your body	St. Mary's Hospital or referring hospital	X-Ray department (third floor of QEQM)
<b>PET scan</b> (scan that uses a contrast dye – usually given as an injection)	To see exactly where the cancer is and whether it has spread to other parts of your body	Charing Cross Hospital	First floor, north wing
<b>Staging laparoscopy</b> (key hole surgery - a minor operation under general anaesthetic)	To see whether the cancer has spread	St Mary's Hospital	Admission lounge, fourth floor QEQM, or admissions lounge, second floor, Paterson centre

<p><b>EUS</b> (endoscopic ultrasound - combines endoscopy and ultrasound in order to obtain images and information about the oesophagus and stomach)</p>	<p>To provide more information about location of tumour, depth of invasion and surrounding lymph node involvement</p>	<p>St Mary's Hospital or Hammersmith Hospital</p>	<p>Endoscopy department, second floor of QEQM  Hammersmith Hospital, first floor, A Block.</p>
<p><b>Barium swallow</b> (carried out in radiology - you will be given a barium drink while having an x-ray)</p>	<p>To assess if there is any oesophageal narrowing and establish whether an oesophageal stent is an option</p>	<p>St Mary's Hospital</p>	<p>Third floor of QEQM</p>
<p><b>Heart ECHO</b> (an ultrasound of the heart)</p>	<p>To measure how well your heart is working before starting treatment</p>	<p>St Mary's Hospital</p>	<p>Mary Stanford wing, ground floor</p>

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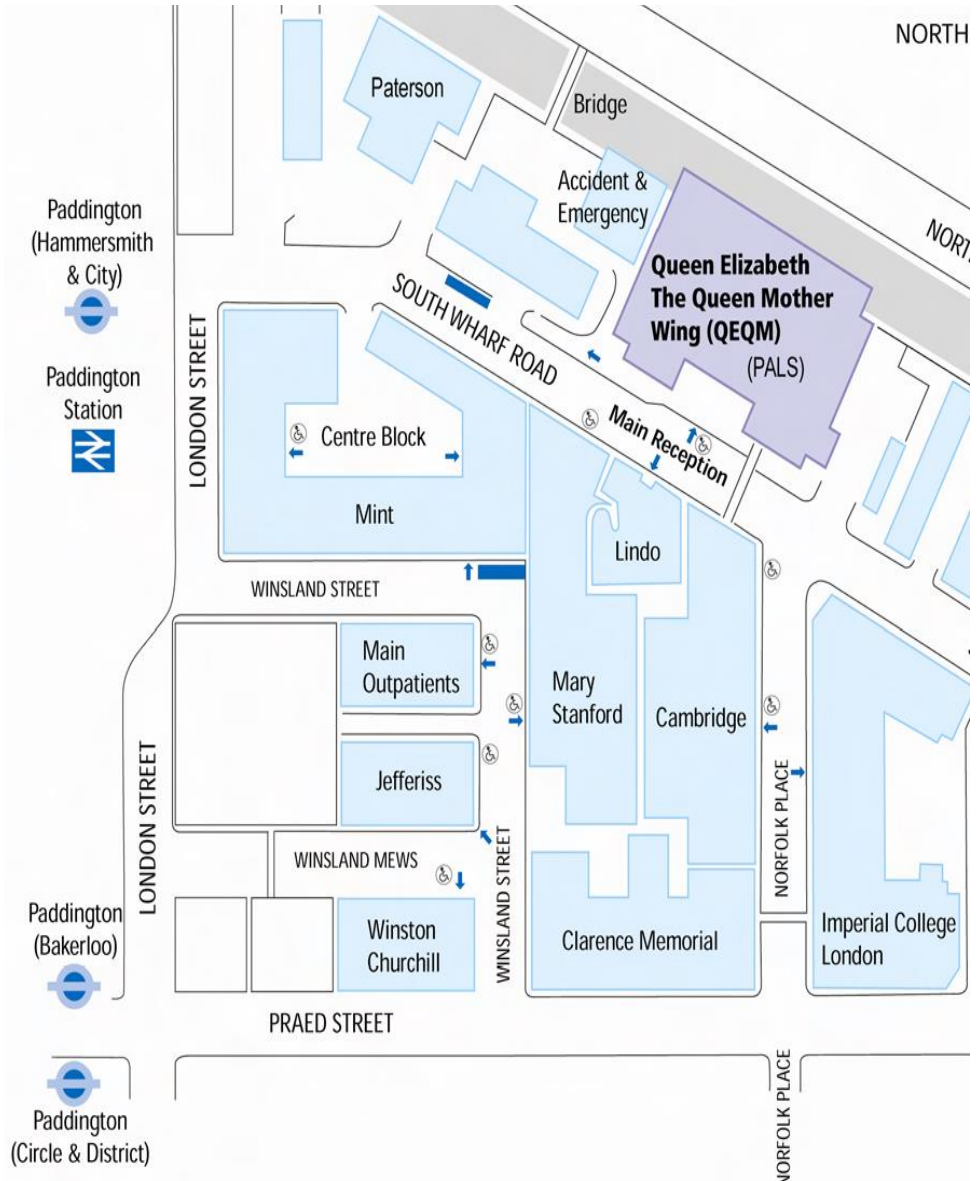
<p><b>Lung function test</b> (to check how well you breathe – you will blow air into a tube)</p>	<p>To measure how well your lungs are working before starting treatment</p>	<p>St Mary's Hospital</p>	<p>Chest and allergy clinic, Mint wing, ground floor</p>
<p><b>Nuclear medicine EDTA</b> (scan that uses a contrast dye, usually given as an injection)</p>	<p>To check how well your kidneys are working before starting treatment</p>	<p>St Mary's Hospital</p>	<p>Third floor of QEQM</p>

Please see the map opposite to check the locations of appointments you may have at St Mary's Hospital. For maps of Charing Cross Hospital and Hammersmith Hospital, please visit [www.imperial.nhs.uk](http://www.imperial.nhs.uk) > Our locations

**St Mary's Hospital, Praed Street, London W2 1NY  
(020) 3312 6666**

**Charing Cross Hospital, Fulham Palace Road London W6 8RF  
(020) 3311 1234**

**Hammersmith Hospital, Du Cane Road, London W12 0HS  
(020) 3313 1000**



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## About me

**Past medical history**

**Medication**

**Drug allergies**



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## My medication

Drug	Start date	Dose	How many per day?



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## Appointments and treatment updates

We hope this will help to avoid breakdown in communication.

**Please note your appointment dates/time here. When you attend, ask the team to add medication changes and any comments to this record and also write in a brief reason. Please ask us to look at this with you during your appointment.**

Appointment date/time	Comments/medication changes

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<b>Appointment date/time</b>	<b>Comments/medication changes</b>





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## How am I feeling today?

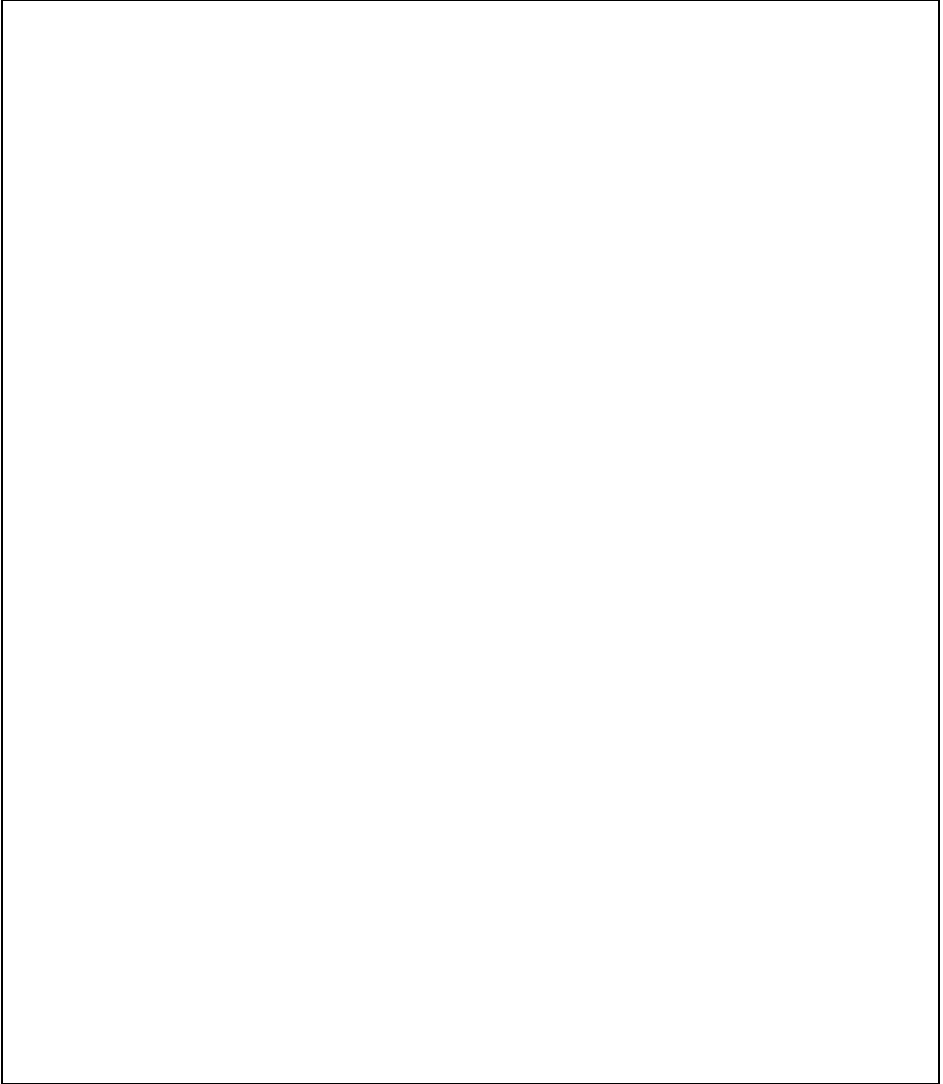
This is a space where you can write or draw how you are feeling from diagnosis until the end of treatment. This can help you see your progression through treatment and can also help when shared with your team as they try to support you throughout the treatment.

A large, empty rectangular box with a thin black border, intended for the user to write or draw their feelings.



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How am I feeling today?

A large, empty rectangular box with a thin black border, intended for a user to write or draw their response to the question above.

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## Information about Imperial College Healthcare NHS Trust

For general hospital information, please visit [www.imperial.nhs.uk](http://www.imperial.nhs.uk)

### **Care and dignity**

We will respect your privacy and dignity and will be sensitive to and respect your religious, spiritual and cultural needs at all times.

### **Your personal information**

Information is kept in accordance with the Trust's data protection policy.

### **Spiritual and pastoral care**

Chaplains are a multi-denominational and multi-faith team working as part of the wider healthcare team. They are available for spiritual, emotional and pastoral support or advice, and also provide a 24-hour emergency call-out service.

You may follow a religious tradition or belief and have specific religious needs. The chaplains are available for people with any faith, providing rituals, prayers and sacraments. Chaplains also offer spiritual and pastoral care for those of no faith, which includes giving time and compassionate attention to people to help them informally work through feelings of distress or anxiety.

If you or your relative/friend wishes to see a member of our multi-faith chaplaincy team for religious or pastoral/spiritual support please ask one of the nurses or doctors and they will arrange this. Alternatively you can contact either the Roman Catholic or Church of England and other faiths on-call chaplain via the hospital switchboard on **020 3311 1234**.

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Your own minister or faith representative is also welcome to visit you in hospital. We have chapels and prayer rooms at Charing Cross Hospital and the times of services are advertised in them:

- Christian chapel, ground floor south wing
- Muslim prayer room, ground floor laboratory block
- sanctuary for all faiths and none in the chapel, ground floor south wing

## Other useful contacts

The following sources of information and support may be of help with your diagnosis and treatment.

### **Macmillan Cancer Information and Support Service at Charing Cross and Hammersmith hospitals**

The information centre at Charing Cross Hospital and the infopod at Hammersmith Hospital provide emotional and practical support, as well as signposting advice to anyone affected by cancer. These drop-in services are set in friendly, non-clinical environments in which people affected by cancer can discuss private and emotional needs with dedicated Macmillan information professionals.

The information centre is located on the ground floor of Charing Cross Hospital. Telephone: **020 3313 4248**

The infopod is located on the ground floor of the Gary Weston Centre at Hammersmith Hospital. Telephone: **020 3313 0171**

### **Maggie's Cancer Caring Centre**

Maggie's is a cancer charity that provides emotional, practical and social support that people with cancer may need. This drop-in

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centre combines striking buildings, calming spaces, professional experts offering support, and the ability to talk and share experiences with a community of people who have been through similar experiences. Maggie's West London is located in the grounds of Charing Cross Hospital but please note it is independent of our hospital. For more information please call 020 7386 1750.

### **Macmillan Cancer Support Helpline**

This is a free line of support and information for people affected by cancer, who have questions about cancer, need support or just someone to talk to.

Telephone: 0808 808 0000

[www.macmillan.org.uk/](http://www.macmillan.org.uk/)

### **Benefit Enquiry Line**

This service provides information on a range of benefits available.

Freephone: 0800 882 200

Textphone: 0800 243 355

### **The Oesophageal Patients Association**

This charity organises support groups around the UK 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.

Telephone: 0121 704 9860

Website: [www.opa.org.uk](http://www.opa.org.uk)

### **Surgical support group**

Every first Monday of the month, from 12.30 to 13.30 at the Fountains Abbey pub (first floor), Praed Street, Paddington.

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## Oesophageal, stomach, liver and pancreatic support group

Every first and third Thursday of the month, from 14.00 to 15.30 at Maggie's West London, Charing Cross Hospital.

### 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 3313 0088** (Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals), or **020 3312 7777** (St Mary's and Western Eye hospitals). You can also email PALS at [pals@imperial.nhs.uk](mailto:pals@imperial.nhs.uk). 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 express your concerns in **writing** to:

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

### Alternative formats

This leaflet can be provided on request in large print, as a sound recording, in Braille, or in alternative languages. Please contact the communications team on **020 3312 5592**.

### Wi-fi

We have a free wi-fi service (for basic filtered browsing) and a premium wi-fi service (requiring payment) at each of our five hospitals. Look for WiFiSPARK\_FREE or WiFiSPARK\_PREMIUM