

## Understanding Stomach and Oesophageal Cancers

A guide for people with cancer, their families and friends

Cancer Information

For information & support, call



#### **Understanding Stomach and Oesophageal Cancers**

A guide for people with cancer, their families and friends.

First published April 2009. This edition November 2015 © Cancer Council Australia 2015. ISBN 978 1 925136 61 6

Understanding Stomach and Oesophageal Cancers is reviewed approximately every two years. Check the publication date above to ensure this copy of the booklet is up to date.

Editor: Joanne Bell. Designer: Matt Turk. Printer: SOS Print + Media Group

#### Acknowledgements

This edition has been developed by Cancer Council Queensland on behalf of all other state and territory Cancer Councils as part of a National Publications Working Group initiative.

We thank the reviewers of this booklet: Prof Mark Smithers, Director, Upper GI/Soft Tissue Unit, Princess Alexandra Hospital, Professor, Discipline of Surgery, The University of Queensland; Katie Benton, Dietitian and Nutritionist, Upper Gastrointestinal Unit, Department of Nutrition and Dietetics, Princess Alexandra Hospital, QLD; Jeff Bull, Upper GI Cancer Clinical Practice Consultant, Cancer Services, Flinders Medical Centre, SA; Prof Bryan Burmeister, Senior Radiation Oncologist, Princess Alexandra Hospital, Dept Chair MSAC, Cancer Council Queensland; Frank Hughes, 13 11 20 Nurse, Cancer Council Queensland; June Leijon, Consumer; Dr Julia Maclean, Clinical Specialist, Speech Pathology, Cancer Care Centre, St George Hospital, NSW; A/Prof Euan Walpole, Medical Director, Cancer Services, Princess Alexandra Hospital & Southern Area Health Service, QLD.

This booklet is funded through the generosity of the people of Australia.

#### Note to reader

Always consult your doctor about matters that affect your health. This booklet is intended as a general introduction to the topic and should not be seen as a substitute for medical, legal or financial advice. You should obtain independent advice relevant to your specific situation from appropriate professionals, and you may wish to discuss issues raised in this book with them.

All care is taken to ensure that the information in this booklet is accurate at the time of publication. Please note that information on cancer, including the diagnosis, treatment and prevention of cancer, is constantly being updated and revised by medical professionals and the research community. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this booklet.

#### **Cancer Council**

Cancer Council is Australia's peak non-government cancer control organisation. Through the eight state and territory Cancer Councils, we provide a broad range of programs and services to help improve the quality of life of people living with cancer, their families and friends. Cancer Councils also invest heavily in research and prevention. To make a donation and help us beat cancer, visit cancer.org.au or call your local Cancer Council.



**Cancer Council Australia** 

Level 14, 477 Pitt Street, Sydney NSW 2000 Telephone 02 8063 4100 Facsimile 02 8063 4101 Email info@cancer.org.au Website cancer.org.au ABN 91 130 793 725

## Introduction

This booklet has been prepared to help you understand more about cancer of the oesophagus and stomach. Many people feel understandably shocked and upset when told they have oesophageal or stomach cancer. We hope this booklet will help you understand how these cancers are diagnosed and treated. We also include information about support services.

We cannot advise about the best treatment for you. You will need to discuss this with your doctors. However, we hope this information will answer some of your questions and help you think about what you want to ask your health care team.

This booklet does not need to be read from cover to cover – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary. You may like to pass this booklet to your family and friends for their information.

#### How this booklet was developed

This information was developed with help from medical experts and people affected by oesophageal and stomach cancers.

If you or your family have any questions, call Cancer Council **13 11 20**. We can send you more information and connect you with support services in your area. Turn to the last page of this book for more details.

## Contents

What is cancer?4
The oesophagus and stomach6
Key questions
What are oesophageal and stomach cancers?8
What are the risk factors?10
How common are these cancers?11
What are the symptoms of oesophageal and stomach cancers?12
Diagnosis14
Endoscopy14
Endoscopic ultrasound (EUS)
Further tests
Staging and grading18
Prognosis
Which health professionals will I see?20
Making treatment decisions23
Talking with doctors23
A second opinion24
Taking part in a clinical trial24
Treatment
Surgery
After oesophageal or stomach surgery
Radiotherapy
Chemotherapy32
Palliative treatment

Managing side effects	
Poor appetite and weight loss	
Difficulty swallowing	
Reflux and choking	
Dumping syndrome	
Anaemia	41

### Looking after yourself......43

Relationships with others	.44
Sexuality, intimacy and fertility	.44
Life after treatment	. 45
After treatment: follow up	.46
What if the cancer returns?	.46

Seeking support4	17
Practical and financial help	47
Talk to someone who's been there	47

Caring for someone with cancer	
Useful websites	
Question checklist	51
Glossary	
How you can help	56

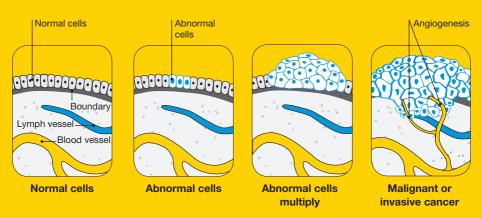


Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

Sometimes cells don't grow, divide and die in the usual way. This may cause blood or lymph fluid in the body to become abnormal, or form a lump called a tumour. A tumour can be benign or malignant.

**Benign tumour** – Cells are confined to one area and are not able to spread to other parts of the body. This is not cancer.

**Malignant tumour** – This is made up of cancerous cells, which have the ability to spread by travelling through the bloodstream or lymphatic system (lymph fluid).

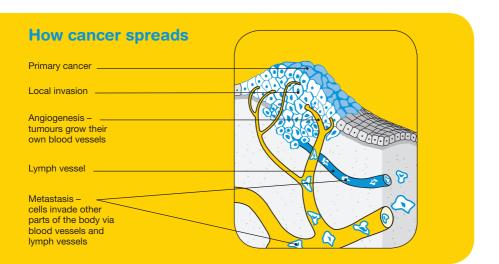


#### How cancer starts

The cancer that first develops in a tissue or organ is called the primary cancer. A malignant tumour is usually named after the organ or type of cell affected.

A malignant tumour that has not spread to other parts of the body is called localised cancer. A tumour may invade deeper into surrounding tissue and can grow its own blood vessels (called angiogenesis).

If cancerous cells grow and form another tumour at a new site, it is called a secondary cancer or metastasis. A metastasis keeps the name of the original cancer. For example, stomach cancer that has spread to the bowel is called metastatic stomach cancer, even though the person may be experiencing symptoms caused by problems in the bowel.



# The oesophagus and stomach

The oesophagus and stomach are part of the upper gastrointestinal (GI) tract and the digestive system.

The oesophagus is a long tube that delivers food, fluids and saliva from the mouth and throat to the stomach.

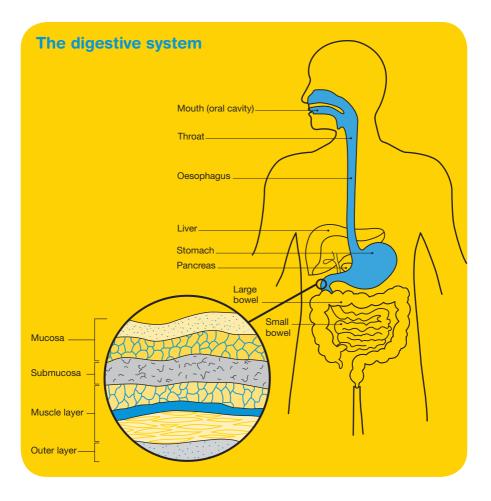
The stomach is a hollow, muscular organ in the upper left part of the abdomen, located between the end of the oesophagus and the beginning of the small bowel (small intestine). The stomach stores food that has been swallowed and assists with the absorption of some vitamins and minerals. The stomach also acts to pass the food and water into the rest of the digestive system, including the small and large bowel, where most of the processing of food takes place.

The different layers of tissue (known as the wall) in the oesophagus and stomach are:

- **mucosa** the moist innermost layer, which helps move food in the oesophagus. In the stomach it produces fluids that start breaking the food down.
- **submucosa** supports the mucosa and gives it blood to survive and take away any of the nutrients.
- **muscle layer (muscularis)** pushes food down the oesophagus. In the stomach it helps to mash the food up and assists with pushing the food into the digestive system in a controlled way.
- **outer layer (serosa)** surrounds the layers of the stomach. It does not exist around the oesophagus.

In the stomach, acidic (gastric) juices are released from glands in the stomach mucosa. These juices break food down into a thick fluid,

which then moves into the small bowel. When the broken-down food is in the small bowel, nutrients from the food are absorbed into the bloodstream. The waste matter moves into the large bowel (large intestine), where fluids are reabsorbed back into the body and the rest is passed out of the body as a bowel movement.





## Q: What are oesophageal and stomach cancers?

A: Oesophageal and stomach cancers are malignant tumours found in the tissues of the oesophagus or stomach. Both cancers start in the mucosa. As they grow deeper into the oesophageal or stomach wall the risk that they might spread to other parts of the body increases.

#### **Oesophageal cancer**

This cancer can be found anywhere in the oesophagus. In western countries such as Australia this cancer is most commonly found in the lower section of the oesophagus and where the oesophagus meets the stomach (gastrooesophageal junction).

Oesophageal cancer can occur in different types of cells that exist in the oesophagus. The main types of cancer are:

• Squamous cell carcinoma – begins in the cells lining the oesophagus (mucosa), which are called squamous cells. This type of cancer is more common in the middle and upper part of the oesophagus and is more common in Asia, although it is still diagnosed in Australia.

• Adenocarcinoma – begins in the glandular tissue of the mucosa, which is found in the lower part of the oesophagus.

If oesophageal cancer is not found and treated early, it can grow through the wall into nearby structures. Oesophageal cancers can also spread into the lymphatic system to nearby lymph nodes and through the bloodstream to other parts of the body, most commonly the liver. It can also invade the windpipe, lungs and the lining around the heart.

#### **Stomach cancer**

Most stomach cancers start in the lining (mucosa) in the upper part of the stomach. This type of cancer is called adenocarcinoma of the stomach. Stomach cancer is also known as gastric cancer.

If it is not found and treated early, stomach cancer can grow through the stomach wall into nearby organs such as the pancreas and bowel. Stomach cancer can also spread into the lymphatic system to nearby lymph nodes or through the bloodstream to other parts of the body, such as the lungs. It may also spread to the lining of the abdominal cavity (peritoneum), which can cause swelling in the abdomen.

#### Rare oesophageal and stomach cancers

There are other less common types of cancer that can affect the oesophagus and stomach, including sarcomas, lymphomas, gastrointestinal stromal tumours (GIST), carcinoid tumours and small cell carcinomas. These types of cancer aren't discussed in this booklet and treatment may differ. Call Cancer Council **13 11 20** for information about these rarer types of cancer, or speak to someone in your medical team.

### **Q: What are the risk factors?**

A: The exact causes of oesophageal and stomach cancers are unknown, but the following factors may increase your risk. Having one or more of these risk factors does not mean you will develop oesophageal or stomach cancer. See your doctor if you are concerned about your risk factors or any symptoms you are experiencing.

#### Risk factors for oesophageal and stomach cancers

Common risk factors include smoking, high alcohol consumption, and a diet low in fresh fruit and vegetables.

Oesophageal cancer	Stomach cancer
<ul> <li>medical conditions, including gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus (see opposite)</li> <li>a personal or family history of gastro-oesophageal disorders, such as hernia, polyps, ulceration or oesophagitis</li> <li>eating smoked, salted, pickled or poorly-refrigerated food</li> <li>obesity</li> <li>exposure to certain chemical fumes, fertilisers or dry-cleaning agents</li> <li>frequent drinking of very hot liquids.</li> </ul>	<ul> <li>infection with Helicobacter pylori (H. pylori), a type of bacteria found in the stomach</li> <li>low red blood cell levels (pernicious anaemia)</li> <li>chronic inflammation of the stomach (chronic gastritis)</li> <li>a personal or family history of stomach cancer</li> <li>inheriting a genetic change that causes the bowel disorders familial adenomatous polyposis (FAP) or hereditary non-polyposis colorectal cancer (HNPCC).</li> </ul>

#### **GORD** and Barrett's oesophagus

Gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus are risk factors for oesophageal cancer.

People who have repeated episodes of reflux (heartburn) may be diagnosed with GORD. This is when stomach acid backs up into the oesophagus. Over time, the walls of the oesophagus become damaged, causing inflammation or loss of tissue (oesophagitis).

In some people this may cause the cells lining the oesophagus to be replaced by a different type of cell. This is called Barrett's oesophagus.

### Q: How common are these cancers?

A: Over 1300 people are diagnosed with oesophageal cancer in Australia each year.<sup>1</sup> This is an uncommon cancer, making up 1.4% of cancer cases in men and 0.8% of cancer cases in women.<sup>1,3</sup> However the incidence of adenocarcinoma of the oesophagus in Australia is increasing.

Each year, around 2000 people in Australia are diagnosed with stomach cancer.<sup>2</sup> Stomach cancer makes up 2% of cancer cases in men and 1.4% of cancer cases in women.<sup>2,3</sup>

Both cancers are more common in men – 65% of people diagnosed with oesophegeal cancer<sup>1</sup> and 70% of people diagnosed with stomach cancer<sup>2</sup> are male.

Around 80% of oesophageal and stomach cancers are diagnosed in people aged 60 years and older.<sup>1,2</sup> The average age that people are diagnosed with cancers of the oesophagus and stomach is around 71.<sup>1,2</sup>

### Q: What are the symptoms of oesophageal and stomach cancers?

A: In their early stages, oesophageal and stomach cancers may not cause symptoms. These cancers are usually slow-growing and may grow for many years before any symptoms are noticed. This means that they are not usually diagnosed until the cancer is more advanced.

Symptoms of oesophageal and stomach cancers are listed in the box on the following page. These symptoms are common to many other conditions and do not necessarily mean that you have cancer.

However, if you experience any of these symptoms and they are ongoing, make an appointment with your general practitioner (GP).

● A routine check-up with my GP, involving various blood tests, led to gastro-intestinal testing that unearthed early stage oesophageal cancer. ● June

#### **Oesophageal cancer symptoms**

- difficulty swallowing
- pain when swallowing
- new or worsening heartburn or reflux
- development of upper abdominal discomfort especially when eating
- vomiting blood
- black-coloured or bloody stools
- persistent unexplained tiredness
- food or fluids 'catching' in the throat or episodes of choking when swallowing
- unexplained weight loss

#### Stomach cancer symptoms

- pain or burning sensation in the abdomen
- indigestion
- frequent burping
- heartburn or reflux
- a sense of fullness, even after a small meal
- persistent nausea and/or vomiting with no apparent cause
- unintentional loss of appetite and/or weight
- swelling of the abdomen or feeling bloated
- vomit containing blood
- unexplained tiredness, which may be due to anaemia
- black-coloured or bloody stools



Your GP will examine you and refer you for further tests. The diagnostic blood tests, procedures or scans you have will vary depending on your symptoms. Most tests can be performed on an outpatient basis and will not require an overnight stay in hospital.

## Endoscopy

An endoscopy (also called a gastroscopy, upper GI endoscopy or oesophagoscopy) is the most common diagnostic test.

Before undergoing an endoscopy you will probably be given a light anaesthetic. A thin, flexible tube with a camera on the end (endoscope) will then be passed into your mouth, down your throat and oesophagus, and into your stomach. You will be asked not to eat or drink (fast) for about 4–6 hours before undergoing this procedure.

The doctor will use the endoscope to look at your digestive tract and may remove a small amount of tissue in a procedure known as a biopsy. The removed tissue will later be examined under a microscope by a pathologist to check for signs of disease. Biopsy results are usually available within a few days.

An endoscopy takes about 10 minutes. You may have a sore throat afterwards.

Endoscopies have risks, such as bleeding or getting a small tear or hole in the oesophagus or stomach (perforation). Your doctor should explain all the risks before you consent to having the procedure.

## **Endoscopic ultrasound (EUS)**

In this test, an endoscope with a probe on the end is put down the throat. The probe releases soundwaves, which echo when they bounce off anything solid such as an organ or tumour. This procedure is less common than an endoscopy.

This test shows the layers of the stomach wall, as well as nearby lymph nodes and other parts of the body directly outside the stomach. It can show whether the cancer has spread into the oesophageal or stomach wall, nearby tissues or lymph nodes.

During the scan, tissue samples may be taken (by biopsy) from the oesophagus, stomach, and nearby organs.

Before undergoing this test you will be given an anaesthetic. You will also be asked not to eat or drink (fast) for about 4–6 hours beforehand.

## **Further tests**

Most people have scans or other imaging tests to see if the cancer has spread from its original site.

#### **CT** scan

A computerised tomography (CT) scan uses x-ray beams to take pictures of the inside of your body. Unlike a standard x-ray, which takes a single picture, a CT scan uses a computer to compile many pictures. These scans are usually done at a radiology clinic or hospital. You may have an injection or be asked to drink a medical dye before the scan. The dye will help make the scan pictures clearer and may make you feel flushed or hot for a few minutes. Rarely, more serious reactions to the dye can occur, such as low blood pressure or breathing difficulties. The treatment centre will have staff and equipment to treat any problems if they occur.

You will need to lie still on a table while the CT scanner, which is large and round like a doughnut, slowly moves around you. The scan itself is painless and takes only a few minutes, but preparation time can take 10–30 minutes.

The dye used for a CT scan is called contrast solution and may contain iodine. If you have any allergies, let the person performing the scan know in advance. You should also tell the doctor if you're diabetic, have kidney disease or are pregnant.

#### **PET/CT** scan

This scan is often used for oesophageal cancer and sometimes used for stomach cancer. For this scan, a PET scan is performed at the same time as a CT scan using a special machine that can do both scans. This allows the two results to be compared in order to provide more detailed and accurate information about the cancer.

A PET (positron emission tomography) scan is a specialised imaging test that is able to detect very small cancer cells that may not have been detected on a CT scan, and is available at most major hospitals. A PET scan shows 'hot spots' in the body where there are active cells, such as cancer cells. Not all PET hot spots indicate cancer.

Before the scan, you will be injected with a glucose solution that contains some radioactive material. You will be asked to wait for 30–90 minutes as the solution spreads through your body. You will need to lie still during this time. The glucose solution gathers in the cells, including cancer cells, which are using more energy. The scan itself takes around 30 minutes.

#### Laparoscopy

A laparoscopy is usually done as part of the diagnostic tests for stomach cancer and less commonly for oesophageal cancer. A laparoscopy is also sometimes used before major surgery.

You will be admitted to hospital and given a general anaesthetic for this procedure. The doctor will inflate your abdomen with gas and make small cuts in your abdomen. A thin tube called a laparoscope will be inserted into your body. Through this tube, the doctor can look for small amounts of cancer that may have spread into the liver or lining of the abdomen, which are too small to be seen on CT or PET scans. It's also possible to take tissue samples for biopsy during this procedure.

#### Less common tests

Some people have other tests, such as an ultrasound scan, bone scan or bronchoscopy. These are not commonly used. For information about these tests and scans, talk to your health care team or call Cancer Council 13 11 20.

## Staging and grading

Your doctor will assign a staging and grading category to the cancer, which will help your health care team decide the best treatment for you. These categories are worked out using information from the diagnostic tests and tissue biopsy.

**Stage** – The stage describes the extent of the cancer and whether it has spread from the original site to other parts of the body. Doctors commonly use the TNM staging system to describe the different stages of oesophageal and stomach cancers.

TNM system	
T (Tumour) 0–4	Indicates how far the tumour has grown into the oesophagus or stomach wall. The higher the number, the deeper the tumour and the greater the risk of spread.
N (Nodes) 0–3	Shows whether the cancer has spread to nearby lymph nodes. 0 indicates no nodes affected. 1, 2 or 3 indicate increasing node involvement.
M (Metastasis) 0–1	Indicates whether the cancer has spread (metastasised) to other organs (1) or it hasn't (0).

**Grade** – This gives an idea of how quickly the cancer cells may be growing. This is assessed by the pathologist based on information from the biopsy. Low-grade cancer cells tend to grow slowly, while high-grade cancer cells may grow quickly.

If you are having trouble understanding staging and grading, ask someone in your medical team to explain it to you in a way that makes sense to you. You can also call Cancer Council 13 11 20 to clarify the information you have been given and what it means.

## Prognosis

Prognosis means the predicted outcome of a disease. Generally, the earlier that oesophageal or stomach cancer is diagnosed, the better the prognosis.

You will need to discuss your prognosis with your doctor. However, it is not possible for any doctor to predict the exact course of your illness.

The following factors are important in assessing your prognosis:

- test results
- the rate and depth of tumour growth
- whether the cancer has spread
- how well you respond to treatment
- age
- level of fitness
- medical history, including other medical conditions.

•• I had surgery for stomach cancer, which is hard because my stomach is now so much smaller. I have good days and bad days, but I'm back at work and I exercise every week. My prognosis for the future is good.  $99 \ \tau_{im}$ 

## Which health professionals will I see?

Your GP will arrange the first tests to assess your symptoms. If these tests do not rule out cancer, you will usually be referred to a specialist doctor who will arrange further tests and advise you about treatment options.

Health professional	Role
endoscopist	a specialist doctor (surgeon or gastroenterologist) who diagnoses and treats diseases of the gastrointestinal tract
upper gastrointestinal surgeon	a specialist doctor who treats diseases of the upper digestive system using surgery
medical oncologist	a specialist doctor who prescribes and coordinates the course of chemotherapy
radiation oncologist	a specialist doctor who prescribes and coordinates the course of radiotherapy
nurse practitioner	senior clinical nurse involved in assessing, diagnosing, treating and managing disease
cancer nurse coordinator or clinical nurse consultant	provides ongoing education, liaises with other care providers, and supports you throughout diagnosis, treatment and recovery

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT). This team will meet regularly to design and discuss the most appropriate treatment plan for you, and will support you on an ongoing basis. The team may include some or all of the health professionals listed below.

Health professional	Role
dietitian	recommends an eating plan for your nutritional needs while you are in treatment and recovery
physiotherapist	assists in physical rehabilitation and restoring movement after surgery
speech pathologist	helps with your rehabilitation if the cancer or treatment has affected your ability to talk or swallow
social worker	helps provide emotional support and practical assistance to you and your carers
psychologist or counsellor	helps you manage your emotional wellbeing and cope with changes to your life resulting from cancer or treatment
palliative care team	offer a range of services for people with advanced cancer to improve their quality of life and ensure their physical, practical, emotional and spiritual needs are met



#### **Key points**

- A range of tests are used to diagnose oesophageal and stomach cancers.
- Endoscopy is the main diagnostic test. This allows doctors to look inside the digestive tract and take tissue samples (biopsies).
- An endoscopic ultrasound (EUS) can show how far the cancer has spread into the oesophageal or stomach wall.
- Biopsied tissue is examined under a microscope to find out more about the cells. This shows if cancer is present, how far the cancer has spread (its stage), and how quickly it is growing (its grade).
- You may also have scans including a CT scan or PET/CT scan, which show pictures of the inside of your body.

- Other procedures, such as a laparoscopy, can show if the cancer has spread to the liver or abdomen.
- Based on the test results and your general health, your doctor can provide some information about your prognosis (the predicted outcome of your disease). Your prognosis is also affected by the treatment you choose and how successful it is.
- You will be cared for by a range of health professionals who work together in a multidisciplinary team (MDT).

22

## Making treatment decisions

Sometimes it is difficult to decide on the type of treatment to have. You may feel that everything is happening too fast. Check with your doctor how soon your treatment should start, and take as much time as you can before making a decision.

Understanding the disease, the available treatments and possible side effects can help you weigh up the pros and cons of different treatments and make a well-informed decision that's based on your personal values. You may also want to discuss the options with your doctor, friends and family.

You have the right to accept or refuse any treatment offered. Some people with more advanced cancer choose treatment even if it only offers a small benefit for a short period of time. Others want to make sure the benefits outweigh the side effects so that they have the best possible quality of life.

## **Talking with doctors**

When your doctor first tells you that you have cancer, you may not remember the details about what you are told. Taking notes or recording the discussion may help. Many people like to have a family member or friend go with them to take part in the discussion, take notes or simply listen.

If you are confused or want clarification, you can ask questions – see page 51 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

## A second opinion

You may want to get a second opinion from another specialist to confirm or clarify your doctor's recommendations or reassure you that you have explored all of your options. Specialists are used to people doing this.

Your doctor can refer you to another specialist and send your initial results to that person. You can get a second opinion even if you have started treatment or still want to be treated by your first doctor. You might decide you would prefer to be treated by the doctor who provided the second opinion.

## Taking part in a clinical trial

Your doctor or nurse may suggest you take part in a clinical trial. Doctors run clinical trials to test new or modified treatments and ways of diagnosing disease to see if they are better than current methods. For example, if you join a randomised trial for a new treatment, you will be chosen at random to receive either the best existing treatment or the modified new treatment.

Over the years, trials have improved treatments and led to better outcomes for people diagnosed with cancer.

It may be helpful to talk to your specialist or clinical trials nurse, or get a second opinion. If you decide to take part, you can withdraw at any time. For more information, call Cancer Council 13 11 20 for a free copy of *Understanding Clinical Trials and Research* or visit australiancancertrials.gov.au.



Surgery is a common type of treatment for oesophageal and stomach cancer. Some people have chemotherapy or radiotherapy either on their own or in combination. These treatments may also be given in combination with surgery in one of two ways:

**Neoadjuvant treatment** – Chemotherapy and/or radiotherapy given before surgery. The aim is to shrink the cancer before surgery and to destroy any cancer cells that may have spread away from the primary cancer site. Neoadjuvant treatment appears to increase the chance of successful treatment for oesophageal and stomach cancers.

Adjuvant treatment – Chemotherapy and/or radiotherapy given after surgery. Adjuvant treatment is used to destroy any cancer cells that may remain in the body. This treatment will be offered if pathology results indicate that all cancer cells have not been removed by the surgery.

Your doctor will discuss the recommended treatment options with you.

## Surgery

The type of surgery you have will depend on the location of the tumour and how advanced the cancer is. You will be advised how to prepare for surgery. For example, you may need to change your diet or fast beforehand. If you are a smoker, you will be assisted to stop smoking before surgery.

#### **Oesophageal cancer surgery**

During oesophageal cancer surgery, the surgeon will remove the cancerous tissue, including part of the oesophagus, the upper part of the stomach, and some nearby lymph nodes. The surgical approach and amount of oesophagus removed may differ depending on the location of the cancer in the oesophagus.

**Oesophagectomy** – To remove the oesophagus, the surgeon will need to gain access separately to the upper abdomen and to the chest through the ribs on the sidewall of the chest. This may be done by opening the chest and the abdomen or by using a telescope to perform keyhole surgery for some or all of the procedure.

Once the cancerous sections of the oesophagus are removed (along with part of the upper stomach, lymph nodes and other tissue) the healthy part of the oesophagus is reconnected to the remaining part of the stomach by turning the stomach into a tube. This will allow you to swallow and eat relatively normally. In rare cases, the oesophagus is connected to the small bowel or large bowel if it cannot be reconnected to the stomach.

507 705

Endoscopic resections (ER), including endoscopic mucosal resections (EMR) are becoming the preferred option for the treatment of very early-stage oesophageal and stomach cancers, and the diagnostic staging of early oesophageal cancers, as they involve less risk and a faster recovery. During this procedure, the tumour is removed through a long, flexible tube (endoscope). This is usually a day or overnight stay procedure.

#### Stomach cancer surgery

During stomach cancer surgery, the surgeon will remove the cancerous tissue and part or all of the stomach, leaving as much healthy tissue as possible. The goal of surgery is the complete removal of the cancer, including any affected lymph nodes. The amount of stomach tissue removed will vary accordingly. Surgery is performed through a cut in the upper part of the abdomen. In some selected cases, keyhole surgery may be recommended.

**Subtotal or partial gastrectomy** – The cancerous part of the stomach is removed, along with nearby fatty tissue (omentum) and lymph nodes. The upper stomach and oesophagus are usually left intact.

**Total gastrectomy** – Removal of the whole stomach, along with nearby fatty tissue (omentum), lymph nodes and parts of adjacent organs, if necessary. The surgeon reconnects the oesophagus to the small bowel. The top part of this connection (which is a tube of intestine) takes over some of the function of the stomach. Often, a small feeding tube is placed further down the small bowel and out through the abdomen. You can be given food through this tube while the join between the oesophagus and small bowel heals. The tube is usually removed after 2–6 weeks.

#### **Risks of oesophageal and stomach surgery**

As with any major surgery, oesophageal and stomach surgery has risks. Complications may include: infection, bleeding, blood clots, damage to nearby organs or leaking from the connections between the oesophagus and stomach or small bowel. Some people may experience an irregular heartbeat, but this usually settles within a few days. Your surgeon will discuss these risks with you before surgery and you will be carefully monitored for any side effects afterwards.

Pneumonia is a common risk after oesophageal surgery. To reduce the risk of pneumonia you will be taught breathing or coughing exercises to do after surgery to help keep your lungs clear.

## After oesophageal or stomach surgery

You will have some pain and discomfort for several days after your surgery, but you will be given pain relief medication to manage this. You will be unable to eat or drink initially after surgery and will then be gradually introduced to an oral diet.

After surgery you will have several tubes in your body, including a catheter to measure urine output. You may have an intravenous (IV) drip, which is used to replace your body's fluids until you are able to drink and eat again, as well as a feeding tube. The number and location of tubes will depend on the type of surgery you have. Generally, surgery for oesophageal cancers is more complex and requires many temporary tubes and lines including a tube into the chest.

Most people are ready to go home around 10 days after stomach cancer surgery, and about 10–15 days after oesophageal cancer surgery. After oesophageal surgery, some people may need to go home with continued nutrition support using the feeding tube.

#### **Feeding tubes**

It is common for a feeding tube to be inserted at the time of your surgery. This tube will help you to meet your nutritional needs after surgery. A feeding tube can be placed into your stomach or small intestine through an opening on the outside of your abdomen. Alternatively, the tube may be inserted through your nostril.

Many people find that having a feeding tube eases the pressure and discomfort associated with eating while adjusting to their new eating habits after surgery. Medications can also be given through the feeding tube.

A dietitian will advise you on the type and amount of feeding formula you will need. Your health care team can also tell you how to keep the tube clean, prevent wear, leakage and blockages, and when to replace the tube.

It can take time to adjust to a feeding tube. It may help to talk to your family, a counsellor, or nurse, or you can call Cancer Council 13 11 20 for information and support.

After surgery to the stomach, many people don't absorb vitamin D and calcium well. This can cause a loss in bone density (osteoporosis). The bones may become weak which may cause pain and an increased risk of fractures. For more information, talk to your doctor. It may also help to see a dietitian.

#### **Eating after surgery**

Depending on your recovery, you may be able to start eating foods again before you leave hospital. The hospital dietitian can prepare eating plans for you and work out whether you need any supplements to help meet your nutritional needs. They can also answer any questions you may have relating to food and eating.

You will be advised to start off with liquids, such as soup, and then move on to soft foods for about a week.

When you are ready, you can try eating some solid foods. You may be advised to eat 6–8 small meals or snacks throughout the day.

Some people find it difficult to cope with dietary changes and gastrointestinal symptoms after surgery. Your health care team can help you manage these side effects and let you know whether they will be temporary or permanent. Your surgeon, speech pathologist and counsellor may also provide support.

For more information about managing some of the side effects of surgery, see the *Managing side effects* chapter on page 36.

## Radiotherapy

Radiotherapy treatment uses high-energy x-rays to damage or kill cancer cells so they cannot multiply. It is most commonly used to treat oesophageal cancers, usually in combination with chemotherapy. Before starting treatment you will have a planning appointment where a CT (computerised tomography) scan is performed. The radiotherapy team will use the images from the scan to plan your treatments. Treatment is carefully planned to destroy as many cancer cells as possible while causing the least possible harm to your normal tissue. The technician may make some small permanent tattoos or temporary marks on your skin so that the same area is targeted during each treatment session.

You will usually have treatment as an outpatient once a day, Monday to Friday, for 2–5 weeks. Each treatment takes only a few minutes and is not painful. You will lie on a table under a machine that delivers radiation to the affected parts of your body. Your doctor will advise you on the number of treatment sessions you need.

#### Side effects

Many people will develop temporary side effects, such as fatigue and skin reactions during their treatment. Skin in the treatment area may become red and sore during or immediately after treatment. Other side effects may include:

- nausea and/or vomiting
- diarrhoea
- painful swallowing, if oesophageal cancer
- decreased appetite and/or weight loss.

Ask your treatment team for advice about dealing with any side effects or call Cancer Council 13 11 20 to request a free copy of *Understanding Radiotherapy*.

## Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The aim of treatment is to destroy cancer cells, while causing the least possible damage to healthy cells. You may have chemotherapy combined with radiotherapy.

Chemotherapy is generally administered into a vein in your arm through a drip (intravenously) or through a tube called a port, catheter or vascular access device. Alternatively it can be given as tablets. Most people receive a combination of drugs. These may be given on one day or continuously using a small pump that is linked to the tube implanted into the vein. There may be a rest period of 2–3 weeks before receiving the next round of chemotherapy. The treatment process for chemotherapy can vary. Some people receive treatment on a weekly basis for up to six weeks.

You usually don't have to stay overnight in hospital to have chemotherapy. Ask your doctor which drugs you are receiving, what side effects you may experience, and how long your treatment will last.

Many people find they need to take time to recover following each chemotherapy session.

If you feel unwell or have a fever higher than 38°C, call your doctor immediately or, if after hours, go to the hospital emergency department.

32

#### Side effects

Everyone reacts differently to chemotherapy. Some people don't experience any side effects, while others have several. The side effects you experience will depend on the drugs you receive.

Side effects may include:

- nausea
- vomiting
- appetite changes (see page 37)
- weight loss
- mouth ulcers
- skin and nail changes
- numbness or tingling in the hands or feet (peripheral neuropathy)
- ringing in the ears (tinnitus)
- fatigue and tiredness
- changed bowel habits (e.g. constipation, diarrhoea)
- hair loss or thinning
- lowered immunity (e.g. more prone to get infections)
- infertility (see page 44).

Chemotherapy side effects are usually temporary, and measures can be taken to prevent or reduce them. Talk to your oncologist or a member of your health care team about any side effects you are experiencing and how to manage them.

For more information call Cancer Council 13 11 20 to request a free copy of the booklet *Understanding Chemotherapy* or download it from your local Cancer Council website.

## **Palliative treatment**

Palliative treatment seeks to improve quality of life by reducing the symptoms of advanced cancer without aiming to cure the disease.

Palliative treatment may include radiotherapy, chemotherapy or other medication. These treatments can assist with managing symptoms such as pain, swallowing difficulty and nausea as well as slowing the spread of the cancer. For example, radiotherapy can help to relieve pain and make swallowing easier if an oesophageal cancer cannot be removed.

For people with advanced oesophageal cancer who are unable to have surgery, chemotherapy and/or radiotherapy and are having trouble swallowing food and fluids, a flexible tube (a stent) is sometimes inserted into the oesophagus. The stent expands the oesophagus to allow fluid and food to pass into the stomach more easily. This stent also prevents food and saliva going into the lungs and causing infection. The stent does not treat the cancer but will allow you to eat and drink more normally.

It is commonly assumed that palliative treatment is for people at the end of their life; however, it may be beneficial for people at any stage of advanced disease.

Palliative care is managed in various ways throughout Australia and is tailored to each individual. Your GP or palliative care team will talk to you about the best approach for you. Call Cancer Council 13 11 20 for more information or free booklets about palliative care and advanced cancer, or visit your local Cancer Council website.

## Key points

- Oesophageal and stomach cancers are usually treated with surgery. Some people also have chemotherapy and/or radiotherapy before or after surgery, or as their only treatment.
- Your health care team will advise you how to prepare for treatment and manage any side effects.
- The type of surgery you have depends on the site of the cancer and how extensive it is.
- Surgery may remove part or all of the oesophagus and/ or stomach. The remaining parts of the digestive system are usually stitched together so that food can still be swallowed and digested.
- Surgery will affect your eating and digestion. Learning to adapt to these changes will take time. A dietitian can help with your recovery.

- An endoscopic mucosal resection may be performed for very early-stage oesophageal and stomach cancers. It can usually be done as a day procedure.
   Eating returns to normal soon after the procedure.
- Radiotherapy treatment uses high-energy rays to damage or kill cancer cells so they cannot multiply. It can cause side effects, such as tiredness, red skin or diarrhoea. Most side effects are temporary.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The drugs can cause side effects, such as a sore mouth or hair loss. Most side effects are temporary.
- Palliative treatment seeks to improve quality of life by reducing the symptoms of advanced cancer without aiming to cure the disease.

## Managing side effects

Oesophageal and stomach cancers and their treatment can cause many side effects. Many of these side effects are permanent and may affect your ability to eat, digest foods, and absorb essential nutrients. This chapter explains typical side effects and how to manage them.

After treatment, some foods you used to eat may cause digestive problems. You will need to try different foods and ways of eating to find out what works for you. You may need to change your eating habits, such as eating smaller meals more often throughout the day.

It's important to make sure you are eating and drinking enough to maintain your weight. If you are eating less than usual it is often recommended that you choose high energy, high protein foods. Previous dietary restrictions and guidelines may be relaxed when you are recovery from surgery. Ask your doctor for a referral to a dietitian with experience in cancer care.

Some people find it difficult to cope emotionally with the changes to their eating habits. You may feel self-conscious or worry about eating in public or with friends. These reactions are natural. It may help to talk about how you feel with your family and friends, or speak with a counsellor or someone who has been through a similar experience. They may be able to give you advice on how to adjust. It may take time and support to adjust to your new way of eating.

Call Cancer Council **13 11 20** for a free copy of *Nutrition and Cancer* or to ask to speak to a Cancer Connect volunteer who has had a similar cancer experience.

## Poor appetite and weight loss

After surgery you may have a poor appetite caused by changes to your digestive system. Your stomach may be smaller and you might feel full more quickly. You may not feel like eating or you may have lost your sense of taste.

Chemotherapy and radiotherapy can also affect your appetite, due to nausea, irritation to the oesophagus or a sore mouth. To avoid malnutrition and weight loss, try the tips below.

- Snack during the day eat 5–6 small meals rather than three large ones each day.
- Ask your family and friends to cook for you and offer you food throughout the day.
- Keep a selection of snacks in handy locations, e.g. in your bag or car.
- Test your ability to eat different foods. Experiment with recipes

   your taste and tolerance for some foods may have changed and may continue to change.
- Tell your doctor or dietitian if you have pain or discomfort when swallowing.

- Ask your dietitian how you can increase your kilojoules.
- Make the most of the times you feel hungry or when you crave certain foods but be careful not to become too full by eating too quickly.
- Avoid filling up on liquids, unless it's a hearty, nourishing soup. Don't drink at mealtimes.
- Prevent dehydration by drinking liquids between meals (e.g. 30–60 minutes before or after meals).
- Don't eat late at night. This may make you uncomfortable and disturb your sleep.

● Life changed as we knew it after my husband had surgery for oesophageal cancer. Reigniting his sense of wanting to eat again has taken time. ● Leslee

## **Difficulty swallowing**

Before or after surgery, radiotherapy or chemotherapy treatments, you may find it difficult to swallow solid foods. It is important to change your diet so that you can still get enough nutrition, and to prevent losing weight and strength.

The following tips may help you if you are having difficulty swallowing.

tips

- Make food softer, e.g. use a slow cooker to keep food moist or mash your food with a fork.
- Snack on soft foods between meals, such as avocado, yoghurt, custard, ice-cream, diced tinned fruit, and milkshakes.
- Try eating soft, nutritious foods, such as scrambled eggs, porridge, soup and casseroles.
- Add extra gravy and sauce to your meals.

- Consider adding nutritional supplements to your diet to meet your nutritional requirements.
- Chew carefully and slowly, sitting still and upright. Try to avoid talking while you are eating.
- Wash the food down with small sips of fluid.
- Talk to your doctor or dietitian if you are losing weight, or if it is getting more difficult to swallow food.

38

## **Reflux and choking**

Many people experience reflux following surgery. This can cause heartburn, nausea and discomfort in your chest. Medications to reduce stomach acid may improve these symptoms.

Some people who have had surgery or radiotherapy for oesophageal cancer choke or cough while eating. This may be due to scar tissue. It is important to see your doctor if this continues.

- Limit spicy foods, fizzy drinks, alcohol and citrus fruits to prevent reflux.
- Take small sips of liquid to reduce coughing or choking.
- Sit up straight during meals and for at least 30 minutes after eating to help food digest.
- Try eating your evening meal about four hours before going to bed. Or eat your main meal earlier in the day and have only a small snack in the evening.
- Avoid bending over too far.
- Chew foods well and eat slowly. Avoid talking while eating.

- Keep your chest higher than your abdomen when sleeping

   try using extra pillows or a foam wedge. Try to avoid lying on your left side, often reflux is worse in this position.
- Avoid dry foods, e.g. tough meat or doughy bread. Or use sauces and spreads to assist swallowing.
- Don't overexert yourself, as this can cause reflux.
- Ask your doctor for advice about medications that may help.
- Wear loose-fitting clothing.
- See your doctor if solid foods cause coughing or if food seems to be getting stuck.

## **Dumping syndrome**

If your surgery has changed the normal structure of your stomach, partially digested food and or food containing high amounts of simple sugar, such as cordial, can go into the small bowel too quickly. This may cause cramps, nausea, racing heart, sweating, bloating, diarrhoea or dizziness. This is called dumping syndrome. Symptoms usually begin 15–30 minutes after eating.

Sometimes symptoms occur 1–2 hours after a meal. These are called late symptoms, which tend to cause weakness, light-headedness and sweating, and are usually worse after eating foods high in sugar.

Symptoms usually improve over time. If you experience these problems, talk to a dietitian, who can help you work out how to change your meals to reduce the symptoms. Your doctor may also prescribe medication to help.

- Eat small meals slowly so your body can sense when it is full.
- Take note of which foods cause problems – record and avoid them. Surgery may have impaired your ability to absorb or tolerate certain foods, such as those containing lactose, fructose or gluten.
- Avoid foods and drinks high in sugar, e.g. cordial or soft drinks.
- Eat starchy food (e.g. pasta, rice or potato) and meals high in protein.
- Drink between meals rather than at mealtimes.

## Anaemia

People who have had a total gastrectomy, and sometimes a subtotal gastrectomy, cannot absorb vitamin B12 from food or oral supplements. As a result, they may be unable to make enough red blood cells, which carry oxygen around the body. This can lead to a condition known as pernicious anaemia. The most common early symptom of anaemia is tiredness. Your skin will look pale and you may also feel breathless, get headaches, a racing heart and loss of appetite. You will need regular vitamin B12 injections.

A gastrectomy may also reduce your ability to absorb iron, causing iron deficiency anaemia, and you may need iron supplements.

- Talk to your doctor if you have symptoms of anaemia.
- Rest when you need to and don't overexert yourself.
- Limit tea and coffee, as this can prevent iron absorption.
- Find out what kind of anaemia you have and how it can be treated. Ask your GP or dietitian if you need vitamin B12 injections, iron or other supplements, and whether certain foods can help.
- Eat foods rich in iron and B vitamins, such as meat, eggs and dark green leafy vegetables.
- Eat foods high in vitamin C (e.g. red or orange fruits and vegetables) in the same meal as iron-rich foods, as vitamin C helps the body absorb iron.
- If you smoke, talk to your GP about quitting, call Quitline on 13 7848, or visit quitnow.gov.au. Tobacco can worsen your symptoms.



### **Key points**

- Surgery to the oesophagus and stomach can cause significant side effects and affect the way you eat. This can affect your physical and emotional wellbeing.
- After treatment, you may have a poor appetite, find it difficult to eat certain foods, or feel full quickly. This can lead to weight loss and malnutrition.
- Physical changes to the way you eat and digest food following treatment may include reflux (heartburn), coughing and choking.
   Dumping syndrome is less common. Eating several small meals a day slowly can help with these symptoms.
- Sitting up during and after meals can help swallowing and digestion. It's best to wait about four hours after a meal before going to bed and to avoid eating late meals.

- To avoid dehydration, drink fluid throughout the day, in between meals. It is best not to drink much liquid at mealtimes.
- Dietitians can help tailor eating plans to suit your individual needs. They can also give you advice on nutritional supplements if you need to increase your vitamin or mineral intake. You may need tablets, powdered supplements, injections or infusions. Making changes to your diet may also help.
- Talk to your doctor or dietitian if you have ongoing trouble with eating and digestion, have symptoms of anaemia or if you keep losing weight.
- Talking to a counsellor or someone who has been through a similar experience to you may help you cope with the changes.

## C Looking after yourself

Cancer can cause physical and emotional strain. It's important to try to look after your wellbeing as much as possible.

**Nutrition** – Eating healthy food can help you cope with treatment and side effects. A dietitian can help you manage special dietary needs or eating problems, and choose the best foods for your situation. Call Cancer Council 13 11 20 for a free copy of the *Nutrition and Cancer* booklet.

**Staying active** – Physical activity may help to reduce tiredness, improve circulation and elevate mood. The amount and type of exercise you do depends on what you are used to, how you feel, and your doctor's advice. Cancer Council's *Exercise for People Living with Cancer* booklet provides more information about the benefits of exercise, and outlines simple exercises that you may want to try.

**Complementary therapies** – These therapies are used with conventional medical treatments. You may have therapies such as massage, relaxation and acupuncture to increase your sense of control, decrease stress and anxiety, and improve your mood. Let your doctor know about any therapies you are using or thinking about trying, as some may not be safe or evidence-based.

Alternative therapies are used instead of conventional medical treatments. These therapies, such as coffee enemas and magnet therapy, can be harmful. For more information, call 13 11 20 for a free copy of the *Understanding Complementary Therapies* booklet or visit your local Cancer Council website.

## **Relationships with others**

Having cancer can affect your relationships with family, friends and colleagues. This may be because cancer is stressful, tiring and upsetting, or as a result of more positive changes to your values, priorities, or outlook on life.

Give yourself time to adjust to what's happening, and do the same for others. People may deal with the cancer in different ways, for example by being overly positive, playing down fears, or keeping a distance. It may be helpful to discuss your feelings with each other.

## Sexuality, intimacy and fertility

Cancer can affect your sexuality in physical and emotional ways. The impact of these changes depends on many factors, such as treatment and side effects, your self-confidence, and if you have a partner. Although sexual intercourse may not always be possible, closeness and sharing can still be part of your relationship.

If you are able to have sex, you may be advised to use certain types of contraception to protect your partner or avoid pregnancy for a certain period of time. Your doctor will talk to you about the precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, talk to your doctor before starting treatment.

Call Cancer Council 13 11 20 for free copies of *Sexuality, Intimacy and Cancer, Fertility and Cancer* and *Emotions and Cancer*, or download the booklets from the website.

44

## Life after treatment

For most people, the cancer experience doesn't end on the last day of treatment. Life after cancer treatment can present its own challenges. You may have mixed feelings when treatment ends, and worry if every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to 'normal life', but they don't want life to return to how it was before cancer. Take some time to adjust to the physical and emotional changes, and re-establish a new daily routine at your own pace.

Cancer Council 13 11 20 can help you connect with other people who have had cancer, and provide you with information about the emotional and practical aspects of living well after cancer.

### **Dealing with feelings of sadness**

If you have continued feelings of sadness, have trouble getting up in the morning or have lost motivation to do things that previously gave you pleasure, you may be experiencing depression. This is quite common among people who have had cancer.

Talk to your GP, as counselling or medication – even for a short time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible. Your local Cancer Council may also run a counselling program.

The organisation beyondblue has information about coping with depression and anxiety. Go to **beyondblue.org.au** or call **1300 224 636** to order a fact sheet.

## After treatment: follow-up

After treatment, you will need regular check-ups to monitor your health and confirm that the cancer hasn't come back. You will also receive continued support by your allied health team as you need it, or you may be referred to local services.

Tests may include occasional scans, as well as physical and visual examinations of your digestive system. Over time, if there are no further problems, your check-ups will become less frequent. If you notice any new symptoms in-between check-ups, you should let your GP or specialist know as soon as possible.

## What if the cancer returns?

For some people, the oesophageal or stomach cancer does come back after treatment. This is known as a relapse or recurrence.

If the cancer returns, you may require further treatment. This may be similar to what you had after your initial diagnosis or you may be offered a different type of treatment. This may include chemotherapy or radiotherapy. Sometimes people have palliative treatment to ease their symptoms (see page 34).

It is possible for the cancer to come back in another part of your body. In this case, you may have treatment that focuses specifically on the area of your body where the cancer has returned.



Cancer may cause you to experience a range of emotions, such as fear, sadness, anxiety, anger or frustration. It can also cause practical and financial problems.

## **Practical and financial help**

There are many services that can help deal with practical or financial problems caused by the cancer. Benefits, pensions and programs can help pay for prescription medicines, transport costs or utility bills. Home care services, aids and appliances can also be arranged to help make life easier.

Ask the hospital social worker which services are available in your local area and if you are eligible to receive them.

If you need legal or financial advice, you should talk to a qualified professional about your situation. Cancer Council offers free legal and financial services in some states and territories for people who can't afford to pay – call 13 11 20 to ask if you are eligible.

## Talk to someone who's been there

Coming into contact with other people who have had similar experiences to you can be beneficial. You may feel supported and relieved to know that others understand what you are going through and that you are not alone.

People often feel they can speak openly and share tips with others who have gone through a similar experience.

You may find that you are comfortable talking about your diagnosis and treatment, relationships with friends and family, and hopes and fears for the future. Some people say they can be even more open and honest in these support settings because they aren't trying to protect their loved ones.

## **Types of support**

There are many ways to connect with others for mutual support and to share information. This includes:

- **face-to-face support groups** often held in community centres or hospitals
- **telephone support groups** facilitated by trained counsellors
- **peer support programs** match you with someone who has had a similar cancer experience, e.g. Cancer Connect
- **online forums** such as cancerconnections.com.au.

Talk to your nurse, social worker or Cancer Council about what is available in your area.

• My family members don't really understand what it's like to have cancer thrown at you, but in my support group, I don't feel like I have to explain. 99 sam

# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. Being a carer can be stressful and cause you much anxiety. Try to look after yourself – give yourself some time out and share your worries and concerns with somebody neutral, such as a counsellor or your doctor.

Many cancer support groups and cancer education programs are open to carers, as well as people with cancer. Support groups and some types of programs can offer valuable opportunities to share experiences and ways of coping.

Support services such as Home Help, Meals on Wheels or visiting nurses can help you in your caring role. There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Phone 1800 242 636 or visit carersaustralia.com.au for more information and resources.

You can also call Cancer Council 13 11 20 to find out more about carers' services and get a copy of the *Caring for Someone with Cancer* booklet.

• Caring for someone with oesophageal cancer is hard work, in particular trying to offer nutritious and interesting food that will encourage them to eat again. It's also really important to get support for yourself as a carer. 99 Leslee



The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information.

### **Australian**

Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Carers Australia	carersaustralia.com.au
Department of Health	health.gov.au
healthdirect Australia	healthdirect.gov.au

## International

Macmillan Cancer Support	macmillan.org.uk
American Cancer Society	cancer.org
National Cancer Institute	cancer.gov

## Questions checklist

You may find this checklist helpful when thinking about the questions you want to ask your doctor about your disease and treatment. If your doctor gives you answers that you don't understand, it is okay to ask for clarification.

- What type of cancer do I have?
- How far has the cancer spread? How fast is it growing?
- What treatment do you recommend and why?
- Are there other treatment choices for me? If not, why not?
- What are the risks and possible side effects of each treatment?
- How long will treatment take? Will I have to stay in hospital?
- How much will treatment cost? How can the cost be reduced?
- Will I have a lot of pain with the treatment? How will this be managed?
- How will the treatment affect the way I eat and digest food?
- Should I change my diet during or after treatment?
- Can I be referred to a dietitian?
- Are the latest tests and treatments for this type of cancer available in this hospital?
- Are there any clinical trials or research studies I could join?
- How frequently will I need check-ups after treatment?
- Who should I go to for my check-up appointments?
- Are there any complementary therapies that might help me?
- If the cancer comes back, how will I know?
- How soon will I be able to go back to work? Travel overseas?
- Will my digestive system ever go back to feeling normal?

51



## Glossary

#### abdomen

The part of the body between the chest and hips, which contains the stomach, liver, bowel, bladder and kidneys.

#### adenocarcinoma

A cancer that starts in glandular tissue.

#### adjuvant therapy

A treatment given with or shortly after another treatment to enhance its effectiveness.

#### anaemia

Deficiency in the number or quality of red blood cells.

#### ascites

Fluid build-up in the abdomen, making it swollen and bloated.

#### **Barrett's oesophagus**

Abnormal changes in the cells that line the lower oesophagus. This may be a risk factor for oesophageal cancer.

#### benign

Not cancerous or malignant.

#### biopsy

The removal of a small sample of tissue from the body for examination under a microscope to diagnose disease.

#### bone scan

A test in which a radioactive substance is injected and a scan is done to measure the growth of any cancer in the bones.

#### bronchoscopy

A diagnostic test to examine the lungs and respiratory system.

#### cancer

A disease of the body's cells that starts in the genes. Damaged genes cause cells to behave abnormally, and they may grow into a lump called a tumour.

#### catheter

A hollow, flexible tube through which fluids can be passed into the body or drained from it.

#### cells

The basic building blocks of the body. A human is made of billions of cells, which are adapted for different functions.

#### chemotherapy

The use of drugs to kill or slow the growth of cancer cells.

#### **CT** scan

A computerised tomography scan. This scan uses x-rays to create a picture of the body.

#### digestive system

The body system that processes food and drink, absorbs nutrients and disposes of solid waste. Also called the gastrointestinal (GI) tract.

#### dumping syndrome

When partially digested food moves into the small bowel too quickly, causing symptoms such as dizziness and diarrhoea.

#### endoscope

The flexible tube used during an endoscopy.

## endoscopic mucosal resection (EMR)

A type of surgery for stomach and early stage oesophageal cancer. Tissue is removed using an endoscope.

#### endoscopic ultrasound (EUS)

A diagnostic test. An endoscope with a probe on the end is inserted into the body. The probe releases soundwaves that are translated into a picture on a computer.

#### endoscopy

A diagnostic test. An endoscope is inserted into the oesophagus so the upper digestive tract can be examined. Also called a gastroscopy.

## familial adenomatous polyposis (FAP)

A condition that causes polyps to form in the large bowel, which will become cancerous if untreated. FAP is also a risk factor for stomach cancer.

#### gastrectomy

The surgical removal of part or all of the stomach.

#### gastric juices

Acidic juices in the stomach that help to break down food.

#### gastroenterologist

A specialist doctor who diagnoses and treats disorders of the digestive system.

#### gastrointestinal (GI) tract

See digestive system.

#### gastro-oesophageal junction

The point where the stomach meets the oesophagus.

## gastro-oesophageal reflux disease (GORD)

A condition when stomach acid leaks back into the oesophagus, causing irritation.

#### gastroscopy

See endoscopy.

#### grade

The appearance of the cancer cells at pathology.

#### heartburn

A sensation of tightness or burning in the chest, which is often caused by stomach acid backing up into the oesophagus (reflux).

#### Helicobacter pylori (H. pylori)

Bacteria that can live in the stomach and small bowel and may lead to stomach ulcers and cancer. hereditary non-polyposis colorectal cancer (HNPCC)

A disease affecting the lower GI tract. HNPCC may be a risk factor for bowel cancer. Also called Lynch syndrome.

#### laparoscopy

Surgery using a laparoscope, which is inserted into the body through a small incision. Also called keyhole surgery.

#### large bowel

The organ that stores waste until it can be passed out of the body.

#### lymph nodes

Small, bean-shaped structures that form part of the lymphatic system. Also called lymph glands.

#### lymphatic system

A network of tissues, capillaries, vessels, ducts and nodes that removes excess fluid from tissues, absorbs fatty acids and transports fat, and produces immune cells.

#### malignant

Cancer. Malignant cells can spread (metastasise) and cause death if they cannot be treated.

#### metastasis

A cancer that has spread from another part of the body. Also known as a secondary cancer.

#### mucosa

Moist tissue that lines organs of the body, such as the digestive tract, lungs and nose. It is the innermost layer of the oesophagus and stomach.

#### muscle layer

The tissue layer surrounding the mucosa and submucosa in the digestive tract.

#### neoadjuvant therapy

A treatment given before the primary treatment to enhance the primary treatment's effectiveness.

#### oesophageal cancer

A malignant tumour found in the oesophagus, usually in the gastrooesophageal junction.

#### oesophagectomy

The surgical removal of all or part of the oesophagus.

#### oesophagoscopy

The examination of the oesophagus with an endoscope.

#### oesophagus

The tube that carries food from the throat into the stomach.

#### omentum

A protective apron of fatty tissue over the abdominal organs.

#### osteoporosis

Thinning of the bones that can lead to bone pain and fractures.

#### palliative treatment

Treatment that seeks to improve quality of life by reducing the symptoms of advanced cancer without aiming to cure the disease.

#### partial gastrectomy

See subtotal gastrectomy.

#### peritoneum

The lining of the abdomen.

#### pernicious anaemia

A type of anaemia caused by vitamin B12 not being absorbed, which affects red blood cell development.

## **PET** (positron emission tomography) scan

This specialised imaging test uses a radioactive glucose solution to identify cancer cells in the body.

#### pharynx

The throat. This is a muscular tube about 10cm long that extends from the nose to the top of the larynx (voice box) and oesophagus.

#### radiotherapy

The use of high-energy rays to damage or kill cancer cells so they cannot multiply.

#### reflux

When stomach acid is released back up into the oesophagus.

#### serosa

The outermost layer of the digestive system, which is made up of fat and connective tissue.

#### small bowel

The organ in the abdomen that receives food from the stomach and absorbs nutrients.

#### squamous cell carcinoma

A cancer that starts in squamous cells of the body (such as in the lining of the oesophagus).

54

#### staging

Using test results to determine the extent of a cancer and whether the disease has spread from the original site to other parts of the body.

#### stent

A flexible tube inserted into the oesophagus or between the oesophagus and stomach to keep these passageways open and make eating and drinking easier.

#### stomach

The hollow, muscular organ between the end of the oesophagus and the beginning of the small bowel that stores and breaks down food.

#### stomach cancer

A malignant tumour in the tissue of the stomach.

#### submucosa

The layer of the digestive system next to the mucosa. It has glandular cells that produce mucus and moisten the mucosa.

#### subtotal gastrectomy

The surgical removal of part of the stomach.

#### total gastrectomy

The surgical removal of the entire stomach.

#### ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. An ultrasound scan can be used to measure the size and position of a tumour.

#### upper GI endoscopy

See endoscopy.

#### References

- 1. Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: Oesophageal cancer, AIHW, Canberra, 2015.
- Australian Institute of Health and Welfare (AIHW), Australian Cancer Incidence and Mortality (ACIM) books: Stomach cancer, AIHW, Canberra, 2015.
- Australian Institute of Health and Welfare 2014. Cancer in Australia: an overview. Cancer series no 90. Canberra: AIHW.

#### Can't find what you're looking for?

For more cancer-related words, visit:

- cancercouncil.com.au/words
- cancervic.org.au/glossary
- cancersa.org.au/glossary.

## 🔒 How you can help

At Cancer Council we're dedicated to improving cancer control. As well as funding millions of dollars in cancer research every year, we advocate for the highest quality care for cancer patients and their families. We create cancer-smart communities by educating people about cancer, its prevention and early detection. We offer a range of practical and support services for people and families affected by cancer. All these programs would not be possible without community support, great and small.

Join a Cancer Council event: Join one of our community fundraising events such as Daffodil Day, Australia's Biggest Morning Tea, Relay For Life, Girls Night In and Pink Ribbon Day, or hold your own fundraiser or become a volunteer.

**Make a donation:** Any gift, large or small, makes a meaningful contribution to our work in supporting people with cancer and their families now and in the future.

**Buy Cancer Council sun protection products:** Every purchase helps you prevent cancer and contribute financially to our goals.

Help us speak out for a cancer-smart community: We are a leading advocate for cancer prevention and improved patient services. You can help us speak out on important cancer issues and help us improve cancer awareness by living and promoting a cancer-smart lifestyle.

Join a research study: Cancer Council funds and carries out research investigating the causes, management, outcomes and impacts of different cancers. You may be able to join a study.

To find out more about how you, your family and friends can help, please call your local Cancer Council.



Being diagnosed with cancer can be overwhelming. At Cancer Council, we understand it isn't just about the treatment or prognosis. Having cancer affects the way you live, work and think. It can also affect our most important relationships.

When disruption and change happen in our lives, talking to someone who understands can make a big difference. Cancer Council has been providing information and support to people affected by cancer for over 50 years.

Calling 13 11 20 gives you access to trustworthy information that is relevant to you. Our cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

If you are finding it hard to navigate through the health care system, or just need someone to listen to your immediate concerns, call 13 11 20 and find out how we can support you, your family and friends.

Cancer Council services and programs vary in each area. 13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



If you need information in a language other than English, an interpreting service is available. Call 13 14 50.



If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service. www.relayservice.gov.au



For information and support on cancer-related issues, call Cancer Council **13 11 20**. This is a confidential service.

## Visit your local Cancer Council website

Cancer Council ACT actcancer.org

Cancer Council NSW cancercouncil.com.au

Cancer Council NT nt.cancer.org.au Cancer Council Queensland cancerqld.org.au

Cancer Council SA cancersa.org.au

Cancer Council Tasmania cancertas.org.au

Cancer Council Victoria cancervic.org.au

Cancer Council WA cancerwa.asn.au

Cancer Council Australia cancer.org.au

This booklet is funded through the generosity of the people of Australia. To support Cancer Council, call your local Cancer Council or visit your local website. NOV 2015 CAN1162