

# Understanding Stomach and Oesophageal Cancers

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



For information & support, call **13 11 20**

# Understanding Stomach and Oesophageal Cancers

A guide for people with cancer, their families and friends

First published April 2009. This edition October 2021.

© Cancer Council Australia 2021. ISBN 978 0 6489506 4 6

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

Editor: Jenny Mothoneos. Designer: Ali Wright. Printer: IVE Group.

## Acknowledgements

This edition has been developed by Cancer Council NSW on behalf of all other state and territory Cancer Councils as part of a National Cancer Information Subcommittee initiative. We thank the reviewers of this booklet: Dr Spiro Raftopoulos, Gastroenterologist, Sir Charles Gairdner Hospital, WA; Peter Blyth, Consumer; Jeff Bull, Upper Gastrointestinal Cancer Nurse Consultant, Cancer Services, Southern Adelaide Local Health Network, SA; Mick Daws, Consumer; Dr Steven Leibman, Upper Gastrointestinal Surgeon, Royal North Shore Hospital, NSW; Prof Michael Michael, Medical Oncologist, Lower and Upper Gastrointestinal Oncology Service, and Co-Chair Neuroendocrine Unit, Peter MacCallum Cancer Centre, VIC; Dr Andrew Oar, Radiation Oncologist, Icon Cancer Centre, Royal Brisbane Hospital, QLD; Rose Rocca, Senior Clinical Dietitian, Upper Gastrointestinal, Nutrition and Speech Pathology Department, Peter MacCallum Cancer Centre, VIC; Letchemi Valautha, Consumer; Lesley Woods, 13 11 20 Consultant, Cancer Council WA. We also thank the health professionals, consumers and editorial teams who have worked on previous editions of this title.

## 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](http://cancer.org.au) or call your local Cancer Council.



*Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past, present and emerging.*



**Cancer Council Australia** Level 14, 477 Pitt Street, Sydney NSW 2000 ABN 91 130 793 725

**Telephone** 02 8256 4100 **Email** [info@cancer.org.au](mailto:info@cancer.org.au) **Website** [cancer.org.au](http://cancer.org.au)

# About this booklet

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

We cannot give advice about the best treatment for you. You need to discuss this with your doctors. However, this information may answer some of your questions and help you think about what to ask your treatment team (see page 60 for a question checklist).

This booklet contains separate information for stomach cancer and oesophageal cancer – just read the parts that are useful to you. Some medical terms that may be unfamiliar are explained in the glossary (see page 61). 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 a range of health professionals and people affected by these cancers. It is based on international clinical practice guidelines.<sup>1-2</sup>



If you or your family have any questions or concerns, call **Cancer Council 13 11 20**. We can send you more information and connect you with support services in your area. You can also visit your local Cancer Council website (see back cover).




# Contents

<b>What is cancer?</b>	<b>4</b>
<b>The oesophagus and stomach</b>	<b>6</b>
<b>Key questions</b>	<b>8</b>
What is stomach cancer?	8
Is stomach cancer common?	8
What is oesophageal cancer?	9
Is oesophageal cancer common?	9
What are the symptoms?	10
What are the risk factors?	11
Which health professionals will I see?	12
<b>Diagnosis</b>	<b>14</b>
Endoscopy and biopsy	14
Further tests	15
Staging	19
Prognosis	20
<b>Making treatment decisions</b>	<b>22</b>
<b>Treatment for stomach cancer</b>	<b>24</b>
Endoscopic resection for stomach cancer	25
Surgery for stomach cancer	25
What to expect after surgery	28
Chemotherapy for stomach cancer	30
Targeted therapy for stomach cancer	31
Immunotherapy for stomach cancer	32
Radiation therapy for stomach cancer	32
Palliative treatment	33

<b>Treatment for oesophageal cancer</b>	<b>35</b>
Endoscopic resection for oesophageal cancer	35
Surgery for oesophageal cancer	36
Radiation therapy for oesophageal cancer	39
Chemotherapy for oesophageal cancer	41
Immunotherapy for oesophageal cancer	42
Palliative treatment	43
<b>Managing side effects</b>	<b>45</b>
How treatment will affect eating	45
Poor appetite and weight loss	46
Swallowing difficulties	47
Reflux and choking	48
Dumping syndrome	49
Anaemia and osteoporosis	50
<b>Looking after yourself</b>	<b>52</b>
<b>Life after treatment</b>	<b>54</b>
Follow-up appointments	55
What if the cancer returns?	55
<b>Seeking support</b>	<b>56</b>
Support from Cancer Council	57
Useful websites	58
<b>Caring for someone with cancer</b>	<b>59</b>
<b>Question checklist</b>	<b>60</b>
<b>Glossary</b>	<b>61</b>
<b>How you can help</b>	<b>64</b>

### Key to icons

Icons are used throughout this booklet to indicate:

-  More information
-  Alert
-  Tips

# What is cancer?

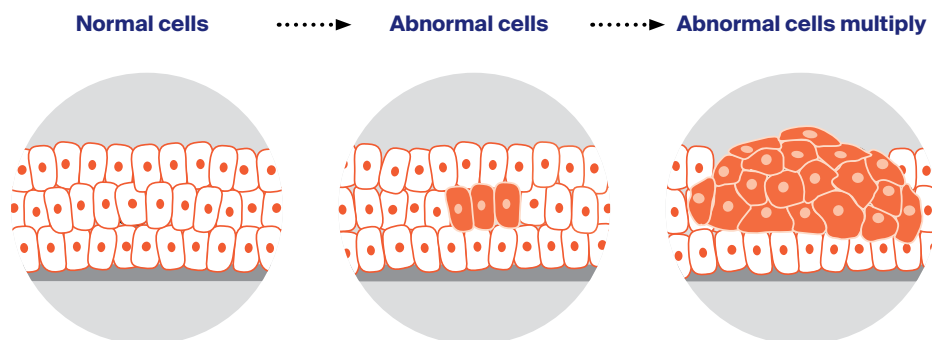
Cancer is a disease of the cells. Cells are the body's basic building blocks - they make up tissues and organs. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries.

Normally, cells multiply and die in an orderly way, so that each new cell replaces one lost. Sometimes, however, cells become abnormal and keep growing. These abnormal cells may turn into cancer.

In solid cancers, such as stomach or oesophageal cancer, the abnormal cells form a mass or lump called a tumour. In some cancers, such as leukaemia, the abnormal cells build up in the blood.

## How cancer starts

---

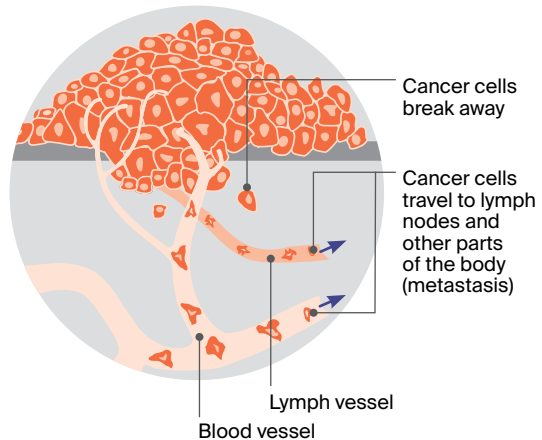
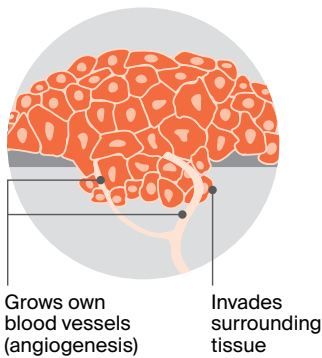


Not all tumours are cancer. Benign tumours tend to grow slowly and usually don't move into other parts of the body or turn into cancer. Cancerous tumours, also known as malignant tumours, have the potential to spread. They may invade nearby tissue, destroying normal cells. The cancer cells can break away and travel through the bloodstream or lymph vessels to other parts of the body.

The cancer that first develops in a tissue or organ is called the primary cancer. It is considered localised cancer if it has not spread to other parts of the body. If the primary cancer 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 liver is called metastatic stomach cancer, even though the cancer may be in the liver.

## How cancer spreads

### .....▶ Malignant cancer

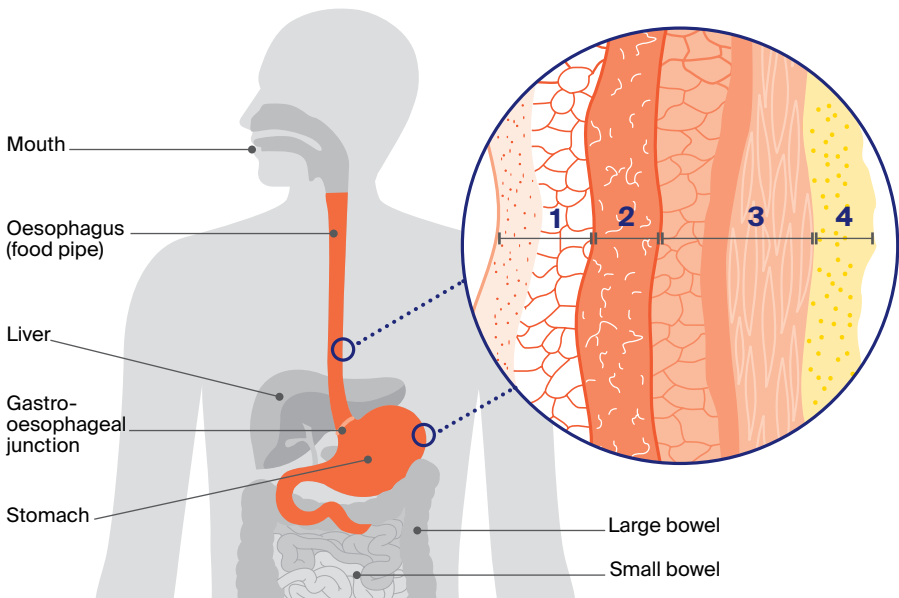


# The oesophagus and stomach

The oesophagus and stomach are part of the upper gastrointestinal (GI) tract, which is part of the digestive system. The digestive system helps the body break down food and turn it into energy.

The oesophagus (food pipe) is a long, muscular tube. The stomach is a hollow, muscular sac-like organ. The top part of the stomach joins to the end of the oesophagus and the other end joins to the beginning of the small bowel.

## Anatomy of the oesophagus and stomach





## What the oesophagus and stomach do

The oesophagus moves food, fluid and saliva from the mouth and throat to the stomach. A valve (sphincter) at the lower end of the oesophagus stops acid and food moving from the stomach back into the oesophagus.

The stomach stores food and breaks it down (digests it). Juices and muscle contractions in the stomach break down food into a thick fluid, which then moves into the small bowel. In the small bowel, nutrients from the broken-down food are absorbed into the bloodstream. The waste moves into the large bowel, where fluids are absorbed into the body and the leftover matter is turned into solid waste (known as faeces, stools or poo).

Layer of tissue	In the oesophageal wall	In the stomach wall
<b>1. mucosa</b> (moist innermost layer)	<ul style="list-style-type: none"><li>made up of squamous cells (thin, flat cells)</li></ul>	<ul style="list-style-type: none"><li>made up of glandular cells (column-shaped cells)</li><li>produces fluids to help break down food and mucus to protect the stomach lining</li></ul>
<b>2. submucosa</b> (supports the mucosa)	<ul style="list-style-type: none"><li>glands in the submucosa make fluid (mucus)</li><li>this fluid helps to move food through the oesophagus</li></ul>	<ul style="list-style-type: none"><li>provides blood and nutrients to the stomach</li></ul>
<b>3. muscle layer</b>	<ul style="list-style-type: none"><li>known as the muscularis propria</li><li>produces contractions to help push food down the oesophagus and into the stomach</li></ul>	<ul style="list-style-type: none"><li>known as the muscularis externa</li><li>produces contractions to help break down food and push it into the small bowel</li></ul>
<b>4. outer layer</b>	<ul style="list-style-type: none"><li>known as the adventitia</li><li>connective tissue that supports the oesophagus</li></ul>	<ul style="list-style-type: none"><li>known as the serosa</li><li>a smooth membrane that surrounds the stomach</li></ul>

# Key questions

## Q: What is stomach cancer?

**A:** Stomach cancer develops when cells in any part of the stomach grow and divide in an abnormal way. Tumours can begin anywhere in the stomach, although most start in the stomach's inner layer (mucosa). This type of cancer is called adenocarcinoma of the stomach (also known as gastric cancer).

If it is not found and treated early, stomach cancer can spread to nearby lymph nodes or to other parts of the body, such as the liver and lungs. It may also spread to the lining of the wall of the abdomen (peritoneum). Rarely, it can grow through the stomach wall into nearby organs such as the pancreas and bowel.

## Q: Is stomach cancer common?

**A:** About 2400 people are diagnosed with stomach cancer in Australia each year. Men are twice as likely as women to be diagnosed with stomach cancer. It is more common in people over 60, but it can occur at any age.<sup>3</sup>

## Rare types of stomach and oesophageal cancer

---

Some less common types of cancer can start in the stomach and oesophagus. These include small cell carcinomas, lymphomas, neuroendocrine tumours and gastrointestinal stromal tumours. These types of cancer aren't discussed in this booklet and treatment may be different. For more information, call Cancer Council 13 11 20.

---



Some cancers start at the point where the stomach meets the oesophagus (called the gastro-oesophageal junction). Depending on the type of gastro-oesophageal cancer, it may be treated similarly to stomach cancer or oesophageal cancer.

## Q: What is oesophageal cancer?

**A:** Oesophageal cancer begins when abnormal cells develop in the innermost layer (mucosa) of the oesophagus. A tumour can start anywhere along the oesophagus. There are two main types:

**Oesophageal adenocarcinoma** – This often starts near the gastro-oesophageal junction and is linked with Barrett’s oesophagus (see page 12). Adenocarcinomas are the most common form of oesophageal cancer in Australia.

**Oesophageal squamous cell carcinoma** – This starts in the thin, flat cells of the mucosa, which are called squamous cells. It often begins in the middle and upper part of the oesophagus. In Australia, oesophageal squamous cell carcinoma is less common than oesophageal adenocarcinoma.

If it is not found and treated early, oesophageal cancer can spread to nearby lymph nodes or to other parts of the body, most commonly the liver and lungs. It can also grow through the oesophageal wall and into nearby structures.

## Q: Is oesophageal cancer common?

**A:** This is an uncommon cancer. In Australia, about 1650 people are diagnosed with oesophageal cancer each year. Men are much more likely than women to be diagnosed with this cancer.<sup>3</sup>

## Q: What are the symptoms?

**A:** Stomach and oesophageal cancers may not cause symptoms in their early stages. Common symptoms are listed in the table below. These symptoms can also be caused by many other conditions and do not necessarily mean that you have cancer. Speak with your general practitioner (GP) if you are concerned.

### Common symptoms

#### Stomach cancer

- unexplained weight loss or loss of appetite
- difficulty swallowing
- indigestion – e.g. pain or burning sensation in the abdomen (heartburn), frequent burping, or stomach acid coming back up into the oesophagus (reflux)
- persistent nausea and/or vomiting with no apparent cause
- abdominal (stomach) pain
- feeling full after eating even a small amount
- swelling of the abdomen or feeling bloated
- unexplained tiredness, which may be due to low red blood cells (anaemia)
- vomit that has blood in it
- black or bloody stools

#### Oesophageal cancer

- difficulty swallowing
- new heartburn or reflux
- reflux that doesn't go away
- food or fluids “catching” in the throat or episodes of choking when swallowing
- pain when swallowing
- unexplained weight loss or loss of appetite
- feeling uncomfortable in the upper abdomen, especially when eating
- unexplained tiredness that won't go away
- vomit that has blood in it
- black or bloody stools

## Q: What are the risk factors?

**A:** The exact causes of stomach and oesophageal cancers are not known. Research shows that the factors listed in the table below may increase your risk. Having one or more of these risk factors does not mean you will develop cancer. Some people have these risk factors and do not develop stomach or oesophageal cancer.

### Factors known to increase risk

#### Stomach cancer

- older age (being over 60)
- infection with the bacteria *Helicobacter pylori* (*H. pylori*)
- treating non-cancerous conditions with a subtotal gastrectomy (see page 26)
- smoking tobacco
- low red blood cell levels related to pernicious anaemia
- a family history of stomach cancer
- having an inherited genetic condition like familial adenomatous polyposis (FAP), Lynch syndrome, hereditary diffuse gastric cancer (HDGC), gastric adenocarcinoma and proximal polyposis of the stomach (GAPPS)
- chronic inflammation of the stomach (chronic gastritis)
- being overweight or obese
- drinking alcohol
- eating foods preserved by salting

#### Oesophageal cancer

##### Adenocarcinoma

- being overweight or obese
- medical conditions, including gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus (see next page)
- smoking tobacco
- older age (being over 60)
- having an inherited genetic condition such as Peutz-Jeghers syndrome (PJS) or Cowden syndrome

##### Squamous cell carcinoma

- drinking alcohol
- smoking tobacco
- older age (being over 60)
- damage to the oesophagus from hot or corrosive liquids such as acid

## Q: Which health professionals will I see?

**A:** Your GP will assess your symptoms and arrange the first tests to check your general health. You will usually be referred to a specialist such as a gastroenterologist or an upper gastrointestinal surgeon for an endoscopy (see pages 14–15) and further tests.

If you are diagnosed with stomach or oesophageal cancer, the specialist will consider treatment options. Often these will be discussed with other health professionals at what is known as a multidisciplinary team (MDT) meeting.

During and after treatment, you will see a range of health professionals who specialise in different aspects of your care. The most common health professionals are listed in the table opposite. You won't necessarily see all these people.

## GORD and Barrett's oesophagus

---

Reflux is when stomach acid goes back into the oesophagus. Some people with reflux are diagnosed with gastro-oesophageal reflux disease (GORD).

Over time, stomach acid can damage the lining of the oesophagus and cause inflammation or ulcers (oesophagitis). This causes the cells lining the oesophagus to change to look like the cells lining the small bowel. This condition is called

Barrett's oesophagus and it can lead to oesophageal adenocarcinoma.

If you have Barrett's oesophagus, your doctor may recommend you have regular endoscopies to look for early changes to the cells that may cause cancer.

Most people who have Barrett's oesophagus will not develop oesophageal cancer.

---

## Health professionals you may see

<b>gastroenterologist*</b>	diagnoses and treats some disorders of the digestive system; may perform endoscopies and insert feeding tubes
<b>upper gastrointestinal surgeon*</b>	diagnoses, treats and performs surgery for diseases of the upper digestive system (such as cancer); performs endoscopies and inserts feeding tubes
<b>medical oncologist*</b>	treats cancer with drug therapies such as chemotherapy, targeted therapy and immunotherapy (systemic treatment)
<b>radiation oncologist*</b>	treats cancer by prescribing and overseeing a course of radiation therapy
<b>cancer care coordinator</b>	coordinates your care, liaises with MDT members and supports you and your family throughout treatment; may be a clinical nurse consultant (CNC), nurse consultant (NC) or clinical nurse specialist (CNS)
<b>nurse</b>	administers drugs and provides care, information and support throughout treatment
<b>dietitian</b>	helps with nutrition concerns and recommends changes to diet during treatment and recovery
<b>physiotherapist</b>	helps with restoring movement and mobility, and preventing further injury
<b>speech pathologist</b>	evaluates and treats communication, voice and swallowing difficulties during and after treatment
<b>social worker, psychologist</b>	link you to support services and help with emotional and practical issues associated with cancer and treatment
<b>palliative care team</b>	work closely with the GP and cancer specialists to help control symptoms and maintain quality of life

\* *Specialist doctor*

# Diagnosis

If your GP suspects that you have stomach or oesophageal cancer, they will examine you and refer you to a specialist for further tests. The main tests are endoscopy and biopsy (the removal of a tissue sample). You may have other tests to check your overall health and see if the cancer has spread. Your specialist will combine the test results to work out the overall stage and prognosis of the cancer (see pages 19–20).

## Endoscopy and biopsy

An endoscopy (also called a gastroscopy, oesophagoscopy or upper endoscopy) is a procedure that allows your doctor to look at the lining of your gastrointestinal tract. It is usually done as day surgery.

**Having an endoscopy** – You will be told not to eat or drink (fast) for six hours before an endoscopy. In some cases, you can drink clear fluids until two hours before the procedure. Your doctor will let you know about this. Before an endoscopy, some specialists may spray the throat with a local anaesthetic to numb it, but more commonly you will be given a sedative into a vein to make the procedure more comfortable. A long, flexible tube with a light and small camera on the end (endoscope) will then be passed into your mouth, down your throat and oesophagus, and into your stomach and small bowel.

**Taking a biopsy** – If the doctor sees any areas that look like cancer, they may remove a small amount of tissue from the stomach or oesophageal lining. This is known as a biopsy. A specialist doctor called a pathologist will examine the tissue under a microscope to check for signs of cancer. Biopsy results are usually available in 5–7 days.



An endoscopy takes about 10 minutes. You will need to have someone take you home after the procedure, as you may feel drowsy or weak. You may have a sore throat afterwards and feel a little bloated. Endoscopies have some risks, such as bleeding or getting a small tear or hole in the stomach or oesophagus (perforation). These risks are very uncommon. Your doctor should explain all the risks before asking you to agree (consent) to the procedure.

## **Endoscopic ultrasound (EUS)**

You may have an EUS at the same time as a standard endoscopy. The doctor will use an endoscope with an ultrasound probe on the tip or with a built-in ultrasound device. The probe releases soundwaves that echo when they bounce off anything solid, such as an organ or tumour. This test helps work out whether the cancer has spread into the oesophageal or gastric wall, nearby tissues or lymph nodes. During the EUS, your doctor may use the ultrasound to guide a needle into the area they want to look at and take tissue samples.

## **Further tests**

If the biopsy shows you have stomach or oesophageal cancer, you will have some of the following tests to work out whether the cancer has spread to other areas of your body. This is called staging (see page 19). Some of the tests may be repeated during or after treatment to check your health and see how well the treatment is working.

## **Blood tests**

You may have blood tests to assess your general health, check for a low red blood cell count (anaemia), and see how well your liver and kidneys are working. Blood tests can also help show if you are getting enough vitamins or minerals.

## CT scan

A computerised tomography (CT) scan uses x-ray beams to create detailed, cross-sectional pictures of the inside of your body. It helps show the size of the cancer and if it has spread. You may have a CT scan of your:

- chest, abdomen and pelvis for stomach cancer
- neck, chest, abdomen and pelvis for oesophageal cancer.

Before a CT scan, you may have an injection of dye and/or be asked to drink a liquid dye. If you have an injection, a cannula is inserted into a vein on your arm. This dye, known as contrast, helps ensure that anything unusual can be seen more clearly. The dye may cause a warm feeling throughout your body, and leave a metallic taste in your mouth for a few minutes. Rarely, more serious reactions may occur.

The CT scan machine is large and round like a doughnut. You will need to lie still on a table while the scanner moves around you. The scan itself is painless and takes only a few minutes, but it usually takes 10–30 minutes for the sonographer to prepare the CT machine and insert the cannula.

## PET–CT scan

A positron emission tomography (PET) scan combined with a CT scan is a specialised imaging test. The CT scan helps pinpoint the location of any abnormalities found by the PET scan. For oesophageal cancer,



Before having scans, tell the doctor if you have any allergies or have had a reaction to contrast during previous scans. You should also let them know if you have diabetes or kidney disease or are pregnant or breastfeeding.

a PET-CT scan is most commonly used to see if the cancer has spread to other parts of the body. As a PET-CT scan is not useful in finding some types of stomach cancers, Medicare does not currently cover the cost of this test.

To prepare for a PET-CT scan, you will be asked not to eat or drink (fast) for a period of time. Before the scan, you will be injected with a glucose solution containing a small amount of radioactive material. Cancer cells show up brighter on the scan because they take up more glucose solution than normal cells do.

You will be asked to sit quietly for 30–90 minutes as the glucose spreads through your body, then you will be scanned. The scan itself takes about 30 minutes. Let your doctor know if you are claustrophobic, as you need to be in a confined space for the scan.

## Laparoscopy

This procedure allows your doctor to look for signs that the cancer has spread to the outer layer of the stomach and the lining of the wall of the abdomen, which are known as the peritoneum. A laparoscopy is used to stage stomach and oesophageal cancers. Your doctor will explain the risks before asking you to agree to the procedure.

A laparoscopy is usually done as day surgery under general anaesthetic. The doctor will make small cuts in your abdomen and pump in gas to inflate it. A tube with a light and camera attached (a laparoscope) will then be inserted into your body. The camera projects images onto a monitor so the doctor can see cancers that are too small to be seen on CT or PET-CT scans. The doctor may take more tissue samples for biopsy. After the procedure you may feel bloated and the gas in your abdomen may cause pain in your shoulder.

## Staging endoscopic resection

If you are diagnosed with very early cancer in the stomach or oesophagus, you may have an endoscopic resection.

This procedure may help your doctor work out whether the cancer has spread to the lymph nodes. For some people, the resection also treats the cancer and further treatment is not needed. An endoscopic resection is often done as a day procedure but in some cases, you may stay in hospital overnight for observation.

For more information, see *Endoscopic resection for stomach cancer* on page 25 and *Endoscopic resection for oesophageal cancer* on page 35.

## Molecular testing

If you are diagnosed with advanced cancer in the stomach or gastro-oesophageal junction, your doctor may test the biopsy sample to see whether one of the available targeted therapy or immunotherapy drugs would be suitable for you.

The test will look for particular features within the cancer, such as changes to the HER2 protein, a special protein known as PD-L1, or a marker called microsatellite instability (MSI). This type of testing is known as molecular testing.

For more information, see *Targeted therapy for stomach cancer* on page 31 and *Immunotherapy for stomach cancer* on page 32.



For an overview of what to expect at every stage of your cancer care, visit [cancer.org.au/cancercareguides/oesophagogastric-cancer](https://cancer.org.au/cancercareguides/oesophagogastric-cancer). This is a short guide to what is recommended, from diagnosis to treatment and beyond.

## Staging

The tests described on pages 14–18 help show whether you have stomach or oesophageal cancer and whether it has spread. Working out how far the cancer has spread is called staging. It helps your doctors recommend the best treatment for you.

The TNM staging system is the method most often used to stage stomach and oesophageal cancers. The specialist gives numbers to the size of the tumour (T1–4), whether or not lymph nodes are affected (N0–N3), and whether the cancer has spread or metastasised (M0 or M1). The lower the numbers, the less advanced the cancer.

The TNM scores are combined to work out the overall stage of the cancer, from stage 1 to stage 4 (see table below). Ask your doctor to explain what the stage of the cancer means for you. You can also call Cancer Council 13 11 20.

### Stages of stomach and oesophageal cancers

<b>stage 1</b>	<b>early or limited cancer</b>	tumours are found only in the stomach or oesophageal wall lining
<b>stages 2–3</b>	<b>locally advanced cancer</b>	tumours have spread deeper into the layers of the stomach or oesophageal wall and to nearby lymph nodes
<b>stage 4</b>	<b>metastatic or advanced cancer</b>	tumours have spread beyond the stomach or oesophageal wall to nearby lymph nodes or parts of the body, or to distant lymph nodes and parts of the body

## Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for anyone to predict the exact course of the disease. Instead, your doctor can give you an idea about the general prognosis for people with the same type and stage of cancer.

To work out your prognosis and advise you on treatment options, your doctor will consider your test results; the type of cancer; the size of the cancer and how far it has grown into other tissue; whether the cancer has spread to the lymph nodes; how it might respond to treatment; and your age, level of fitness and medical history.

Generally, the earlier stomach or oesophageal cancer is diagnosed, the better the outcome of treatment. If cancer is found after it has spread, it may not respond as well to treatment.

# Key points about diagnosing stomach and oesophageal cancers

---

## Main tests

- An endoscopy is the main test used to diagnose stomach or oesophageal cancer. This allows your doctor to look inside the lining of the digestive tract and take tissue samples (known as biopsies).
- You may have an endoscopic ultrasound (EUS) to show how far the cancer has spread into the oesophageal or stomach wall or lymph nodes.
- A pathologist examines the tissue sample under a microscope to find out more about the cells. This shows if cancer is present and how quickly it is growing.

---

## Other tests

Other tests can give more information about the cancer. These tests may include:

- imaging scans (CT or PET-CT) to show whether the cancer has spread from the stomach or oesophageal wall
- a laparoscopy to see whether the cancer has spread to the lining of the abdomen or other organs
- endoscopic resection to see if the cancer has spread to the lymph nodes; may also be used to treat cancer
- molecular testing to look for particular features in the cancer cells.

---

## Staging

The cancer will be given a stage to describe how far it has spread in the body. This allows your doctors to recommend the best treatment for you.

---



# 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, or you might be anxious to get started.

Check with your specialist how soon treatment should begin, as it may not affect the success of the treatment to wait a while. Ask them to explain the options, and take as much time as you can before making a decision.

**Know your options** – Understanding the disease, the available treatments, possible side effects and any extra costs can help you weigh up the options and make a well-informed decision. Check if the specialist is part of a multidisciplinary team (see page 12) and if the treatment centre is the most appropriate one for you – you may be able to have treatment closer to home, or it might be worth travelling to a centre that specialises in a particular treatment.

**Record the details** – When your doctor first says you have cancer, you may not remember everything you are told. Taking notes can help, or you might like to ask if you can record the discussion. It is a good idea to have a family member or friend go with you to appointments to join in the discussion, write notes or simply listen.

**Ask questions** – If you are confused or want to check anything, it is important to ask your specialist questions. Try to prepare a list before appointments (see page 60 for suggestions). If you have a lot of questions, you could talk to a cancer care coordinator or nurse.



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

**It's your decision** – Adults have the right to accept or refuse any treatment that they are offered. For example, some people with advanced cancer choose treatment that has significant side effects even if it gives only a small benefit for a short period of time. Others decide to focus their treatment on quality of life. You may want to discuss your decision with the treatment team, GP, family and friends.

► See our *Cancer Care and Your Rights* booklet.

## Should I join 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.

You may find it helpful to talk to your specialist, clinical trials nurse or GP, or to get a second opinion. If you decide to take part in a clinical trial, you can withdraw at any time. For more information, visit [australiancancertrials.gov.au](http://australiancancertrials.gov.au).

► See our *Understanding Clinical Trials and Research* booklet.

# Treatment for stomach cancer

Your health care team will recommend treatment based on where the cancer is in the stomach, and whether it has spread (the stage). Treatment will also depend on your age, medical history, nutritional needs and general health.

Surgery is often part of the treatment for stomach cancer that has not spread. For some people with very early stomach cancer, an endoscopic resection may be the only treatment needed. If the cancer has spread, treatment may also include chemotherapy, targeted therapy, immunotherapy or radiation therapy.

- ▶ See our booklets on surgery, chemotherapy and radiation therapy, and fact sheets on targeted therapy and immunotherapy.

## What to do before treatment starts

---

### **Improve diet and nutrition –**

People with stomach cancer often lose a lot of weight and can become malnourished. Your doctor will usually refer you to a dietitian for advice on how to slow down the weight loss by changing your diet, taking liquid supplements or having a feeding tube (see page 27). This will help improve your strength, reduce side effects, and may mean the treatment works better.

### **Stop smoking –**

If you smoke, aim to quit before starting treatment. If you keep smoking, you may not respond as well to treatment. For support, see your doctor or call the Quitline on 13 7848.

### **Begin or continue an exercise**

**program –** Exercise will help build up your strength for recovery. Talk to your doctor or physiotherapist about the right type of exercise for you.

---

## Endoscopic resection for stomach cancer

Very early-stage tumours in the inner layers of the stomach (mucosa) may be removed with an endoscope through endoscopic resection (ER). Endoscopic mucosal resection (EMR) and endoscopic submucosal dissection (ESD) are two types of endoscopic resection.

For some people, an endoscopic resection may be the only treatment they need. This procedure usually means staying overnight in hospital. Preparation and recovery are similar to an endoscopy (see pages 14–15), but there is a slightly higher risk of bleeding or getting a small tear or hole in the stomach (perforation).

## Surgery for stomach cancer

Surgery aims to remove all of the stomach cancer while keeping as much of the stomach as possible. This may involve having several procedures during the operation. The surgeon will also remove some healthy tissue around the cancer to reduce the risk of the cancer returning. Different types of surgery can be used. The type you have will depend on where the cancer is in the stomach.

### How the surgery is done

The surgery will be done under a general anaesthetic. There are two ways to perform surgery for stomach cancer:

- in a laparotomy (open surgery), the surgeon makes a long cut in the upper part of the abdomen from the breastbone to the bellybutton
- in a laparoscopic surgery (minimally invasive or keyhole surgery), the surgeon will make some small cuts in the abdomen, then insert a thin instrument with a light and camera (laparoscope) into one of the cuts. The surgeon puts tools into the other cuts and performs the surgery using the images from the camera for guidance.

Laparoscopic surgery usually means a smaller scar, which means the hospital stay is shorter and the recovery faster, but it's not always possible to have this type of surgery. Open surgery may be considered a better option in many situations.

## Types of surgery

**Subtotal or partial gastrectomy** – Only part of the stomach is removed when the cancer is in the lower part of the stomach. Nearby fatty tissue (omentum) and lymph nodes are also removed. The upper stomach and oesophagus are usually left in place.

**Total gastrectomy** – The whole stomach is removed when the cancer is in the upper or middle part of the stomach. Nearby fatty tissue (omentum), lymph nodes and parts of nearby organs, if necessary, are also removed. The surgeon rejoins the oesophagus to the small bowel.

**Lymphadenectomy (lymph node dissection)** – As the cancer might have spread to nearby lymph nodes, your doctor will also remove some lymph nodes from around your stomach. This reduces the risk of the cancer coming back and helps a specialist doctor called a pathologist more accurately work out the stage of the cancer.

## Risks of stomach surgery

As with any major operation, surgery for stomach cancer has risks. Your surgeon will talk to you about the risks and complications of stomach surgery. These may include infection, bleeding, damage to nearby organs, or leaking from the joins between the small bowel and either the oesophagus or stomach. Some people's heartbeat can become irregular, but this usually settles in a few days. You will be carefully monitored for any side effects. For more information on what to expect after surgery, see pages 28–29.

## Having a feeding tube

---

Before or after surgery, you may need a feeding tube to help you manage issues with eating and drinking, and get the nutrition you need.

You may receive all of your nutrition through this tube, or it may be used to supplement the food you eat.

### When feeding tubes are used

Some people with stomach or oesophageal cancer will have a feeding tube before treatment to help them maintain their weight and build up their strength.

Other people will have a feeding tube after surgery until they are able to eat and drink normally. You can be given specially prepared feeding formula through this tube. If you go home with the feeding tube in place, a dietitian will let you know the type and amount of feeding formula you need to take.

### How feeding tubes help

Many people find that having a feeding tube makes eating easier and less uncomfortable. Medicines can also be given through some feeding tubes, although you cannot do this with very small feeding tubes because they may become blocked.

### How feeding tubes are placed

A feeding tube can be placed into your small bowel either through a nostril (nasojejun tube) or with an operation that places a tube through the skin of your abdomen (jejunostomy or J-tube).

### How to care for a feeding tube

Your treatment team will show you how to care for the tube to keep it clean and prevent leaking and blockages, and when to replace the tube. You can avoid getting infections by washing your hands before using the tube, and keeping the tube and your skin dry.

Your doctor will remove the feeding tube when it is no longer required.

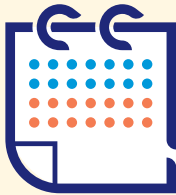
### How to cope with a feeding tube

Having a feeding tube is a major change and it's common to have a lot of questions. Getting used to having a feeding tube takes time. For information, talk to a dietitian or nurse. A counsellor or psychologist can provide emotional support and coping strategies. You can also call Cancer Council 13 11 20 for information and support.

## What to expect after surgery

This is a general overview of what to expect. The process varies from hospital to hospital, and everyone will respond to surgery differently.

### Recovery time



- When you wake up after the operation, you will be in a recovery room near the operating theatre or in the intensive care unit.
- Most people will need a high level of care. You can expect to spend time in the high dependency unit or intensive care unit before moving to a standard ward.
- How long you stay in hospital will depend on the type of stomach surgery you had, your age and your general health.
- You will probably be in hospital for 3–10 days, but it can take 3–6 months to fully recover from a gastrectomy.
- Talk to your treatment team if you have any concerns about caring for yourself at home. If you think you will need home nursing care, ask about services in your area.

### Help with your recovery



- You will have some pain and discomfort for several days after surgery, which will be managed with pain medicines. You may be given tablets or injections, or you may have patient-controlled analgesia (PCA), which delivers a measured dose of pain medicine through a drip when you press a button.
- Let your doctor or nurse know if you're in pain so they can adjust your medicines to make you as comfortable as possible. Do not wait until the pain is severe.
- You may have a dressing over the wound. The doctor or nurse will talk to you about how to keep the wound clean and free from infection when you go home.
- After surgery you will have several tubes in your body, which will be removed as you recover. You may have a drip in your arm to give you pain relief and to replace your body's fluids until you are able to drink and eat again. You may have a tube from your bladder (catheter) to collect urine in a bag. You may also have a feeding tube.

## Eating and drinking



- You will be unable to eat or drink straight after surgery.
- When you can eat again, you will usually start with milk, soup, yoghurt and ice-cream. Then you will move to pureed foods and then to soft foods. This process happens over a number of weeks. Your treatment team will let you know when you are ready for more solid food.
- Eating 6–8 small meals or snacks throughout the day is easier to manage than a few large meals. Ask the hospital dietitian for advice about meal and snack ideas and whether you need to take any nutritional supplements.
- A feeding tube may be put into the small bowel through a cut in the abdomen (see page 27). Special feeding formula is given through this tube while the join between the oesophagus and small bowel heals. The tube is usually removed after 3–4 weeks.
- For more information about eating after surgery, see pages 45–51.

## Activity and exercise



- Your treatment team will probably encourage you to walk the day after surgery. Gentle exercise has been shown to help people manage some treatment side effects, speed up a return to usual activities and improve quality of life. Ask your doctor or nurse for guidance on the right activity levels for you and if there are any suitable exercise programs available in your area.
- You will have to wear compression stockings for a couple of weeks to help the blood in your legs circulate and reduce the risk of developing blood clots.
- Check whether you need to avoid driving and heavy lifting for a few weeks after the surgery.
- A physiotherapist will teach you breathing or coughing exercises to help keep your lungs clear and reduce the risk of a chest infection.

## Chemotherapy for stomach cancer

Chemotherapy uses drugs to kill or slow the growth of cancer cells.

For stomach cancer, it is used:

- **before surgery (neoadjuvant chemotherapy)** – to shrink large tumours and destroy any cancer cells that may have spread
- **after surgery (adjuvant chemotherapy)** – to reduce the chance of the cancer coming back
- **as palliative treatment** – to help control the cancer and improve quality of life and prolong overall survival (see page 33).

Chemotherapy is usually given by injecting the drug into a vein in the arm. It may also be given through a tube that is implanted and stays in your vein throughout treatment (called a port-a-cath or PICC line), or as tablets you swallow. You will usually receive treatment as an outpatient.

Most people have a combination of chemotherapy drugs over several treatment sessions, with rest periods of 2-3 weeks in-between. Together, the session and rest period are called a cycle. Your doctor will talk to you about how long your treatment will last.

### Side effects of chemotherapy

The side effects of chemotherapy vary and depend on the drugs you receive. Your medical oncologist or nurse will discuss the likely side effects with you. Most side effects are temporary, and steps can be taken to prevent or reduce their severity.

Side effects may include feeling sick (nausea), vomiting, sore mouth or mouth ulcers, appetite changes and difficulty swallowing (see pages 46–47), skin and nail changes, numbness in the hands or feet, ringing in the ears or hearing loss, constipation or diarrhoea, and hair loss or thinning. You may also be more likely to catch infections.



*“I found it really beneficial to participate in a clinical trial looking at what combination of treatment worked best for stomach cancer. The treatment path I trialled was preoperative chemotherapy, a total gastrectomy, and postoperative chemotherapy.”* PETE

## Targeted therapy for stomach cancer

This is a type of drug treatment that attacks specific features of cancer cells to stop the cancer growing and spreading.

HER2 (human epidermal growth factor receptor 2) is a protein that causes cancer cells to grow. If you have HER2 positive advanced stomach or gastro-oesophageal junction cancer, you may be given a targeted therapy drug called trastuzumab. This drug destroys the HER2 positive cancer cells or slows their growth. Trastuzumab is given with chemotherapy every three weeks through a drip into a vein.

Another targeted therapy drug called ramucirumab aims to reduce the blood supply to a tumour to slow or stop its growth. It has been approved to treat advanced stomach or gastro-oesophageal junction cancer that has not responded to chemotherapy.

## Side effects of targeted therapy

Ask your doctor what side effects you may experience. Possible side effects of trastuzumab include fever and nausea. In some people, trastuzumab can affect the way the heart works. Possible side effects of ramucirumab include stomach cramps, diarrhoea and high blood pressure. Let your doctor know of any side effects immediately.



You may be able to access other new drugs to treat stomach cancer through clinical trials (see page 23). Talk to your doctor about the latest developments and whether there are any suitable clinical trials for you.

## **Immunotherapy for stomach cancer**

There have been some advances in treating advanced stomach cancer with immunotherapy drugs known as checkpoint inhibitors. These use the body's own immune system to fight cancer.

Checkpoint inhibitors have been approved for use with chemotherapy as the first treatment for people with advanced stomach cancer that has high levels of the protein PD-L1. Checkpoint inhibitors may also be used when chemotherapy hasn't worked or when the tumour has a high level of the marker MSI.

### **Side effects of immunotherapy**

The side effects of immunotherapy can vary – not everyone will experience the same effects. Immunotherapy can cause redness, swelling (inflammation) or pain in any of the organs of the body, leading to common side effects such as fatigue, skin rash and diarrhoea. The inflammation can lead to more serious side effects in some people, but this will be monitored closely and managed quickly.

## **Radiation therapy for stomach cancer**

Also known as radiotherapy, this treatment uses a controlled dose of radiation, such as focused x-ray beams, to kill or damage cancer cells (for more information, see pages 39–40). Radiation therapy for stomach cancer is commonly used to control symptoms of pain, difficulty swallowing or bleeding. It is usually given as a short course

(between one day and two weeks). Occasionally radiation will be given over a longer period (5–6 weeks), either before or after surgery, or if surgery is not possible.

Each treatment takes about 15 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 let you know your treatment schedule. Possible side effects include fatigue, nausea, vomiting, diarrhoea and loss of appetite.

## Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care. Many people think that palliative treatment is for people at the end of life, but it may help at any stage of advanced stomach cancer. It is about helping you live for as long as possible in the most satisfying way you can.

The treatment you are offered will be tailored to your individual needs, and may include surgery, stenting (see page 43), radiation therapy, chemotherapy or other medicines. These treatments can help manage symptoms such as pain, bleeding, difficulty swallowing and nausea. They can also slow the spread of the cancer.

Palliative treatment is one aspect of palliative care, in which a team of health professionals help meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

- ▶ See our *Understanding Palliative Care* and *Living with Advanced Cancer* booklets, and *The Thing About Advanced Cancer* podcast.

## Key points about treating stomach cancer

---

### Treatment options for early stomach cancer

- Surgery is often part of the treatment. This may involve removing part of the stomach (partial gastrectomy) or all of the stomach (total gastrectomy). The remaining parts of the digestive system are usually stitched together so that food can still be swallowed and digested.
- Most people are in hospital for 3–10 days after surgery. It may take 3–6 months before you can return to your usual activities.
- Often chemotherapy is recommended before surgery (neoadjuvant).
- Some small tumours may be removed using a long, flexible tube (endoscopic resection).

---

### Treatment options for advanced stomach cancer

- Some people have chemotherapy and/or radiation therapy before or after surgery to reduce the chance of the cancer coming back.
- If you have advanced stomach or gastro-oesophageal cancer, you may be given a targeted therapy or immunotherapy drug.
- Advanced stomach cancer can be treated palliatively with surgery, radiation therapy, chemotherapy or other medicines to help ease symptoms.

---

### Treatment side effects

- All treatments can cause side effects such as pain, nausea, fatigue, difficulty eating or skin redness.
  - Most side effects are temporary, but some may last longer or be ongoing.
  - Talk to your doctor about how to manage any side effects.
-

# Treatment for oesophageal cancer

The most important factor in planning treatment for oesophageal cancer is the stage of the disease. Your treatment will also depend on your age, nutritional needs, medical history and general health.

Treatment options for oesophageal cancer include surgery, radiation therapy and chemotherapy, either alone or in combination. Treatment will be tailored to your specific situation.

- ▶ See our booklets on surgery, radiation therapy and chemotherapy, and our fact sheet on immunotherapy.

## What to do before treatment

Your doctor will tell you how to prepare for surgery. For example, if you have lost a lot of weight, you may need to see a dietitian, or if you smoke, you may need support to quit (see page 24).

## Endoscopic resection for oesophageal cancer

Very early-stage tumours in the lining of the oesophageal wall (mucosa) may be removed with an endoscope through endoscopic resection (ER). For some people, an endoscopic resection may be the only treatment they need.

This procedure is often done as a day procedure but occasionally needs an overnight stay in hospital. Preparation and recovery are similar to an endoscopy (see pages 14–15), but there is a slightly higher risk of bleeding or getting a small tear or hole in the oesophagus (perforation).

## Surgery for oesophageal cancer

When oesophageal cancer is inside the oesophageal wall, surgery is often recommended as long as you are well enough.

Surgery aims to remove all of the cancer while keeping as much normal tissue as possible. The surgeon will also remove some healthy tissue around the cancer to reduce the risk of the cancer coming back. You may have an endoscopic resection or an oesophagectomy depending on where the tumour is growing and how advanced the cancer is.

### How the surgery is done

To remove the cancer, the surgery can be done in two ways:

- in open surgery, the surgeon will make a large cut in the chest and the abdomen
- in laparoscopic surgery (minimally invasive or keyhole surgery), the surgeon will make some small cuts in the abdomen and/or between the ribs, then insert a thin instrument with a light and camera (laparoscope) into one of the cuts to see inside the body. Sometimes a small cut is made at the base of the neck on the left side. This may be used to join the oesophagus and stomach back together.

Laparoscopic surgery usually means a smaller scar, which means the hospital stay is shorter and the recovery faster, but it's not always possible to have this type of surgery. Open surgery may be considered a better option in many situations.



Surgery for oesophageal cancer is complex. Surgeons that regularly perform this type of surgery have better outcomes, which means you might need to travel to a specialist centre to have surgery. Call Cancer Council 13 11 20 to ask about patient travel assistance that may be available.

## Oesophagectomy (surgical resection)

Surgery to remove part or all of the oesophagus is called oesophagectomy. Nearby affected lymph nodes are also removed. It is common to have chemotherapy and/or radiation therapy before surgery, as this approach has been shown to have better results.

Depending on where in the oesophagus the cancer is, the surgeon may also remove part of the upper stomach. This is the preferred option for cancer that has spread deeper into the wall of the oesophagus or to nearby lymph nodes.

Once the parts with cancer have been removed, the stomach is pulled up and rejoined to the healthy part of the oesophagus. This will allow you to swallow and, in time, eat relatively normally. If the oesophagus cannot be rejoined to the stomach, the oesophagus will be connected to the small bowel, or a part of the bowel will be used to replace the part of the oesophagus that was removed. These procedures will help you swallow.

## Risks of oesophageal surgery

As with any major surgery, oesophageal surgery has risks. These may include infection, bleeding, blood clots, damage to nearby organs, leaking from the joins between the oesophagus and stomach or small bowel, pneumonia (see next page) and voice changes. Some people may have an irregular heartbeat, but this usually settles within a few days.

Surgical scars can narrow the oesophagus (known as oesophageal stricture) and make it difficult to swallow. If the oesophagus becomes too narrow, your doctor may need to stretch the walls of the oesophagus (dilatation). For some people, this procedure may need to be repeated several times. Your surgeon will discuss these risks with you before surgery, and you will be carefully monitored for any side effects.

## What to expect after oesophageal surgery

Recovery after oesophageal surgery is similar to stomach surgery (see pages 28–29), but there are some differences. For more information, see *Managing side effects* on pages 45–51.

### Recovery time



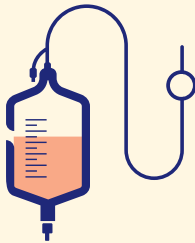
You will probably be in hospital for 7–10 days, but you may stay longer if you have any complications. It may take 6–12 months to feel completely better after an oesophagectomy.

### Eating and drinking



Immediately after oesophageal surgery, you will not be able to eat or drink. Often a temporary feeding tube is inserted at the time of the surgery (see page 27). Once you begin eating, it is common to start with fluids such as soup, and then move onto pureed and then soft foods for a few weeks. It is best to eat 5–6 small meals or snacks throughout the day.

### Drips and drains



You'll have a feeding tube (see page 27) to get the nutrition you need and another tube (nasogastric tube) to drain fluids from the stomach. The tubes will be removed before you leave hospital.

### Breathing problems

Controlling pain will help avoid problems with breathing that can lead to pneumonia. A physiotherapist can teach you breathing or coughing exercises to help keep your lungs clear. You may also be taught how to use an incentive spirometer, a device you breathe into to help your lungs expand and prevent a chest infection.



## Radiation therapy for oesophageal cancer

Also known as radiotherapy, this treatment uses a controlled dose of radiation, such as focused x-ray beams, to kill or damage cancer cells. The radiation is targeted at the cancer, and treatment is carefully planned to do as little harm as possible to healthy body tissue near the cancer.

Radiation therapy may be given alone or combined with chemotherapy (see chemoradiation below). Chemoradiation is often used before surgery to shrink large tumours and destroy any cancer cells that may have spread. If you have chemoradiation, you'll have a break of 4–12 weeks between radiation therapy and surgery to allow the treatment to have its full effect. Radiation therapy, with or without chemotherapy, is used as the main treatment for oesophageal cancer that has not spread to other parts of the body and cannot be removed surgically.

Before starting treatment, you will have a planning appointment that will include a CT scan. The technician may make some small

## Chemoradiation for oesophageal cancer

Treatment with radiation therapy and chemotherapy is known as chemoradiation. The chemotherapy drugs make the cancer cells more sensitive to radiation therapy.

Oesophageal cancer may be treated with chemoradiation before surgery to shrink the cancer and make it easier to remove. Chemoradiation may also be used as the main

treatment when the tumour can't be removed safely with surgery, or if the doctor thinks the risk with surgery is too high.

If you have chemoradiation, you will usually have chemotherapy a few hours before some radiation therapy appointments. Your doctor will talk to you about the treatment schedule and how to manage any side effects.

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 4–5 weeks. If radiation therapy is used palliatively (see page 43), you may have a short course of 1–10 sessions. Each treatment takes about 20 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 let you know your treatment schedule.

## Side effects of radiation therapy

Some people will develop temporary side effects during or shortly after treatment. The lining of the oesophagus can become sore and inflamed (oesophagitis). This can make swallowing and eating difficult. In rare cases, you may need a temporary feeding tube (see page 27) to help you get enough nutrition. Other possible side effects include fatigue, skin redness, loss of appetite and weight loss. Most side effects improve within four weeks of treatment finishing.

Very rarely, long-term side effects can develop. The oesophagus can develop scar tissue and get narrower (known as oesophageal stricture). Stretching the walls of the oesophagus (dilatation) can make it easier to swallow food and drink. Radiation therapy can also cause irritation and swelling (inflammation) in the lungs, causing shortness of breath.

*“My diagnosis of oesophageal cancer came as a complete shock. I had chemotherapy and radiation therapy to shrink the tumour, and then went home to recover for six weeks before surgery.”* JOHN

## Chemotherapy for oesophageal cancer

Chemotherapy uses drugs to kill or slow the growth of cancer cells. The aim is to destroy cancer cells, while causing the least possible damage to healthy cells. Chemotherapy for oesophageal cancer may be given alone or it may be combined with radiation therapy (see *Chemoradiation for oesophageal cancer* on page 39).

For oesophageal cancer, chemotherapy may be used:

- **before surgery (neoadjuvant chemotherapy)** – to shrink a large tumour and destroy any cancer cells that may have spread
- **after surgery (adjuvant chemotherapy)** – to reduce the chance of the disease coming back
- **on its own (palliative treatment)** – for people unable to have surgery or where cancer has spread to different parts of the body.

Chemotherapy is usually given by injecting the drugs into a vein in the arm. It may also be given through a tube that is implanted and stays in your vein throughout treatment (called a port-a-cath or PICC line), or as tablets you swallow. You will usually receive treatment as an outpatient.

Most people have a combination of chemotherapy drugs over several treatment sessions. For each session, the drugs may be given on one day, or continuously over several days using a small pump that is attached to the implanted tube. There may be a rest period of a few weeks between each treatment session.

### Side effects of chemotherapy

How you react to chemotherapy will vary, depending on the drugs you receive, how often you have treatment, and your general fitness and health. Some people have few side effects, while others have many. Most side effects are temporary, but some may last longer or be ongoing.

Your treatment team can help you prevent or manage any side effects. Common side effects may include nausea and/or vomiting, sore mouth or mouth ulcers, appetite changes and difficulty swallowing (see pages 46–47), skin and nail changes, numbness or tingling in the hands or feet, ringing in the ears or hearing loss, changed bowel habits (e.g. constipation, diarrhoea), and hair loss or thinning. You may also be more likely to catch infections. If you feel unwell or have a temperature of 38°C or higher, seek urgent medical attention.

## **Immunotherapy for oesophageal cancer**

There have been some advances in treating advanced oesophageal cancer with immunotherapy drugs known as checkpoint inhibitors. These use the body's own immune system to fight cancer.

Clinical trials (see page 23) are testing checkpoint inhibitors for oesophageal cancer after surgery (adjuvant treatment). Checkpoint inhibitors are also given to some people with advanced oesophageal cancer as a first-line treatment together with chemotherapy. New immunotherapy drugs are changing rapidly. Talk to your doctor about whether immunotherapy is an option for you.

### **Side effects of immunotherapy**

The side effects of immunotherapy can vary – not everyone will experience the same effects.

Immunotherapy can cause redness, swelling or pain (inflammation) in any of the organs of the body, leading to common side effects such as fatigue, skin rash and diarrhoea. The inflammation can lead to more serious side effects in some people, but this will be monitored closely and managed quickly.

## Palliative treatment

Palliative treatment helps to improve people's quality of life by managing the symptoms of cancer without trying to cure the disease. It is best thought of as supportive care. Many people think that palliative care is for people at the end of life, but it can help at any stage of advanced oesophageal cancer.

Treatments will be tailored to your individual needs. For example, radiation therapy can help to relieve pain and make swallowing easier by helping to shrink a tumour that is blocking the oesophagus. Palliative treatments can also slow the spread of the cancer.

Palliative treatment is one aspect of palliative care, in which a team of health professionals help meet your physical, emotional, cultural, spiritual and social needs. The team also supports families and carers.

▶ See our *Understanding Palliative Care* booklet.

## Having a stent

People with advanced oesophageal cancer who are having trouble swallowing and do not have any other treatment options may have a flexible tube (stent) inserted into the oesophagus.

The stent expands the oesophagus to allow fluid and soft 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. Stents can cause indigestion (heartburn) and discomfort. Occasionally, the stents will move down the oesophagus into the stomach and may need to be removed. For more information about eating and swallowing, see pages 45-47.

## Key points about oesophageal cancer

---

### Treatment options for early oesophageal cancer

- Surgery is often used to treat oesophageal cancer that is found only in the oesophageal wall lining. This may involve removing part or all of the oesophagus (oesophagectomy). The remaining parts of the digestive system are usually stitched together so that food can be swallowed. It's common to have chemotherapy and/or radiation therapy before surgery.
- Some small early-stage tumours may be removed using a flexible tube (endoscopic resection) without removing the oesophagus.

### Treatment options for advanced oesophageal cancer

- People commonly have radiation therapy and/or chemotherapy before surgery. Radiation therapy, with or without chemotherapy, is also used as the main treatment for oesophageal cancer that cannot be removed surgically.
- You may have palliative treatment to manage the symptoms of advanced cancer. This may include inserting an oesophageal stent to help with swallowing.

### Treatment side effects

- All treatments can cause side effects. Most side effects are temporary. Talk to your doctor about how to manage any side effects.
- Surgery will affect how you eat and digest food. You'll need time to get used to these changes. A dietitian can help with your recovery.
- Radiation therapy can cause side effects, such as oesophagitis, which can make swallowing and eating harder.
- Chemotherapy can cause a range of side effects depending on the drugs you have. Common side effects include nausea and a sore mouth.

# Managing side effects

Stomach and oesophageal cancers and their treatment can cause side effects. Some of these side effects are permanent and may change what you can eat, and how you digest foods and absorb essential nutrients. This chapter explains common side effects and how to manage them.

## How treatment will affect eating

During and after treatment, you need to eat and drink enough to get the nutrition you need, maintain your weight and avoid dehydration. If you are eating less than usual, it is often recommended that you have high energy and high protein foods and relax healthy eating guidelines. You may need a feeding tube during or after treatment if you are unable to eat and drink enough to meet your nutritional needs (see page 27). Ask your doctor for a referral to a dietitian with experience in cancer care, who can give you more information.

After treatment, some foods may be uncomfortable to eat and may cause digestive problems. You will need to try different foods and change your eating habits, such as eating smaller meals more often throughout the day.

You may find it hard to accept the differences in how and what you can eat. It's natural to feel self-conscious or worry about eating in public or with friends. It may help to let your family and friends know how you feel, or to 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 adapt to your new way of eating.

► See our *Nutrition and Cancer* booklet.

## Poor appetite and weight loss

After surgery, your stomach will be smaller (or completely removed) and you will feel full more quickly after a meal. You may not feel like eating or you may have lost your sense of taste. It is important to maintain your weight to avoid malnutrition. Even a small drop in your weight (e.g. 3–4 kg), particularly over a short period of time, can make your recovery slower.

Chemotherapy and radiation therapy can cause nausea, irritation to the oesophagus or a sore mouth. These side effects may make eating uncomfortable.



### How to prevent unplanned weight loss

- Have a snack or small meal every 2–3 hours if you have lost your appetite and don't feel hungry.
- Keep a variety of snacks handy (e.g. in your bag or car).
- Eat when you feel hungry or crave certain foods. Eat slowly and stop and rest when you are full.
- Avoid filling up on liquids at mealtimes, unless it's a hearty soup, so you have room for nourishing food.
- Try to drink fluids that add energy (kilojoules), such as milk, milkshakes, smoothies or nutritional supplement drinks recommended by your dietitian.
- Prevent dehydration by drinking fluids between meals (30–60 minutes before or after meals).
- Try eating different foods to see if your taste and tolerance for some foods have changed.
- Ask your dietitian how you can increase your energy and protein intake.
- Don't eat for a few hours before bed. It may make you uncomfortable, bring on reflux and disturb your sleep.



## Swallowing difficulties

You may have difficulty swallowing (dysphagia) before, during or after treatment. This may be because of where the tumour is or because of swelling in the oesophagus after surgery. Signs that swallowing is difficult include taking longer to chew and swallow, coughing or choking while eating or drinking, or food sticking in your mouth or throat like a ball. These symptoms should ease after 10–12 weeks.

Some people find that food and fluid goes into the windpipe instead of the food pipe. This is called aspiration and it can block the airways and make breathing difficult.



### How to eat when it is hard to swallow

- Change the consistency of what you eat by chopping, mincing or pureeing.
- Make food softer (e.g. mash food or use a slow cooker) to keep it moist.
- Between meals, snack on soft foods, such as avocado, yoghurt, ice-cream, diced tinned fruit and drink milkshakes.
- Chew carefully and slowly, sitting still and upright. Try to avoid talking while eating.
- Avoid dry foods – add extra gravy or sauce to your meals.
- Wash food down with small sips of fluid.
- Talk to your doctor or dietitian if you are losing weight. They can help you find foods that give you enough nutrition and help you maintain your weight.
- See a speech pathologist for suggestions on the types of foods to include and ways to eat and drink safely.
- Add nutritional supplement drinks to your diet to help maintain your strength. Examples include Sustagen, Resource and Ensure.

## Reflux and choking

Stomach acid going back into the oesophagus (reflux) is common after surgery for oesophageal cancer. This can cause heartburn, chest discomfort, or your stomach contents to flow up your oesophagus, particularly when lying flat or bending over. Taking medicines to reduce stomach acid generally helps.

After surgery or radiation therapy for oesophageal cancer, scar tissue may cause choking or swallowing problems while eating or drinking. See your doctor if this continues. After an oesophagectomy, the stomach can take longer to empty. You may feel full more quickly or be more likely to vomit or bring up food after eating.



### How to reduce reflux and choking

- Limit spicy foods, fatty foods, fizzy drinks, alcohol and citrus fruits to prevent reflux.
- Take small sips of liquid to reduce coughing or choking.
- Chew foods well, eat slowly, and don't talk while eating.
- To help food digest, sit up straight when eating and for at least 30 minutes after.
- Have your main meal earlier in the day and eat a small snack in the evening.
- After an oesophagectomy, stay upright for 2–4 hours after eating. Eat your evening meal more than four hours before going to bed.
- Avoid positions where your head is below your stomach (e.g. when bending over too far), particularly after eating.
- Keep your chest higher than your stomach when sleeping by lifting the head of your bed with blocks about the thickness of a house brick. The whole bed should be tilted slightly.
- Ask your doctor how much physical activity you can do, as this can sometimes cause reflux.

# Dumping syndrome

If surgery has changed the structure of your stomach, partially digested food can go into the small bowel too quickly. This can especially be a problem with fluids containing high amounts of simple sugar, such as soft drinks, juices and cordial. You may have cramps, nausea, racing heart, sweating, bloating, diarrhoea or dizziness. This combination of symptoms 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.



## How to manage dumping syndrome

- Have small meals throughout the day. Chew your food well.
- Eat slowly so your body can sense when it is full.
- Surgery may affect how you tolerate certain foods. Keep a record of foods that cause problems and talk to a dietitian for suggestions on what to eat to reduce the symptoms.
- Avoid eating highly processed foods and eat fresh, unprocessed foods.
- Avoid foods and drinks high in sugar (e.g. cordial, soft drinks, cakes and biscuits). Eating large amounts of these foods can lead to diarrhoea and pain.
- Eat meals high in protein (e.g. lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds and legumes/beans).
- Eat starchy foods (e.g. pasta, rice or potato).
- Drink liquids between meals rather than at mealtimes.
- Symptoms usually improve over time. If they don't, ask your doctor for advice about medicines that may help.

## Anaemia and osteoporosis

Surgery to remove the stomach will mean you will be unable to absorb some vitamins and minerals from food. This may lead to low levels of:

- **calcium** – over time, your bones may become weak and brittle, and break more easily (osteoporosis), which may cause pain
- **vitamin B12** – low B12 levels can cause a condition called pernicious anaemia. The most common symptom is tiredness. Other symptoms include pale skin, breathlessness, headaches, a racing heart and appetite loss. You will need regular vitamin B12 injections after a total gastrectomy, and may need vitamin B12 injections if your levels are low (without having had total gastrectomy)
- **iron** – low iron levels can cause iron deficiency anaemia. You may need iron supplements, which are usually given as an intravenous (IV) infusion because iron taken by mouth can't be absorbed easily.



### Tips for managing anaemia

- Talk to your doctor if you have symptoms of anaemia or osteoporosis.
- Find out what type of anaemia you have and how to treat it.
- Rest when you need to and try not to do too much.
- Eat foods rich in iron, such as meat, eggs and softened dark green leafy vegetables.
- Eat foods high in vitamin C (e.g. red or orange fruits and vegetables) to help your body absorb iron from iron-rich foods, especially plant-based sources.
- Avoid drinking tea and coffee with meals, as these can prevent your body absorbing iron.
- If you smoke, talk to your GP about quitting or call the Quitline on 13 7848 for support and information. Smoking tobacco can make symptoms worse.

## Key points about managing side effects

---

### Common changes

- After treatment for stomach or oesophageal cancer, most people find the way their digestive system works has changed.
- 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 may include reflux, heartburn, coughing and choking. Dumping syndrome is less common.

---

### Managing changes

- Eating several small meals a day slowly, and sitting up during and after meals, can help swallowing and digestion.
- It's best to avoid eating meals late in the day and to wait about four hours after a meal before going to bed.
- You may need a feeding tube before, during or after treatment to provide nutrition while you recover your ability to swallow.
- To avoid dehydration, try to drink fluids in small amounts throughout the day.
- Dietitians can help develop eating plans to suit your individual needs and provide advice about suitable nutritional supplements.
- Talk to your doctor, nurse or dietitian if issues with eating and digestion don't get better, or if you keep losing weight.
- You may feel self-conscious when eating. Talking to a counsellor or someone who has been through a similar experience may help you cope with the changes.

# Looking after yourself

Cancer can cause physical and emotional strain, so it's important to look after your wellbeing. Cancer Council has free booklets and programs to help you during and after treatment. Call 13 11 20 to find out more, or visit your local Cancer Council website (see back cover).

**Eating well** – Healthy food can help you cope with treatment and side effects. See pages 45–51 for information about coping with eating problems after treatment and choosing the best foods for your situation.

▶ See our *Nutrition and Cancer* booklet.

**Staying active** – Physical activity can reduce tiredness, improve circulation and lift mood. The right exercise for you depends on what you are used to, how you feel, and your doctor's advice.

▶ See our *Exercise for People Living with Cancer* booklet.

**Complementary therapies** – Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as massage, relaxation and acupuncture can 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.

▶ See our *Understanding Complementary Therapies* booklet.



Alternative therapies are therapies used instead of conventional medical treatments. These are unlikely to be scientifically tested, may prevent successful treatment of the cancer and can be harmful. Cancer Council does not recommend the use of alternative therapies as a cancer treatment.

**Work and money** – Cancer can change your financial situation, especially if you have extra medical expenses or need to stop working. Getting professional financial advice and talking to your employer can give you peace of mind. You can also check whether any financial assistance is available to you by asking a social worker at your hospital or treatment centre or calling Cancer Council 13 11 20.

▶ See our *Cancer and Your Finances* and *Cancer, Work & You* booklets.

**Relationships** – Having cancer can affect your relationships with family, friends and colleagues in different ways. Cancer is stressful, tiring and upsetting, and this may strain relationships. The experience of having cancer may also result in positive changes to your values, priorities or outlook on life. Give yourself time to adjust to what's happening, and do the same for those around you. It may help to discuss your feelings with each other.

▶ See our *Emotions and Cancer* booklet.

**Sexuality** – 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.

▶ See our *Sexuality, Intimacy and Cancer* booklet.

**Contraception and fertility** – If you have sex, you may need to use certain types of contraception to protect your partner or avoid pregnancy for a time. Your doctor will explain what precautions to take. They will also tell you if treatment will affect your fertility permanently or temporarily. If having children is important to you, discuss the options with your doctor before starting treatment.

▶ See our *Fertility and Cancer* booklet.

# 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 that every ache and pain means the cancer is coming back.

Some people say that they feel pressure to return to "normal life". It is important to allow yourself time to adjust to the physical and emotional changes, and establish a new daily routine at your own pace. Your family and friends may also need time to adjust.

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

► See our *Living Well After Cancer* booklet.

## 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, because counselling or medication – even for a short time – may help. Some people can

get a Medicare rebate for sessions with a psychologist. Cancer Council may also run a counselling program in your area.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit [beyondblue.org.au](http://beyondblue.org.au). For 24-hour crisis support, call Lifeline 13 11 14 or visit [lifeline.org.au](http://lifeline.org.au).



## Follow-up appointments

After treatment ends, you will have regular appointments to monitor your health, manage any long-term side effects and check that the cancer hasn't come back or spread. You will also be able to discuss how you're feeling and any concerns you have. You may have blood tests, imaging scans or an endoscopy if necessary.

How often you will need to see your doctor will depend on the level of monitoring needed for the type and stage of the cancer. Current treatment guidelines do not recommend a set time frame for follow-up tests. You should also see a dietitian for advice about good nutrition. Check-ups will become less frequent if you have no further problems.

When a follow-up appointment or test is approaching, many people find that they think more about the cancer and may feel anxious. Talk to your treatment team or call Cancer Council 13 11 20 if you are finding it hard to manage this anxiety. Between follow-up appointments, let your doctor know immediately of any symptoms or health problems.

## What if the cancer returns?

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

If the cancer returns, you may have further treatment, including chemotherapy, radiation therapy or surgery. Sometimes people have palliative treatment to ease symptoms (see pages 33 and 43). Treatment may be similar to what you had after your initial diagnosis, or you may be offered a different type of treatment if the cancer comes back in another part of your body.

# Seeking support

A cancer diagnosis can affect every aspect of your life. You will probably experience a range of emotions – fear, sadness, anxiety, anger and frustration are all common reactions. Cancer also often creates practical and financial issues.

There are many sources of support and information to help you, your family and carers navigate all stages of the cancer experience, including:

- information about cancer and its treatment
- access to benefits and programs to ease the financial impact of cancer treatment
- home care services, such as Meals on Wheels, visiting nurses and home help
- aids and appliances
- support groups and programs
- counselling services.

The availability of services may vary depending on where you live, and some services will be free but others might have a cost.

To find good sources of support and information, you can talk to the social worker or nurse at your hospital or treatment centre, or get in touch with Cancer Council 13 11 20.



If your GP refers you to an allied health practitioner such as a dietitian or physiotherapist, you may be eligible for a Medicare rebate. Talk to your GP about developing a Chronic Disease Management Plan to help you manage any ongoing issues.

## Support from Cancer Council

Cancer Council offers a range of services to support people affected by cancer, their families and friends. Services may vary by location.

### Cancer Council 13 11 20



Our experienced health professionals will answer any questions you have about your situation and link you to local services (see inside back cover).

### Information resources



Cancer Council produces booklets and fact sheets on more than 25 types of cancer, as well as treatments, emotional and practical issues, and recovery. Call 13 11 20 or visit your local Cancer Council website.

### Legal and financial support



If you need advice on legal or financial issues, we can refer you to qualified professionals. These services are free for people who can't afford to pay. Financial assistance may also be available. Call Cancer Council 13 11 20 to ask if you are eligible.

### Practical help



Cancer Council can help you find services or offer guidance to manage the practical impacts of cancer. This may include helping you access accommodation and transport services.

### Peer support services



You might find it helpful to share your thoughts and experiences with other people affected by cancer. Cancer Council can link you with individuals or support groups by phone, in person, or online. Call 13 11 20 or visit [cancerCouncil.com.au/OC](http://cancerCouncil.com.au/OC).

## Useful websites

You can find many useful resources online, but not all websites are reliable. These websites are good sources of support and information.

### Australian

Cancer Council Australia	<a href="http://cancer.org.au">cancer.org.au</a>
Cancer Council Online Community	<a href="http://cancercouncil.com.au/OC">cancercouncil.com.au/OC</a>
Cancer Council podcasts	<a href="http://cancercouncil.com.au/podcasts">cancercouncil.com.au/podcasts</a>
Guides to Best Cancer Care	<a href="http://cancer.org.au/cancercareguides">cancer.org.au/cancercareguides</a>
Australian and New Zealand Gastric and Oesophageal Surgery Association	<a href="http://anzgosa.org">anzgosa.org</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Carer Gateway	<a href="http://carergateway.gov.au">carergateway.gov.au</a>
Carers Australia	<a href="http://carersaustralia.com.au">carersaustralia.com.au</a>
Department of Health	<a href="http://health.gov.au">health.gov.au</a>
Dietitians Association of Australia	<a href="http://dietitiansaustralia.org.au">dietitiansaustralia.org.au</a>
Healthdirect Australia	<a href="http://healthdirect.gov.au">healthdirect.gov.au</a>
Gastroenterological Society of Australia	<a href="http://gesa.org.au">gesa.org.au</a>
GI Cancer Institute	<a href="http://gicancer.org.au">gicancer.org.au</a>
Pancare Foundation	<a href="http://pancare.org.au">pancare.org.au</a>
Services Australia	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>

### International

American Cancer Society	<a href="http://cancer.org">cancer.org</a>
Cancer Research UK	<a href="http://cancerresearchuk.org">cancerresearchuk.org</a>
Macmillan Cancer Support (UK)	<a href="http://macmillan.org.uk">macmillan.org.uk</a>
No Stomach for Cancer (US)	<a href="http://nostomachforcancer.org">nostomachforcancer.org</a>

# Caring for someone with cancer

You may be reading this booklet because you are caring for someone with cancer. What this means for you will vary depending on the situation. Being a carer can bring a sense of satisfaction, but it can also be challenging and stressful.

It is important to look after your own physical and emotional wellbeing. Give yourself some time out and share your concerns with somebody neutral such as a counsellor or your doctor, or try calling Cancer Council 13 11 20. There is a wide range of support available to help you with the practical and emotional aspects of your caring role.

**Support services** – Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local services, as well as information and resources, through the Carer Gateway. Call 1800 422 737 or visit [carergateway.gov.au](http://carergateway.gov.au).

**Support groups and programs** – Many cancer support groups and cancer education programs are open to carers as well as to people with cancer. Support groups and programs offer the chance to share experiences and ways of coping.

**Carers Australia** – Carers Australia provides information and advocacy for carers. Visit [carersaustralia.com.au](http://carersaustralia.com.au).

**Cancer Council** – You can call Cancer Council 13 11 20 or visit your local Cancer Council website to find out more about carers' services.

▶ See our *Caring for Someone with Cancer* booklet.

## Question checklist

---

Asking your doctor questions will help you make an informed choice. You may want to include some of the questions below in your own list.

---

### Diagnosis

- What type of cancer do I have?
  - Has the cancer spread? If so, where has it spread? How fast is it growing?
  - Are the latest tests and treatments for this cancer available in this hospital?
  - Will a multidisciplinary team be involved in my care?
  - Are there clinical guidelines for this type of cancer?
- 

### Treatment

- What treatment do you recommend? What is the aim of the treatment?
  - Are there other treatment choices for me? If not, why not?
  - If I don't have the treatment, what should I expect?
  - How long do I have to make a decision?
  - I'm thinking of getting a second opinion. Can you recommend anyone?
  - How long will treatment take? Will I have to stay in hospital?
  - Are there any out-of-pocket expenses not covered by Medicare or my private health cover? Can the cost be reduced if I can't afford it?
  - How will I know if the treatment is working?
  - Are there any clinical trials or research studies I could join?
- 

### Side effects

- What are the risks and possible side effects of each treatment?
  - Will I have a lot of pain? What will be done about this?
  - Can I work, drive and do my normal activities while having treatment?
  - Will the treatment affect my sex life and fertility?
  - How will the treatment affect the way I eat and digest food?
  - Should I change my diet or physical activity during or after treatment?
  - Are there any complementary therapies that might help me?
- 

### After treatment

- How often will I need check-ups after treatment? Who should I see?
  - If the cancer returns, how will I know? What treatments could I have?
-

# Glossary

---

## **abdomen**

The part of the body between the chest and hips, which contains the stomach, spleen, pancreas, liver, gall bladder, bowel, bladder and kidneys. Also known as the belly.

## **adenocarcinoma**

A cancer that starts in the mucus-producing (glandular) cells that form part of the lining of internal organs, such as the stomach and oesophagus.

## **advanced cancer**

Cancer that is unlikely to be cured. In most cases, the cancer has spread to other parts of the body (secondary or metastatic cancer). Treatment can often still control the cancer and manage symptoms.

## **anaemia**

A reduction in the number or quality of red blood cells in the body.

---

## **Barrett's oesophagus**

Abnormal changes in the cells that line the lower oesophagus. A risk factor for oesophageal adenocarcinoma.

## **biopsy**

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

---

## **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 that are adapted for different functions.

## **chemotherapy**

A cancer treatment that uses drugs to kill cancer cells or slow their growth. May be given alone or with other treatments.

## **CT scan**

Computerised tomography scan. This scan uses x-rays to create cross-sectional pictures of the body.

---

## **dilatation**

A type of medical procedure. An object (dilator) is inserted into the oesophagus to stretch the walls and widen the opening.

## **dumping syndrome**

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

---

## **endoscope**

A flexible tube with a light and camera on the end. It is used during diagnostic tests, e.g. to examine the oesophagus or stomach during an endoscopy.

## **endoscopic resection (ER)**

A type of procedure for early-stage stomach or oesophageal cancer. Tissue is removed using an endoscope.

## **endoscopy**

A type of internal examination or diagnostic test. A thin, flexible tube with a light and camera (endoscope) is used to examine the inside of the body. Also called gastroscopy.

---

## **gastrectomy**

The surgical removal of part or all of the stomach.

## **gastrointestinal (GI) tract**

The passage from the mouth to the anus that allows a person to digest food and eliminate waste. The upper GI tract includes the oesophagus and stomach.

## **gastro-oesophageal junction**

The point where the stomach meets the oesophagus.

---

### **gastro-oesophageal reflux disease (GORD)**

A condition where stomach acid leaks into the oesophagus, causing irritation. This is caused by the muscle at the end of the oesophagus not closing properly.

### **gastroscopy**

See endoscopy.

---

### **heartburn (indigestion)**

A sensation of tightness or burning in the chest. Heartburn is caused by stomach acid being released back up into the oesophagus and throat (reflux).

### **HER2**

Human epidermal growth factor receptor 2. A type of protein that is involved in cell growth.

---

### **immunotherapy**

Drugs that use the body's own immune system to fight cancer.

---

### **laparoscopy/laparoscopic surgery**

Surgery done through small cuts in the abdomen using a thin viewing instrument called a laparoscope. Also called keyhole or minimally invasive surgery.

### **laparotomy**

A type of open surgery in which a long cut is made in the abdomen to examine and remove internal organs.

### **lymphatic system**

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

### **lymph nodes**

Small, bean-shaped structures found in groups throughout the body. They help protect the body against disease and infection. Also called lymph glands.

---

### **malignant**

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

### **metastasis (plural: metastases)**

Cancer that has spread from a primary cancer in another part of the body. Also known as secondary or advanced cancer.

### **mucosa**

Moist tissue that lines organs of the body. The mucosal layer is the innermost layer of the oesophagus and stomach.

---

### **nutrition**

The process of eating and digesting the food that the body needs.

---

### **oesophagectomy**

The surgical removal of part or all of the oesophagus.

### **oesophagitis**

Inflammation or loss of tissue in the lining of the oesophagus.

### **oesophagoscopy**

The examination of the oesophagus with an endoscope.

### **oesophagus**

The food pipe. The passage that carries food from the throat into the stomach.

### **omentum**

A protective apron of fatty tissue over the abdominal organs.

---

### **palliative treatment**

Medical treatment for people with advanced cancer to help them manage physical and emotional symptoms.

### **pelvis**

The lower part of the trunk of the body: roughly, the area that extends from hip to hip and waist to groin.



### **pernicious anaemia**

A type of anaemia. It is caused by vitamin B12 not being absorbed, which affects the development of red blood cells.

### **PET-CT scan**

Positron emission tomography scan combined with a CT scan. In a PET scan, a person is injected with a small amount of radioactive glucose solution. This makes cancerous areas show up brighter.

---

### **radiation therapy**

The use of targeted radiation to kill or damage cancer cells so they cannot grow, multiply or spread. The radiation is usually in the form of x-ray beams. Also called radiotherapy.

### **reflux**

When stomach acid flows up into the oesophagus.

---

### **squamous cell carcinoma (SCC)**

Cancer that starts in the squamous cells, which are flat cells found on the surface of the skin or in the lining of certain organs, such as the oesophagus.

### **staging**

Performing tests to work out how far a cancer has spread.

### **stent**

A metal or plastic tube placed into a blocked organ to create a passage for substances to pass through.

### **stomach**

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

### **subtotal gastrectomy**

The surgical removal of part of the stomach.

---

### **targeted therapy**

Drugs that attack features of cancer cells to stop the cancer growing and spreading.

### **total gastrectomy**

The surgical removal of the whole stomach.

---

### **Can't find a word here?**

For more cancer-related words, visit:

- [cancercouncil.com.au/words](http://cancercouncil.com.au/words)
- [cancervic.org.au/glossary](http://cancervic.org.au/glossary)

---

## **References**

1. EC Smyth et al. on behalf of the ESMO Guidelines Committee, "Gastric cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 27, suppl. 5, 2016, pp. v38-v49 (incorporating ESMO Guidelines Committee, *eUpdate - Gastric Cancer Treatment Recommendations*, 4 November 2019).
2. F Lordick et al. on behalf of the ESMO Guidelines Committee, "Oesophageal cancer: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up", *Annals of Oncology*, vol. 27, suppl. 5, 2016, pp. v50-v57.
3. Australian Institute of Health and Welfare (AIHW), *Cancer Data in Australia*, viewed 26 May 2021, available from [aihw.gov.au/reports/cancer/cancer-data-in-Australia](http://aihw.gov.au/reports/cancer/cancer-data-in-Australia).



# 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 other Pink events, 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.



# Cancer Council

## 13 11 20

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 experienced health professionals 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.



If you need information in a language other than English, an interpreting service is available. Call 131 450.



If you are deaf, or have a hearing or speech impairment, you can contact us through the National Relay Service. [communications.gov.au/accesshub/nrs](https://communications.gov.au/accesshub/nrs)

---

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

For information & support  
on cancer-related issues,  
call **Cancer Council 13 11 20**

## Visit your local Cancer Council website

---

**Cancer Council ACT**  
[actcancer.org](http://actcancer.org)

**Cancer Council NSW**  
[cancercouncil.com.au](http://cancercouncil.com.au)

**Cancer Council NT**  
[cancer.org.au/nt](http://cancer.org.au/nt)

**Cancer Council Queensland**  
[cancerqld.org.au](http://cancerqld.org.au)

**Cancer Council SA**  
[cancersa.org.au](http://cancersa.org.au)

**Cancer Council Tasmania**  
[cancer.org.au/tas](http://cancer.org.au/tas)

**Cancer Council Victoria**  
[cancervic.org.au](http://cancervic.org.au)

**Cancer Council WA**  
[cancerwa.asn.au](http://cancerwa.asn.au)

**Cancer Council Australia**  
[cancer.org.au](http://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.*

