



Understanding Stomach and Oesophageal Cancers

A guide for people with cancer,
their families and friends

Cancer
information

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13 11 20



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Note to reader

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

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

Cancer Council

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



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Introduction

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. We also include information about support services.

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

This booklet contains separate information for stomach cancer and oesophageal cancer – just read the parts that are useful to you. 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. This booklet is based on international clinical practice guidelines.^{1,2}

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



**Cancer
Council**
13 11 20

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What is cancer?

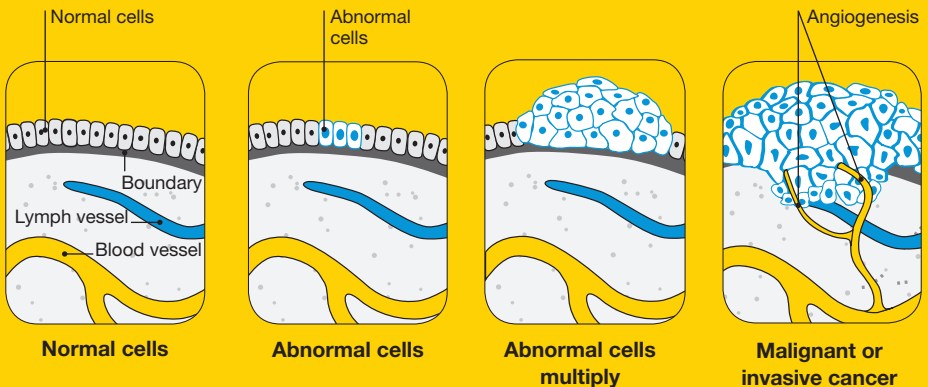
Cancer is a disease of the cells, which are the body's basic building blocks. The body constantly makes new cells to help us grow, replace worn-out tissue and heal injuries. Normally, cells multiply and die in an orderly way.

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

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

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

How cancer starts



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

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

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

How cancer spreads

Primary cancer

Local invasion

Angiogenesis –
tumours grow their
own blood vessels

Lymph vessel

Metastasis –
cells invade other
parts of the body via
blood vessels and
lymph vessels





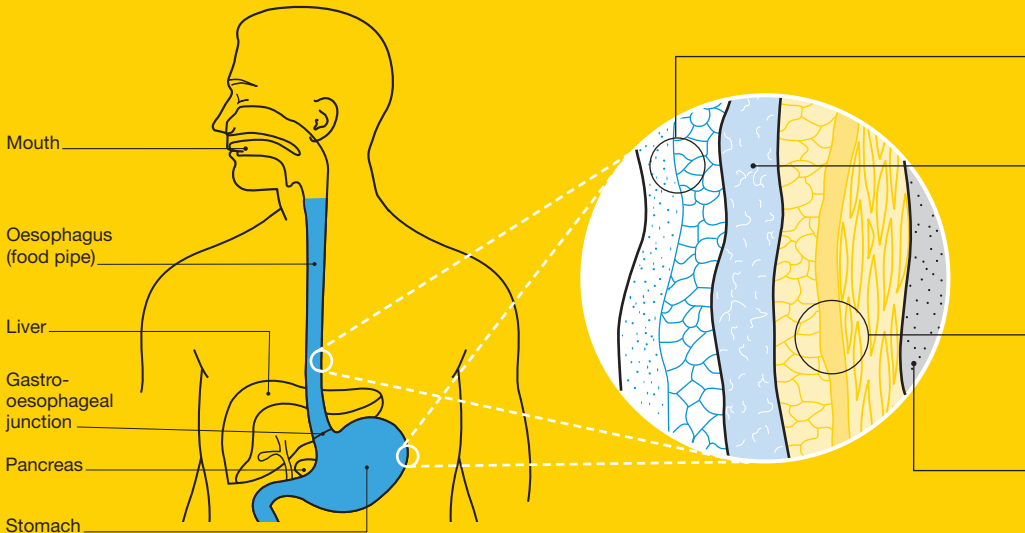
The oesophagus and stomach

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 or gullet) is a long, muscular tube that delivers food, fluids and saliva from the mouth and throat to the stomach. A valve (sphincter) at the end of the oesophagus stops acid and food moving from the stomach back into the oesophagus.

The stomach is a hollow, muscular organ in the upper left part of the abdomen, located between the end of the oesophagus and

The oesophagus and stomach



the beginning of the small bowel (small intestine). The stomach expands to store food that has been swallowed. It also helps with the absorption of some vitamins and minerals.

In the stomach, acidic (gastric) juices are released from glands in the stomach lining (mucosa). These juices 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 matter moves into the large bowel (large intestine), where fluids are reabsorbed back into the body. The solid waste matter is passed out of the body as a bowel movement.

| Layer of tissue | In the oesophageal wall | In the stomach wall |
|---|---|--|
| Mucosa (moist innermost layer) | <ul style="list-style-type: none"> made up of squamous cells | <ul style="list-style-type: none"> contains glands that produce gastric fluids to start breaking down food |
| Submucosa (supports the mucosa) | <ul style="list-style-type: none"> glands in the submucosa produce fluid (mucus) this fluid helps to move food through the oesophagus | <ul style="list-style-type: none"> provides blood and nutrients to the stomach |
| Muscle layer | <ul style="list-style-type: none"> known as the muscularis propria produces contractions to help push food down the oesophagus and into the stomach | <ul style="list-style-type: none"> known as the muscularis externa produces muscle contractions to help break down food and push it into the small bowel in a controlled way |
| Outer layer | <ul style="list-style-type: none"> known as the adventitia connective tissue supporting the oesophagus | <ul style="list-style-type: none"> known as the serosa a smooth membrane that surrounds the stomach |



Key questions

Q: What is stomach cancer?

A: Stomach cancer begins from abnormal cells in the lining (mucosa) of the stomach. Tumours can begin anywhere in the stomach, although most start in the glandular tissue found on the stomach's inner surface. This type of cancer is called adenocarcinoma of the stomach (also known as gastric cancer).

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

Q: How common is stomach cancer?

A: About 2100 people are diagnosed with stomach cancer in Australia each year. Men are two times more likely than women to be diagnosed with stomach cancer. It is more common in people over 60, but it can occur at any age. About one in 121 men and one in 290 women are likely to develop stomach cancer before the age of 75.³

Q: What is oesophageal cancer?

A: Oesophageal cancer begins from abnormal cells in the innermost layer (mucosa) of the oesophagus. A tumour can start at any point along the length of the oesophagus. The two main subtypes are:

- **Oesophageal squamous cell carcinoma** – starts in the thin, flat cells in the lining of the oesophagus, which are called squamous cells. It often begins in the middle and upper part of the oesophagus. In Australia, squamous cell carcinomas are less common than adenocarcinomas.
- **Oesophageal adenocarcinoma** – Barrett’s oesophagus (see page 10) occurs when the squamous cells lining the lower section of the oesophagus change into glandular cells. A tumour that starts in glandular cells is called an adenocarcinoma. Adenocarcinomas are now the most common form of oesophageal cancer in Australia.

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

Less common types of cancer

Other less common types of cancer can affect 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. Call Cancer Council **13 11 20** for information about these types of cancer, or speak to someone in your medical team.

Q: Is oesophageal cancer common?

A: This is an uncommon cancer. In Australia, about 1400 people are diagnosed with oesophageal cancer each year. Men are nearly three times more likely than women to be diagnosed with this cancer. It is more common in people over 60, but can occur at any age. About one in 158 men and one in 575 women are likely to develop oesophageal cancer before the age of 75.⁴

Q: What are the risk factors?

A: The exact causes of stomach and oesophageal cancers are unknown, but the factors listed in the table on the opposite page may increase your risk. However, having one or more of these risk factors does not mean you will develop cancer.

GORD and Barrett's oesophagus

Gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus are risk factors for oesophageal adenocarcinoma. Reflux is when stomach acid backs up into the oesophagus. People who have repeated episodes of reflux may be diagnosed with GORD.

Over time, stomach acid can damage the walls of

the oesophagus, causing inflammation or ulceration (oesophagitis). In some people, this may cause the squamous cells lining the oesophagus to be replaced by glandular cells. This condition, called Barrett's oesophagus, can lead to oesophageal adenocarcinoma. Most people with Barrett's oesophagus will not develop oesophageal cancer.

Known risk factors

Stomach cancer

- older age (being over 60)
- infection with *Helicobacter pylori* (*H. pylori*), a type of bacteria found in the stomach
- having had a subtotal gastrectomy (see page 26) to treat non-cancerous conditions
- smoking
- low red blood cell levels (pernicious anaemia)
- a family history of stomach cancer
- inheriting a genetic change that causes a bowel disorder such as familial adenomatous polyposis or Lynch syndrome
- chronic inflammation of the stomach (chronic gastritis)
- alcohol consumption
- dietary factors – eating foods preserved by salting and processed meats (e.g. bacon, salami or ham)
- being overweight or obese

Oesophageal cancer

Squamous cell carcinoma

- alcohol consumption
- smoking
- older age (being over 60)
- infection with human papilloma virus (HPV)

Adenocarcinoma

- being overweight or obese
- medical conditions, including gastro-oesophageal reflux disease (GORD) and Barrett's oesophagus (see opposite)
- smoking
- older age (being over 60)
- a personal or family history of gastro-oesophageal disorders, such as hernia, polyps, ulceration or oesophagitis

Q: What are the symptoms?

A: Stomach and oesophageal cancers may not cause symptoms in their early stages. This means that they are usually diagnosed when the cancer is more advanced.

Common symptoms are listed in the table below. These symptoms can also occur in many other conditions and do not necessarily mean that you have cancer. Speak with your general practitioner (GP) if you are concerned.

| Stomach cancer | Oesophageal cancer |
|--|---|
| <ul style="list-style-type: none">• unexplained weight loss or loss of appetite• difficulty swallowing• indigestion – e.g. pain or burning sensation in the abdomen (heartburn), frequent burping, reflux• persistent nausea and/or vomiting with no apparent cause• a sense of fullness, even after a small meal• swelling of the abdomen or feeling bloated• unexplained tiredness, which may be due to anaemia• vomit containing blood• black-coloured or bloody stools | <ul style="list-style-type: none">• difficulty swallowing• vomiting blood• black-coloured or bloody stools• food or fluids “catching” in the throat or episodes of choking when swallowing• pain when swallowing• unexplained weight loss or loss of appetite• new or worsening heartburn or reflux• cough, hoarseness• development of upper abdominal discomfort especially when eating• persistent unexplained tiredness |



Diagnosis

If your general practitioner (GP) suspects that you have stomach or oesophageal cancer, they will examine you and refer you for further tests. The main tests for diagnosing stomach and oesophageal cancers are endoscopy and the removal of a tissue sample (biopsy).

Endoscopy and biopsy

An endoscopy (also called a gastroscopy, oesophagoscopy or upper endoscopy) allows your doctor to see inside your digestive tract to examine the lining. This test is usually performed as day surgery.

You will be asked not to eat or drink (fast) for about 4–6 hours before an endoscopy. Before the procedure, your throat will be sprayed with a local anaesthetic and you will probably be given a sedative to help you relax. A 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.

If the doctor sees any suspicious-looking areas, they may remove a small amount of tissue from the stomach or oesophageal lining. This is known as a biopsy. A pathologist will examine the tissue under a microscope to check for signs of disease. Biopsy results are usually available within a few days. This waiting period can be an anxious time and it may help to talk to a supportive friend, relative or health professional about how you are feeling.

An endoscopy takes about 15 minutes. 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). Your doctor should explain all the risks before asking you to consent to the procedure.

Endoscopic ultrasound (EUS)

You may have this test at the same time as a standard endoscopy. The doctor will insert an endoscope with an ultrasound probe on the end. The probe releases soundwaves, which echo when they bounce off anything solid, such as an organ or tumour. This procedure helps determine whether the cancer has spread into the oesophageal wall, nearby tissues or lymph nodes, and whether you are a suitable candidate for surgery. During the scan, your doctor may take further tissue samples from the oesophagus, lymph nodes and nearby organs.

Further tests

If the biopsy shows you have stomach or oesophageal cancer, you will have a number of other tests to find out whether the cancer has spread to other areas of your body. This is called staging (see page 17). The following pages describe tests that are commonly used to help stage stomach and oesophageal cancers. Some tests may be repeated during or after treatment to check your health and how well the treatment is working.

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

Blood tests

You might have blood tests to assess your general health, and to see how well your liver and kidneys are working. The test results can help you and your doctor to make treatment decisions.

CT scan

A computerised tomography (CT) scan uses x-rays and a computer to create a detailed picture of an area inside the body. It helps determine how far the cancer has spread from the primary tumour site. You may have a CT scan of your:

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

Before a CT scan for stomach cancer, you may have an injection or be asked to drink a liquid dye. This helps ensure that anything unusual can be seen more clearly. The dye might make you feel hot all over and leave a strange taste in your mouth for a few minutes. Rarely, more serious reactions can 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 the preparation can take 10–30 minutes.

The dye used in a CT scan can cause an allergic reaction in some people. If you have had an allergic reaction to iodine or dyes during a previous scan, let the medical team know in advance.



PET-CT scan

A positron emission tomography (PET) scan combined with a CT scan is a specialised imaging test. The two scans provide more detailed and accurate information about the cancer. A PET-CT scan is most commonly used to help determine whether stomach or oesophageal cancer has spread to other parts of the body.

A PET scan is able to detect cancer cells that may not have been detected with just a CT scan. 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 the 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 will take around 30 minutes. Let your doctor know if you are claustrophobic as the scanner is a confined space.

Laparoscopy

This procedure allows your doctor to look inside your abdomen and examine the outer layer of the stomach to see if the cancer has spread. A laparoscopy is used to stage:

- stomach cancer to see whether it involves the lining of the abdomen (peritoneum) or other organs
- oesophageal cancer located in the gastro-oesophageal junction that also involves the upper part of the stomach.

A laparoscopy is usually done as day surgery. You will be admitted to hospital and given a general anaesthetic. The

doctor will inflate your abdomen with gas and make small cuts in your abdomen. A tube with a light and camera attached (a laparoscope) will be inserted into your body. Through this tube, the doctor can see cancer cells that are too small to be seen on CT or PET scans. The doctor may take further tissue samples for biopsy. Your doctor will explain the risks before asking you to agree to the procedure.

Gene mutation testing

Some cancers in the stomach and gastro-oesophageal junction are linked with genetic abnormalities. These abnormalities can contribute to the growth of tumours. If other tests show that the stomach cancer is advanced, your doctor might test a tissue sample to see if it contains a particular genetic mutation that may respond to some medicines. See *Targeted therapy for stomach cancer* on page 32 for more details.

Staging

The tests described on pages 13–17 help show whether you have stomach or oesophageal cancer, and whether it has spread from the original site to other parts of the body. Working out how far the cancer has spread is called staging and it helps your health care team decide the best treatment for you.

The TNM staging system is the method most commonly used to describe the different stages of stomach and oesophageal cancers. Each letter is assigned a number to describe the cancer (see table on the next page).

TNM staging system

| | |
|------------------------------|---|
| T (Tumour) 0–4 | Indicates how far the tumour has grown into the oesophagus or stomach wall. The higher the number, the deeper the tumour. |
| N (Nodes) 0–3 | Shows if the cancer has spread to nearby lymph nodes. N0 means the cancer has not spread to the lymph nodes; N1, N2 or N3 indicate increasing node involvement. |
| M (Metastasis) 0–1 | Indicates if the cancer has spread (metastasised) to other parts of the body. M0 means the cancer has not spread; M1 means the cancer has spread. |

Based on the TNM numbers, the doctor then works out the overall stage (I–IV) of the cancer:

- **Stage I** – tumours are found only in the stomach or oesophageal wall lining (known as early or limited disease).
- **Stages II and III** – tumours have spread deeper into the layers of the stomach or oesophageal walls and to nearby lymph nodes (known as locally advanced disease).
- **Stage IV** – tumours have spread beyond the oesophageal/stomach wall to other parts of the body, such as the bones or lungs, or to distant lymph nodes (known as advanced or metastatic disease).

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

Prognosis

Prognosis means the expected outcome of a disease. You may wish to discuss your prognosis and treatment options with your doctor, but it is not possible for any doctor 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.

Generally, the earlier stomach or oesophageal cancer is diagnosed, the better the chances of successful treatment. If cancer is found after it has spread from the primary tumour site, the prognosis is not as good.

Test results, the type of cancer, the rate and depth of tumour growth, the likelihood of response to treatment, and factors such as your age, level of fitness and medical history are important in assessing your prognosis. These factors will also help your doctor advise you on the best treatment options.

Which health professionals will I see?

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

You will be cared for by a range of health professionals who specialise in different aspects of your treatment. This is called a multidisciplinary team (MDT). This team will meet regularly to discuss and plan the most appropriate treatment for you. Turn the page for a list of some of the people who make up this MDT.

| Health professional | Role |
|--|--|
| gastroenterologist* | specialises in disorders of the digestive system; performs endoscopies; inserts feeding tubes |
| upper gastrointestinal surgeon* | treats diseases of the upper digestive system with surgery; performs endoscopies; inserts a feeding tube if required |
| medical oncologist* | treats cancer with drug therapies such as chemotherapy and targeted therapy |
| radiation oncologist* | prescribes and coordinates the course of radiotherapy |
| radiation therapist | plans and delivers radiotherapy treatment |
| cancer nurse coordinator, clinical nurse consultant | coordinate your care, liaise with other members of the MDT, and support you and your family throughout treatment |
| nurse | administers drugs, including chemotherapy; provides care, information and support |
| dietitian | recommends an eating plan for your nutritional needs while you are in treatment and recovery |
| physiotherapist | assists in physical rehabilitation and restoring movement after surgery |
| social worker | links you to support services and helps you with emotional, practical and financial issues |
| psychologist, counsellor | help you manage your emotional response to diagnosis and treatment |
| palliative care team | specialise in pain and symptom control to maximise wellbeing and improve quality of life |

* Specialist doctor



Key points

- A range of tests are used to diagnose stomach and oesophageal cancers.
- Endoscopy is the main diagnostic test. This allows your doctor to look inside the digestive tract and take tissue samples (biopsies).
- You may have an endoscopic ultrasound (EUS) to show how far the cancer has spread into the oesophageal wall.
- A pathologist examines the biopsied tissue under a microscope to find out more about the cells. This shows if cancer is present and how quickly it is growing.
- After the diagnosis is confirmed, you will have further tests to find out whether the cancer has spread.
- A CT or PET-CT scan will help show how far the cancer has spread from the stomach or oesophageal wall.
- Other procedures, such as a laparoscopy, can show whether the cancer has spread to other organs or the abdomen.
- Gene mutation testing of tissue samples is recommended only for some people with advanced (metastatic) stomach cancer.
- Staging a cancer helps your doctors to determine the most appropriate treatment for you.
- Your doctor will talk to you about your prognosis, which is the expected outcome of a disease.
- You will be cared for by a range of health professionals who work together in a multidisciplinary team (MDT).



Making treatment decisions

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

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

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

Talking with doctors

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

If you are confused or want clarification, you can ask questions – see page 60 for a list of suggested questions. If you have several questions, you may want to talk to a nurse or ask the office manager if it is possible to book a longer appointment.

A second opinion

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

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

Taking part in a clinical trial

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

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

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



Treatment for stomach cancer

The most important factor in planning treatment for stomach cancer is the stage of the disease, particularly whether the tumour has spread from its original location. Your treatment will also depend on your age, medical history and general health.

Surgery is the main treatment for stomach cancer that has not spread. If the cancer has spread, treatment will often include chemotherapy (see page 31) or radiotherapy (see page 33), but not surgery.

Preparing for treatment

Improve diet and nutrition – People with stomach cancer often lose a lot of weight and can become malnourished. A dietitian can provide advice on ways to reduce the weight loss through changes to your diet, liquid supplements or a feeding tube. This will help improve your strength and lead to better treatment outcomes.

Stop smoking – If you are a smoker, you will be assisted to stop smoking before surgery. If you continue to smoke, you may not respond as well to treatment and smoking may make any side effects you experience worse. See your doctor, call the Quitline on 13 7848 or visit quitnow.gov.au for support quitting.



For more information on treatments and managing side effects, read Cancer Council's *Understanding Surgery*, *Understanding Chemotherapy* and *Understanding Radiotherapy* booklets.

Surgery for stomach cancer

Surgery aims to remove all of the stomach cancer while keeping as much normal tissue as possible. However, it is essential to remove a small amount of healthy tissue around the cancer to reduce the risk of the cancer coming back. The type of surgery will depend on where the tumour is growing and how advanced the cancer is.

Endoscopic resection (ER)

Small, very early-stage tumours that have not spread from the stomach walls may be removed with an endoscope. This is usually a day or overnight stay procedure. Preparation and recovery are similar to endoscopy (see page 13). This may be the only treatment needed for some people with early-stage stomach cancer.

Gastrectomy (surgical resection)

This procedure removes the cancerous tissue and part or all of the stomach, leaving as much healthy tissue as possible. The goal is to completely remove the cancer, including any affected lymph nodes.

There are two ways to perform a gastrectomy:

- in a laparotomy (open gastrectomy), the surgery is performed through a cut in the upper part of the stomach
- in a laparoscopic (keyhole) gastrectomy, the surgeon will make some small cuts in the abdomen, then perform surgery using a thin telescope to see inside the abdomen and chest.

The hospital stay and recovery time may be similar for both types of surgery. Laparoscopic surgery usually means a smaller scar, however, open surgery may be considered a better option in many situations.

The surgery will be performed under a general anaesthetic. Your surgeon will talk to you about the risks of your procedure.

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

Total gastrectomy – Removal of the whole stomach, along with nearby fatty tissue (omentum), lymph nodes and parts of adjacent organs, if necessary. The surgeon reconnects the oesophagus to the small bowel. The top part of this connection (which is a tube of intestine) takes over some of the stomach's function.

Lymphadenectomy (lymph node dissection) – As the cancer might have spread to nearby lymph nodes, your doctor will usually remove a number of lymph nodes from around your stomach. This reduces the risk of leaving any cancer behind.

Risks of stomach surgery

As with any major surgery, stomach surgery has risks. Complications may include: infection, bleeding, blood clots, damage to nearby organs, or leaking from the connections between the small bowel and either the oesophagus or stomach. Some people may experience an irregular heartbeat, but this usually settles within a few days.

You will be carefully monitored for any side effects afterwards. For more information about ongoing effects after surgery, see the *Managing side effects* chapter (pages 45–51).

Feeding tubes

If you are unable to eat and drink enough to meet your nutritional needs, you may need a feeding tube.

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

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

Other people will have a feeding tube after surgery while their wound is healing.

Your doctor and dietitian will discuss your individual nutrition care needs with you.

Many people find that having a feeding tube eases the pressure and discomfort associated with eating. Medicines can also be given through a feeding tube.

A feeding tube can be placed into your small bowel either through your nostril (nasojunal tube) or through an opening on the outside of your abdomen (known as a jejunostomy or J-tube).

If you go home with the feeding tube in place, a dietitian will advise you on the type and amount of feeding formula you will need.

Your health care team will also tell you how to keep the tube clean, how to prevent wear, leakage and blockages, and when to replace the tube.

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

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

What to expect after stomach surgery

When you wake up after the operation, you will be in a recovery room near the operating theatre. Once you are fully conscious, you will be transferred to a ward where you will stay for 5–10 days until you can go home. It can take about three months to fully recover.

Pain – You will have some pain and discomfort for several days after your surgery, but you will be given pain-relieving medicines to manage this. Let your doctor or nurse know if you are in pain so they can adjust your medicines to make you as comfortable as possible. Do not wait until the pain is severe.

Wound care – You will have a dressing over the wound. Your doctor or nurse will talk to you about how to keep the wound clean once you go home to prevent it becoming infected.

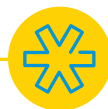
Drips and drains – After surgery you will have several tubes in your body, including a catheter to measure urine output. You may have an intravenous (IV) drip, which is used for pain relief and to replace your body's fluids until you are able to drink and eat again. You may also have a feeding tube.

Dietary changes – You will be unable to eat or drink initially after surgery. Your doctor will advise when you are able to start eating. You will usually start with fluids such as soup, and then move onto soft foods for about a week. When you are ready, you can try eating some solid foods. You may be advised to eat 6–8 small meals or snacks throughout the day. The hospital dietitian can prepare eating plans for you and work out whether

you need any supplements to help meet your nutritional needs. Sometimes, a small feeding tube is placed further down the small bowel through a small cut in the abdomen (see page 27). You can be given specially prepared feeding formula 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 46–49.

Breathing exercises – A physiotherapist will teach you breathing or coughing exercises to help keep your lungs clear. This will reduce the risk of you getting a chest infection.

Activity/exercise – Your health care team will probably encourage you to walk the day after the surgery. Exercise has been shown to help people manage some of the common side effects of treatment, speed up a return to usual activities and improve quality of life. Speak to your doctor if you would like to try more vigorous exercise. You will have to wear compression stockings for a couple of weeks to help the blood in your legs to circulate. You will most likely need to avoid driving for a few weeks after the surgery and avoid heavy lifting.



After surgery to the stomach, many people don't absorb vitamin D and calcium well. This can lead to thinning and weakening of the bones (osteoporosis). This may cause pain and an increased risk of fractures. For more information about how to prevent osteoporosis, talk to your doctor. It may also help to see a dietitian.



Pete's story

I was diagnosed with stomach cancer eight years ago when I was 44. I was really fortunate that the cancer was found early. I was being treated for a stomach ulcer and a follow-up gastroscopy found a tumour in my stomach.

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.

Chemotherapy was very difficult and I struggled with the side effects. My wife at the time gave birth to our little girl while I was having chemotherapy. This was very challenging – I was instructed to be really careful with the baby because of the risks associated with chemotherapy, so I couldn't even change her nappies.

I was also trying to understand that I had cancer and deal with the emotional aspects. I found it really helpful to tap into Cancer Connect peer support. I got a lot of benefit from connecting with someone who'd had a similar type of experience and lived through it. My contact shared his experiences of waking up from surgery with lots of tubes coming out of him, so I wasn't shocked when this happened to me. It was really good to have that awareness prior to the surgery.

Once treatment was finished, it was quite daunting and I was fearful that the cancer would come back somewhere. Eight years later, it hasn't come back, which is fantastic.

I've changed my career path and am studying community services in order to help people through changes in their life. The way you view life is different after cancer. I really appreciate and have a lot of gratitude for what I have now.

Chemotherapy for stomach cancer

Chemotherapy uses drugs to kill or slow the growth of cancer cells. For stomach cancer, chemotherapy is commonly given before surgery to shrink large tumours and destroy any cancer cells that may have spread. It may also be used after surgery to reduce the chance of the disease coming back. Chemotherapy is also used on its own as a palliative treatment.

Chemotherapy is usually given into a vein in your arm through a drip (intravenously). It may also be given through a tube called a port, catheter or vascular access device. Some chemotherapy drugs for stomach cancer are given as tablets.

Most people receive a combination of drugs in repeating cycles spread over several months. There may be a rest period of 2–3 weeks between each cycle of chemotherapy. Your doctor will talk to you about how long your treatment will last.

Side effects of chemotherapy

The side effects of chemotherapy vary greatly for each person. Some people don't experience any side effects, while others have several. Most side effects are temporary. Your treatment team can help you prevent or manage any side effects.

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

Targeted therapy for stomach cancer

Some cancers in the stomach and gastro-oesophageal junction are linked to high levels of HER2 (human epidermal growth factor receptor 2). This protein causes cancer cells to grow uncontrollably. Tumours that have high levels of these receptors are called HER2 positive tumours.

If you have advanced HER2 positive stomach or gastro-oesophageal cancer, you may be treated with a targeted therapy drug called trastuzumab. This drug destroys the HER2 positive cancer cells or reduces their ability to divide and grow. Trastuzumab is given with chemotherapy every three weeks through a drip into a vein.

Side effects of targeted therapy

Ask your doctor what side effects you may experience and how long your treatment will last. Potential side effects of trastuzumab include fever and nausea. In some people, trastuzumab can affect the way the heart works.

It is important to discuss any side effects with your doctor immediately. If left untreated, some side effects can become life-threatening.



You may be able to access new drugs to treat stomach cancer through clinical trials. Talk with your doctor about the latest developments and whether you are a suitable candidate.

Radiotherapy for stomach cancer

Radiotherapy (also known as radiation therapy) uses x-rays to damage or kill cancer cells so they cannot multiply. The radiation is targeted at the parts of the body with cancer. Treatment is carefully planned to do as little harm as possible to healthy body tissue.

Radiotherapy for stomach cancer is usually used to control symptoms when surgery is not suitable. In this case, you will have a simple, short course (1–2 weeks) of external beam radiotherapy. This is unlikely to cause any side effects, apart from some possible nausea. 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 advise you about your treatment schedule.

Palliative treatment

Palliative treatment aims to manage symptoms and improve people's quality of life without trying to cure the disease. It may be beneficial for people at any stage of advanced stomach cancer.

Palliative treatment for stomach cancer may include surgery, stenting (see page 43), radiotherapy, chemotherapy or other medicines. These treatments can help manage symptoms such as pain, bleeding, swallowing difficulty and nausea. They can also slow the spread of the cancer.

For more information or free copies of *Living with Advanced Cancer* and *Understanding Palliative Care*, call Cancer Council 13 11 20.



Key points

- The type of treatment you have for stomach cancer depends on where the cancer is located and how far it has spread.
- Early stomach cancer is usually treated with surgery to remove part or all of the stomach. This operation is called a gastrectomy. The remaining parts of the digestive system are usually stitched together so that food can still be swallowed and digested.
- Some small tumours may be removed using a long flexible tube (endoscopic resection) without removing the stomach.
- Surgery will affect your eating and digestion. Learning to adapt to these changes will take time. A dietitian can help.
- You may need a feeding tube before, during or after treatment to help you meet your nutritional needs.
- Some people also have chemotherapy before or after surgery. Chemotherapy drugs can cause side effects, such as nausea or a sore mouth. Most side effects are temporary.
- If you have advanced HER2 positive stomach or gastro-oesophageal cancer, you may be given a targeted therapy drug called trastuzumab.
- Radiotherapy treatment uses x-rays to damage or kill cancer cells so they cannot multiply. It can cause nausea.
- Advanced or metastatic stomach cancer is treated palliatively with chemotherapy or radiotherapy. It is rarely treated with surgery.
- Palliative treatment seeks to improve quality of life by reducing the symptoms of advanced cancer without aiming to cure the disease.



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, medical history and general health.

Oesophageal cancer that is found early can generally be treated successfully with surgery. If the cancer has spread, you will usually also have chemotherapy and/or radiotherapy.

Surgery for oesophageal cancer

Surgery aims to remove all of the oesophageal cancer while keeping as much normal tissue as possible. However, it is essential to remove a small amount of healthy tissue around the cancer to reduce the risk of the cancer coming back.

The type of surgery will depend on where the tumour is growing and how advanced the cancer is. Your doctor will tell you how to prepare for surgery. For example, you may need to treat any nutritional issues before surgery or, if you are a smoker, stop smoking (see page 24).

Endoscopic resection (ER)

In an endoscopic resection, the tumour is removed using a long, flexible tube (endoscope). This is the preferred option for removing very early-stage oesophageal tumours. It involves less risk and a faster recovery than an oesophagectomy (see page 36). This is usually a day or overnight stay procedure. Preparation and recovery are similar to endoscopy (see page 13). This may be the only treatment needed for some people with early-stage oesophageal cancer.

Oesophagectomy (surgical resection)

This procedure removes the cancerous sections of the oesophagus. Depending on how far the cancer has spread, the surgeon may also remove part of the upper stomach, lymph nodes and other tissue. This is the preferred option for tumours that have spread deeper into the walls of the oesophagus or nearby lymph nodes. You will usually have chemotherapy and/or radiotherapy before an oesophagectomy to shrink large tumours and destroy any cancer cells that may have spread.

To remove the cancerous tissue, the surgeon will need to access the upper abdomen and chest. This may be done in two ways:

- in an open oesophagectomy, the surgeon will open the chest and the abdomen with large surgical cuts
- in a minimally invasive oesophagectomy (keyhole or laparoscopic surgery), the surgeon will make some small cuts in the abdomen and ribs, then insert a thin telescope to see inside the abdomen and chest.

The hospital stay and recovery time may be similar for both types of surgery. Laparoscopic surgery usually means a smaller scar, however, open surgery may be considered a better option in many situations.

Once the cancerous sections have been removed, the stomach is pulled up and reconnected to the healthy part of the oesophagus. This will allow you to swallow and eat relatively normally. Occasionally, if the oesophagus cannot be reconnected to the stomach, the oesophagus will be connected to the small bowel or a piece of large bowel will be used to restore swallowing.

Risks of oesophageal surgery

As with any major surgery, oesophageal surgery has risks. Complications may include: infection, bleeding, blood clots, damage to nearby organs, leaking from the connections between the oesophagus and stomach or small bowel, narrowing of the oesophagus from surgical scars, pneumonia (see page 38) and paralysis of the vocal cords. Some people may experience an irregular heartbeat, but this usually settles within a few days. Your surgeon will discuss these risks with you before surgery and you will be carefully monitored for any side effects afterwards.

What to expect after oesophageal surgery

When you wake up after the operation, you will be in a recovery room near the operating theatre or in the Intensive Care Unit. You can expect to spend time in the Intensive Care Unit and the High Dependency ward before being transferred to a standard ward.

The length of stay in hospital is generally 7–14 days, but it can be significantly longer if any complications occur. It generally takes 6–12 months to fully recover from this operation.



Surgery for oesophageal cancer is complex. To ensure the best outcome, it is recommended that you are treated in a hospital that regularly performs this type of surgery. Call Cancer Council **13 11 20** for information about hospitals in your area or to ask about assistance that may be available if you have to travel a long way for treatment.

Side effects after oesophageal surgery are similar to those after stomach surgery (see pages 28–29). There are some differences:

Drips and drains – In addition to the tubes listed on page 29, you will have a tube down your nose into your stomach (nasogastric tube) to drain fluids from the stomach.

Dietary changes – As with stomach surgery, you will be unable to eat or drink initially after surgery. It is common for a temporary feeding tube to be inserted at the time of your surgery (see page 27). You can be given specially prepared feeding formula through this tube while the join between the oesophagus and stomach heals. Once you begin eating, it is common to start with fluids such as soup, and then move onto soft foods for a few weeks. Your surgeon or dietitian will advise when you can try eating solid foods. You may be advised to eat 6–8 small meals or snacks throughout the day. The hospital dietitian can prepare eating plans and work out whether you need any supplements to help meet your nutritional needs. For more information about eating after surgery, see pages 46–49.

Breathing problems – It is important that your pain is controlled to help avoid problems with breathing that can lead to pneumonia. To reduce the risk of pneumonia, a physiotherapist will teach you breathing or coughing exercises that 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.

For more information about ongoing effects, see the *Managing side effects* chapter (pages 45–51).



John's story

My diagnosis of oesophageal cancer came as a complete surprise. Looking back, I can see that I hadn't been able to eat as much, but I put that down to getting older. It wasn't until I suddenly started vomiting out of the blue that I saw my doctor.

A series of scans revealed I had a blockage in the gullet. An endoscopy confirmed it was oesophageal cancer. Luckily the cancer hadn't spread outside my oesophagus.

I was admitted to hospital for chemotherapy and radiotherapy to shrink the tumour, and then went home to recover for six weeks before having surgery.

For those three months, I was fed through a feeding tube. I found it a bit frightening at first to deal with the feeding tube at home – it was difficult to clear when it got blocked and one night I pulled it out in my sleep and had to go to hospital to have it reinserted.

The surgery was a major procedure: it took eight hours to remove my oesophagus and reconnect my stomach. While recovering, I found the dietitians at the hospital very helpful in suggesting foods I could eat. At first I had a feeding tube, then I started on liquids and soft foods. By the time I left rehab about four weeks after the surgery, I was able to handle most foods.

Once I was home, I followed the dietitian's advice and I haven't had many problems with eating or swallowing. I take a tablet to help prevent regurgitation, sleep sitting up, and eat small meals throughout the day.

Although it took a while before I was game to try some foods, I now eat most things, but in small portions. You learn what foods suit you and what foods don't.

Nearly four years after surgery, I have an almost normal lifestyle with moderation in all things.

Radiotherapy for oesophageal cancer

Radiotherapy (also known as radiation therapy) uses x-rays to damage or kill cancer cells so they cannot multiply. The radiation is targeted at the parts of the body with cancer. Treatment is carefully planned to do as little harm as possible to healthy body tissue.

Radiotherapy may be given alone or combined with chemotherapy. It is commonly used before surgery to shrink large tumours and destroy any cancer cells that may have spread. It is also used as the main treatment for cancers that cannot be removed surgically.

Radiotherapy is usually given externally for oesophageal cancer. Before starting treatment you will have a planning appointment that will include a CT scan. The radiotherapy team will use the images from the scan to plan your treatments. The technician may make some small permanent tattoos or temporary marks on your skin so that the same area is targeted during each treatment session.

You will usually have treatment as an outpatient once a day, Monday to Friday, for 5–7 weeks. 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 advise you on the number of treatment sessions you need.

Side effects of radiotherapy

Many people will develop temporary side effects during or shortly after treatment. Your mouth and throat may become red and sore, and the lining of the oesophagus can become very sore and inflamed (oesophagitis). This can lead to painful swallowing and difficulty

eating. In rare cases you may need a feeding tube (see page 27) to ensure you receive adequate nutrition. Other common side effects include fatigue, skin reactions, decreased appetite and weight loss. Most side effects settle around four weeks after treatment finishes.

More rarely, some people will develop long-term side effects. Radiotherapy can cause scar tissue and narrowing of the oesophagus (known as oesophageal stricture). This can make it difficult to swallow and your doctor may perform a procedure to stretch the walls of the oesophagus (dilatation). Radiotherapy can also create inflammation in the lungs, causing shortness of breath.

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

Chemotherapy 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 combined with radiotherapy.

For oesophageal cancer, chemotherapy is commonly given before surgery to shrink large tumours and destroy any cancer cells that may have spread. It may be used after surgery to reduce the chance of the disease coming back. Chemotherapy is also used on its own for people unable to have surgery.

Chemotherapy is usually given into a vein in your arm through a drip (intravenously). It may also be given through a tube called a port, catheter or vascular access device. You will usually receive treatment as an outpatient.

Most people receive a combination of drugs in repeating rounds of treatment for several months. These may be given on one day or continuously using a small pump that is linked to the tube implanted into the vein. There may be a rest period of a few weeks between each round. Your doctor will talk to you about how long your treatment will last.

Side effects of chemotherapy

The side effects of chemotherapy vary greatly, depending on the drugs you receive, how often you have treatment, and your general fitness and health. 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, changed bowel habits (e.g. constipation, diarrhoea), and hair loss or thinning.

Chemotherapy reduces your white blood cell level, making it harder for your body to fight infections. If you feel unwell or have a temperature higher than 38°C, seek urgent medical attention.

Most side effects are temporary. Your treatment team can help you prevent or manage any side effects. Cancer Council's booklet *Understanding Chemotherapy* has more information.

Palliative treatment

Palliative treatment aims to manage symptoms and improve people's quality of life 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 their life; however, it may be beneficial for people at any stage of advanced oesophageal cancer. It is about living for as long as possible in the most satisfying way you can.

Palliative treatment can help slow the spread of the cancer, and assist with managing symptoms such as pain, swallowing difficulty and nausea. For example, radiotherapy can help to relieve pain and make swallowing easier by helping to shrink a tumour blocking the oesophagus.

People with advanced oesophageal cancer who are having trouble swallowing food and fluids may have a flexible tube (stent) inserted into the oesophagus. The stent expands the oesophagus to allow fluid and food to pass into the stomach more easily. This stent also prevents food and saliva going into the lungs and causing infection. The stent does not treat the cancer but will allow you to eat and drink more normally. For more information about eating and swallowing, see the *Managing side effects* chapter (pages 45–51).

For more information or free copies of *Understanding Palliative Care* and *Living with Advanced Cancer*, call Cancer Council 13 11 20 or visit your local Cancer Council website.



Key points

- The type of treatment you have for oesophageal cancer depends on where the cancer is located and how far it has spread.
- Oesophageal cancer is usually treated with surgery to remove all or part of the oesophagus. This operation is called an oesophagectomy. The remaining parts of the digestive system are usually stitched together so that food can still be swallowed and digested.
- Some small tumours may be removed using a long flexible tube (endoscopic resection) without removing the oesophagus.
- Surgery will affect your eating and digestion. Learning to adapt to these changes will take time. A dietitian can help with your recovery.
- People commonly have radiotherapy and/or chemotherapy before surgery. Radiotherapy and chemotherapy are also used as the main treatments if the cancer has spread.
- Radiotherapy treatment uses x-rays to damage or kill cancer cells so they cannot multiply. It can cause side effects, such as oesophagitis, painful swallowing and difficulty eating.
- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. The drugs can cause side effects, such as a sore mouth or appetite changes. Most side effects are temporary.
- Palliative treatment seeks to improve quality of life by reducing the symptoms of advanced cancer without aiming to cure the disease.
- A stent may be inserted into your oesophagus to allow you to eat and drink more normally.



Managing side effects

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

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

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

Some people find it difficult to cope emotionally with the changes to their eating habits. You may feel self-conscious or worry about eating in public or with friends. These reactions are natural. It may help to talk about how you feel with your family and friends, or 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.

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

Poor appetite and weight loss

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

Chemotherapy and radiotherapy can also affect your appetite, due to nausea, irritation to the oesophagus or a sore mouth. If your oesophagus is very sore from radiotherapy, your doctor may prescribe pain-relieving medicines.



How to prevent unplanned weight loss

- Snack during the day – eat 5–6 small meals rather than three large ones each day.
- Ask your family and friends to cook for you and offer you food throughout the day.
- Keep a selection of snacks handy, e.g. in your bag or car.
- Test your ability to eat different foods. Your taste and tolerance for some foods may have changed and may continue to change.
- Ask your dietitian how you can increase your energy and protein intake.
- Make the most of the times you feel hungry or crave certain foods, but be careful not to become too full by eating too quickly.
- Ensure you have room for nourishing food – avoid filling up on liquids at mealtimes, unless it's a hearty soup.
- Prevent dehydration by drinking liquids between meals (e.g. 30–60 minutes before or after meals).
- Don't eat late at night. This may make you uncomfortable and disturb your sleep.

Difficulty swallowing

Many people with stomach or oesophageal cancer have difficulty swallowing (dysphagia) before, during or after treatment. This may be because of where the tumour is located or as a side effect of treatment. 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.

It is important to change your diet so that you can still get enough nutrition, and to prevent losing weight and strength.



How to manage swallowing difficulties

- Change the consistency of your food by chopping, mincing or pureeing.
- Make food softer, e.g. use a slow cooker to keep food moist or mash your food with a fork.
- Snack on soft foods between meals, such as avocado, yoghurt, custard, ice-cream, diced tinned fruit and milkshakes.
- Try eating soft, nutritious foods, such as scrambled eggs, porridge, soup and casseroles.
- Avoid dry foods – add extra gravy or sauce to your meals.
- Chew carefully and slowly, sitting still and upright. Try to avoid talking while eating.
- Wash the food down with small sips of fluid.
- Talk to your doctor or dietitian if you are losing weight, or if you have pain or discomfort when swallowing.
- You may need to consider adding supplements to your diet to meet your nutritional needs, e.g. a ready-to-use nutritional supplement drink.

Reflux and choking

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

After surgery or radiotherapy for oesophageal cancer, some people choke or cough while eating. This may be due to scar tissue. It is important to 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 after eating.



How to relieve 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 avoid talking while eating.
- To help food digest, sit up straight when eating and for at least another 30 minutes.
- After an oesophagectomy, you should remain upright for four hours after eating. Try eating your evening meal about four hours before going to bed.
- Consider eating your main meal earlier in the day and having a small snack in the evening.
- Avoid bending over too far.
- Keep your chest higher than your abdomen when sleeping by using extra pillows or a foam wedge. Try to avoid lying on your left side, as reflux is often worse in this position.
- Don't overexert yourself, as this can cause reflux.
- See your doctor if solid foods cause coughing or get stuck.

Dumping syndrome

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

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



How to manage dumping syndrome

- Eat small meals throughout the day. Chew your food well.
- Eat slowly so your body can sense when it is full.
- Keep a record of foods that cause problems and avoid them. Surgery may have impaired your ability to absorb or tolerate certain foods, such as those containing lactose, fructose or gluten.
- Talk to a dietitian, who can help you work out how to change your meals to reduce the symptoms.
- Avoid foods and drinks high in sugar, e.g. cordial, soft drinks, cakes and biscuits.
- Eat starchy food, e.g. pasta, rice or potato.
- Eat meals high in protein, e.g. lean meats and poultry, fish, eggs, milk, yoghurt, nuts, seeds, and legumes/beans.
- Drink 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

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

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



Tips for managing anaemia

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



Key points

- Surgery to the stomach and oesophagus can cause significant side effects. This can affect your physical and emotional wellbeing.
- After treatment, you may have a poor appetite, find it difficult to eat certain foods, or feel full quickly. This can lead to weight loss and malnutrition.
- Physical changes to the way you eat and digest food following treatment may include reflux, heartburn, coughing and choking. Dumping syndrome is less common. Eating several small meals a day slowly can help with these symptoms.
- Sitting up during and after meals can help swallowing and digestion. It's best to avoid eating late meals and to wait about four hours after a meal before going to bed.
- To avoid dehydration, try to drink fluid in small amounts throughout the day. It is best not to drink much liquid at mealtimes.
- Dietitians can help tailor eating plans to suit your individual needs. They can also give you advice on nutritional supplements if you need to increase your vitamin or mineral intake. You may need tablets, powdered supplements, injections or infusions.
- Talk to your doctor or dietitian if you have ongoing trouble with eating and digestion, have symptoms of anaemia or if you keep losing weight.
- You may feel self-conscious when eating. Talking to a counsellor or someone who has been through a similar experience to you may help you cope with the changes.



Looking after yourself

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

Nutrition – See the *Managing side effects* chapter (pages 45–51) for information on managing your special dietary needs or eating problems after treatment.

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

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

Alternative therapies are used instead of conventional medical treatments. They are often promoted as cancer cures but they are not scientifically tested or proven to be effective. These therapies, such as coffee enemas and magnet therapy, can be harmful.

For more information, call 13 11 20 for a free copy of *Understanding Complementary Therapies* or download a digital version from your local Cancer Council website.

Relationships with others

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

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

Sexuality, intimacy and fertility

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

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

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

Life after treatment

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

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

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

Dealing with feelings of sadness

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

Talk to your GP, as counselling or medicine – even for a short

time – may help. Some people are able to get a Medicare rebate for sessions with a psychologist. Ask your doctor if you are eligible.

The organisation [beyondblue](https://beyondblue.org.au) has information about coping with depression and anxiety. Go to beyondblue.org.au or call their support service on **1300 22 4636**.

Follow-up appointments

After treatment, you will need regular check-ups to monitor your health and confirm that the cancer hasn't come back. 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. Your doctor may want to see you three to four times a year for the first couple of years. This will gradually decrease to twice a year. You should also see a dietitian for ongoing advice about good nutrition. Check with your doctor if you are unsure of your follow-up plan.

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

What if the cancer returns?

For some people, the 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 or radiotherapy. Sometimes people have palliative treatment to ease their symptoms.

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. In this case, you may have treatment that focuses specifically on the area of your body where the cancer has returned.



Seeking support

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

Practical and financial help

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

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

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

Talk to someone who's been there

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

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

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

Types of support

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

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

Talk to your nurse, social worker or Cancer Council 13 11 20 about what is available in your area.

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



Caring for someone with cancer

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

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

Support services such as Meals on Wheels, home help or visiting nurses can help you in your caring role. You can find local support services, as well as practical information and resources, through the Carer Gateway. Visit carergateway.gov.au or call 1800 422 737.

There are also many groups and organisations that can provide you with information and support, such as Carers Australia, the national body representing carers in Australia. Carers Australia works with the Carers Associations in each of the states and territories. Visit carersaustralia.com.au or phone 1800 242 636 for more information and resources.

Call Cancer Council 13 11 20 to find out more about carers' services and support groups in your area. You can also ask for a copy of the *Caring for Someone with Cancer* booklet, or download a digital version from your local Cancer Council website.



Useful websites

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

Australian

| | |
|---|--------------------------------|
| Cancer Council Australia..... | cancer.org.au |
| Cancer Australia..... | canceraustralia.gov.au |
| Cancer Council Online Community..... | cancercouncil.com.au/OC |
| Carer Gateway..... | carergateway.gov.au |
| Carers Australia..... | carersaustralia.com.au |
| Department of Health..... | health.gov.au |
| Department of Human Services..... | humanservices.gov.au |
| Dietitians Association of Australia..... | daa.asn.au |
| healthdirect Australia..... | healthdirect.gov.au |
| beyondblue..... | beyondblue.org.au |
| Australia and New Zealand Gastric and Oesophageal Surgery Association..... | anzgosa.org |
| Gastroenterological Society of Australia..... | gesa.org.au |
| GI Cancer Institute..... | gicancer.org.au |
| Pancare Foundation..... | pancare.org.au |

International

| | |
|-------------------------------------|-------------------------------|
| American Cancer Society..... | cancer.org |
| Cancer Research UK..... | cancerresearchuk.org |
| Macmillan Cancer Support (UK)..... | macmillan.org.uk |
| National Cancer Institute (US)..... | cancer.gov |
| No Stomach for Cancer (US)..... | nostomachforcancer.org |



Question checklist

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

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



Glossary

abdomen

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

adenocarcinoma

A cancer that starts in glandular cells in the oesophagus or stomach.

anaemia

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

anaesthetic

A drug that stops a person feeling pain during a medical procedure.

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 treatment that uses drugs to kill cancer cells or slow their growth.

CT scan

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

dumping syndrome

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

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 surgery for early-stage stomach or oesophageal cancer. Tissue is removed using an endoscope.

endoscopy

A type of internal examination or diagnostic test. An endoscope is inserted into the oesophagus and stomach so the lining can be examined. Also called a gastroscopy.

familial adenomatous polyposis

A condition that causes polyps to form in the large bowel. The polyps will become cancerous if untreated. A risk factor for stomach cancer.

gastrectomy

The surgical removal of part or all of the stomach.

gastrointestinal (GI) tract

The passage from the mouth to the anus that digests food and eliminates waste. The upper GI tract includes the oesophagus and the stomach.

gastro-oesophageal junction

The point where the stomach meets the oesophagus.

gastro-oesophageal reflux disease (GORD)

A condition when stomach acid leaks into the oesophagus, causing irritation. 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, often caused by reflux.

HER2

Human epidermal growth factor receptor 2. A type of protein found on most cells in the human body.

laparoscopy

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

lymphatic system

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

lymph nodes

Small, bean-shaped glands that collect and destroy bacteria and viruses. Also called lymph glands.

Lynch syndrome

A risk factor for stomach cancer.

malignant

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

metastasis (plural: metastases)

Cancer that has spread from another part of the body. Also called secondary cancer.

mucosa

Moist tissue lining body organs, such as the digestive tract, lungs and nose. The mucosal layer is the innermost layer of the oesophagus and stomach.

nutrition

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

oesophagectomy

The surgical removal of all or part of the oesophagus.

oesophagitis

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

oesophagoscopy

The examination of the oesophagus with an endoscope.

oesophagus

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

omentum

A protective apron of fatty tissue over the abdominal organs.

partial gastrectomy

See subtotal gastrectomy.

peritoneum

The lining of the abdomen.

pernicious anaemia

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

PET scan

Positron emission tomography scan. A scan in which a person is injected with a small amount of radioactive glucose solution to find cancerous areas.

radiotherapy

The use of radiation to kill cancer cells or injure them so they cannot grow and multiply. Also called radiation therapy.

reflux

When stomach acid is released back up into the oesophagus.

squamous cell carcinoma

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

stent

A 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

Treatment that attacks specific particles (molecules) within cells that allow cancer to grow and spread.

total gastrectomy

The surgical removal of the entire stomach.

ultrasound

A non-invasive scan that uses soundwaves to create a picture of part of the body. Used to measure the size and position of a tumour.

upper GI endoscopy

See endoscopy.

Can't find a word here?

For more cancer-related words, visit:

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

References

1. E C 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.
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), *Australian Cancer Incidence and Mortality (ACIM) books: Stomach cancer*, AIHW, Canberra, 2017.
4. Australian Institute of Health and Welfare (AIHW), *Australian Cancer Incidence and Mortality (ACIM) books: Oesophageal cancer*, AIHW, Canberra, 2017.



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 cancer nurses are available to answer your questions and link you to services in your area, such as transport, accommodation and home help. We can also help with other matters, such as legal and financial advice.

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

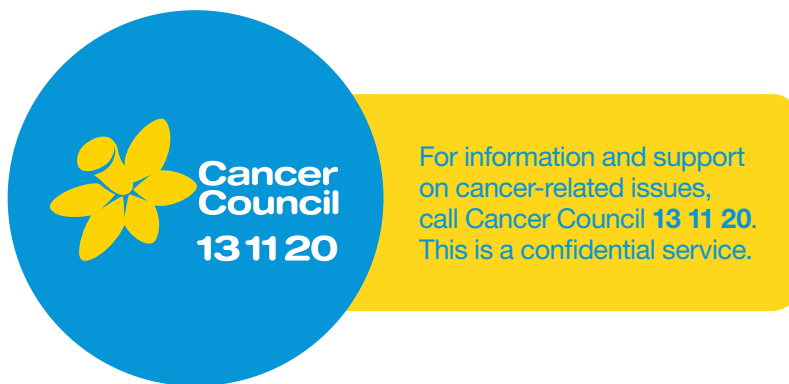
Cancer Council services and programs vary in each area.

13 11 20 is charged at a local call rate throughout Australia (except from mobiles).



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

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



Visit your local Cancer Council website

Cancer Council ACT
actcancer.org

Cancer Council NSW
cancercouncil.com.au

Cancer Council NT
nt.cancer.org.au

Cancer Council Queensland
cancerqld.org.au

Cancer Council SA
cancersa.org.au

Cancer Council Tasmania
cancertas.org.au

Cancer Council Victoria
cancervic.org.au

Cancer Council WA
cancerwa.asn.au

Cancer Council Australia
cancer.org.au

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To support Cancer Council, call your local Cancer Council or visit your local website.*