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A guide to understanding diagnosis and treatment:

OESOPHAGEAL CANCER

Pancare Foundation

Pancare Foundation is Australia's leading not-for-profit organisation committed to inspiring hope, raising awareness and funding research for upper gastrointestinal cancers – pancreatic, liver, stomach, biliary and oesophageal cancers.

To meet the needs of people living with oesophageal cancer, the information in this handbook has been collated from various people, including patients, reputable organisations and a panel of experts comprising:

- **Professor Mehrdad Nikfarjam**, Liver, Pancreas and Biliary Surgeon, Pancare Foundation Medical Advisory Committee Chair
- **Associate Professor Zee Wan Wong**, Medical Oncologist, Head of Oncology Unit, Peninsula Health, The Bays Hospital
- **Shannon Gleeson**, Specialist Pancreatic and Upper Gastrointestinal Cancer Nurse
- **Tiffany Dobson,** Upper Gastrointestinal Cancer Support Nurse
- **Dr Amy Larsen,** Program Enablement Manager and Research Manager
- **Katrina Walsh**, Research Manager
- Pancare Foundation patient and carer advisory working group.

You can view the full reference list in the Resources section of this handbook.

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Note to the Reader

The medical profession and research community are continually updating information about oesophageal cancer. We have taken care to ensure that the information in this handbook reflects the clinical best practice at the time of publication. Sponsoring organisations have not had input into the contents of this document.

This handbook is not a substitute for professional help or advice from medical practitioners. It is important to discuss any medical (physical, emotional and/or general) symptoms, questions or concerns with your health professional as soon as possible.

Pancare Foundation excludes itself from all liability for any injury, loss or damage incurred by use of, or reliance on, the information provided in this handbook.

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Supporting you on your cancer journey

A cancer diagnosis can come as a terrible shock, but we are here to help you every step of the way and to support you and your family and friends.

PanSupport is Pancare Foundation's dedicated support, resource and information service that is available for all Australians affected by upper gastrointestinal cancers – that is, pancreatic, liver, stomach, biliary and oesophageal cancers.

Talk to our specialist PanSupport team today to learn more about:

- a recent diagnosis
- your treatment options
- working with your care team
- managing symptoms
- ways to nurture your health through diet, exercise and strengthening your emotional wellbeing
- practical ways we can support you and your family.

Talk to our specialist support team today

To discover more or book a call with our specialist PanSupport team, visit **pancare.org.au/pansupport** or call toll-free on **1300 881 698**.

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Introduction

This handbook is for anyone who has recently been diagnosed with oesophageal cancer, and for their partners, family members and carers. It gives a general introduction to oesophageal cancer, provides information on tests and investigations that help confirm a diagnosis, and offers an overview of possible treatment options and the wider impact of the diagnosis. The information may also be helpful for anyone who is undergoing investigations for oesophageal cancer and wondering what the next steps might be.

If you have only just been told about your diagnosis, you may be feeling shocked; many people diagnosed with oesophageal cancer would not have had any inkling that they were seriously ill. You may have been feeling unwell for a while and not known what was wrong. You might feel frightened, angry or upset. Just remember that there is no 'right' way to feel – everyone deals with things in their own way.

This handbook is a good place to start looking for up-to-date information relevant to your situation. You don't need to read everything in this handbook in one go. Please remember that you should always consult your doctor about matters that affect your health. This handbook is not a substitute for professional medical, legal or financial advice. You should seek appropriate independent professional advice relevant to your situation; you may wish to discuss anything raised in this handbook with these professionals.

Your guide for using this handbook

This handbook contains key details in colour-coded boxes:

Additional details

Helpful tips

Patient stories

Frequently asked questions

At the back of this handbook, you will find:

- a glossary, which explains common terms about oesophageal cancer (page 45)
- where to find further information and support (page 50).

Contents

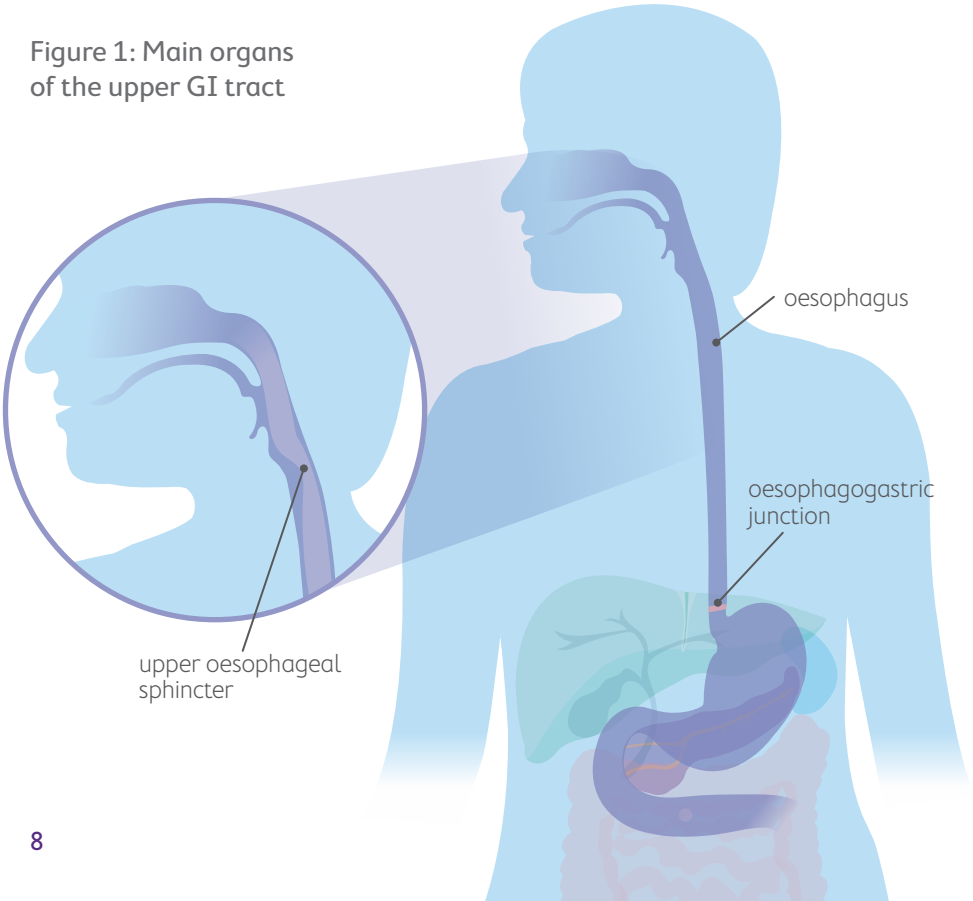
About the oesophagus

The oesophagus forms part of the upper gastrointestinal (GI) tract. The GI tract is a part of the digestive system. The function of the oesophagus is to transport food and fluid from the mouth to the stomach after being swallowed.

The oesophagus is the tube that starts at the back of the mouth and ends in the stomach. It lies behind the windpipe (trachea) and in front of the spine. After you swallow food and liquids, they go down the oesophagus and into the stomach (*Figure 1*). The oesophagus is sometimes known as the 'food pipe' or 'gullet'. It is about 25 centimetres long.

The oesophagus has muscles that squeeze and expand to move food down to the stomach. This motion is called peristalsis (per-ee-stal-sis). Nutrients are not absorbed in the oesophagus.

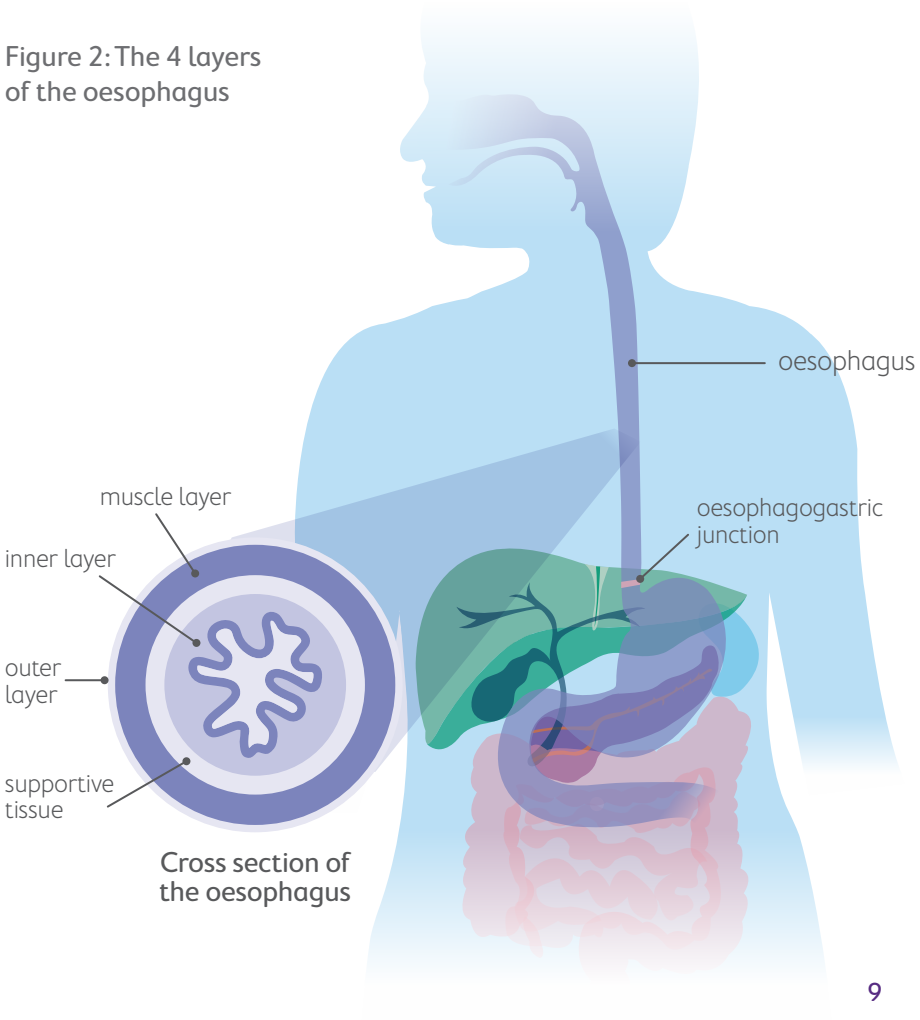
Figure 1: Main organs of the upper GI tract



The oesophagus has 4 layers (*Figure 2*). These are the:

- inner layer, known as the mucosa – this layer is in contact with food
- layer of connective tissue that produces mucus, called the submucosa – mucus helps the oesophagus stay moist
- muscle layer, called the muscularis – this layer pushes food down into the stomach
- outer layer, known as the adventitia – this layer attaches the oesophagus to nearby parts of the body so that it doesn't move around.

Figure 2: The 4 layers of the oesophagus



Oesophagogastric junction and gastric reflux

The oesophagogastric junction is where the oesophagus meets the stomach (*Figure 2, page 9*). This part of the oesophagus is important because it controls the flow of food into the stomach. It also stops the stomach contents from backflowing into the oesophagus.

The oesophagogastric junction has a muscle called a sphincter. This muscle helps prevent stomach acids – which are needed for digesting food – from going up into the oesophagus. Gastric reflux (also known as acid reflux) happens when this muscle relaxes at the wrong time, allowing stomach acids to flow back up into the oesophagus.

Occasional acid reflux is usually not a health concern, although it can be uncomfortable. But if acid reflux happens often, it should be treated to help prevent long-term gastric reflux, also called gastro-oesophageal reflux disease (GORD). GORD increases the risk of developing oesophageal and oesophagogastric cancers.

About oesophageal cancer

Oesophageal cancer occurs when abnormal cells in the oesophagus or oesophagogastric junction grow out of control. There are several risk factors for developing oesophageal cancer.

Oesophageal cancers are divided into two main groups, depending on the type of cell that the cancer grows from:

- **Adenocarcinoma** (the most common type of oesophageal cancer) start in the cells that produce and release mucus and other fluids. Adenocarcinomas are most often in the lower part of the oesophagus, near the stomach.
- **Squamous cell carcinoma** start in the flat cells lining the oesophagus.

Risk factors

Most oesophageal cancers develop with no obvious cause, but some factors are known to increase the risk.

Health risk factors

GORD, also known as long-term acid reflux, may change the cells of the lower oesophagus into the same type of cells that line the stomach.

Another condition, called Barrett's oesophagus, can also be a risk factor for oesophageal cancer. This is where the cells in the lining of the lower oesophagus change into the same type of cells that line the intestine. This change is called metaplasia, and it can progress to a more dangerous, precancerous form called dysplasia. Although rare, these changes can go on to form oesophageal cancer.

Environmental and behavioural risk factors

Environmental and behavioural risk factors for developing oesophageal cancer include:

- smoking tobacco
- drinking alcohol frequently
- not eating enough fresh fruit and vegetables
- obesity
- exposure to certain chemicals.

Hereditary risk factors

Hereditary factors that increase the risk of oesophageal cancer are very rare. They include Peutz–Jeghers syndrome and PTEN (phosphatase and tensin homologue) hamartoma tumour syndrome.

There are currently no genetic tests available to screen for oesophageal cancer.

Towards an oesophageal cancer diagnosis

Reaching a diagnosis of oesophageal cancer can be a lengthy and complex process. When the disease first develops, it often does not cause any obvious symptoms, or the symptoms may be like those caused by common, less serious conditions. This means you may have been sent for several different tests before oesophageal cancer was considered, and you may have had the cancer for some time without knowing.

Oesophageal cancer is usually diagnosed because you have had symptoms such as:

- difficult or painful swallowing
- heartburn or indigestion, especially if it is getting worse
- blood in your vomit
- persistent cough
- black stools
- unexplained fatigue
- feeling of choking when swallowing
- discomfort in the upper abdomen, especially when eating
- unexplained weight loss.

You may have gone to see your regular doctor, or general practitioner (GP), for these symptoms. More serious symptoms, like vomit with blood in it, may have resulted in an emergency admission and further investigations.

Once less serious conditions have been ruled out, your GP may refer you to an upper GI surgeon or gastroenterologist to investigate your symptoms further. You may need several different tests to confirm the diagnosis of oesophageal cancer.

If any symptoms appear or get worse between appointments, or while you are waiting for tests or results, you should let your doctor know right away.

If you have been diagnosed with oesophageal cancer and haven't had any symptoms, it is probably because you had another medical procedure and the cancer was found by chance.

Tests and investigations: what, why and how

The tests used to diagnose your oesophageal cancer will help doctors understand your condition. You may need other tests to confirm the type of oesophageal cancer, where it is, whether it has spread to nearby organs or other parts of the body, and what the best treatment will be for you.

You may not need all the tests described in this section, and you might have other tests that are not included in this handbook. Your specialist will give you more detailed information about the most appropriate tests for you.

Initial investigations

The initial investigations will help doctors understand why you have certain symptoms, and whether they are being caused by a condition; this is called making a diagnosis.

Physical exam and history

The doctor will ask you about your medical history and your health habits. The doctor will also check your body for signs of disease, such as lumps, swelling or anything else that seems unusual.

Blood tests

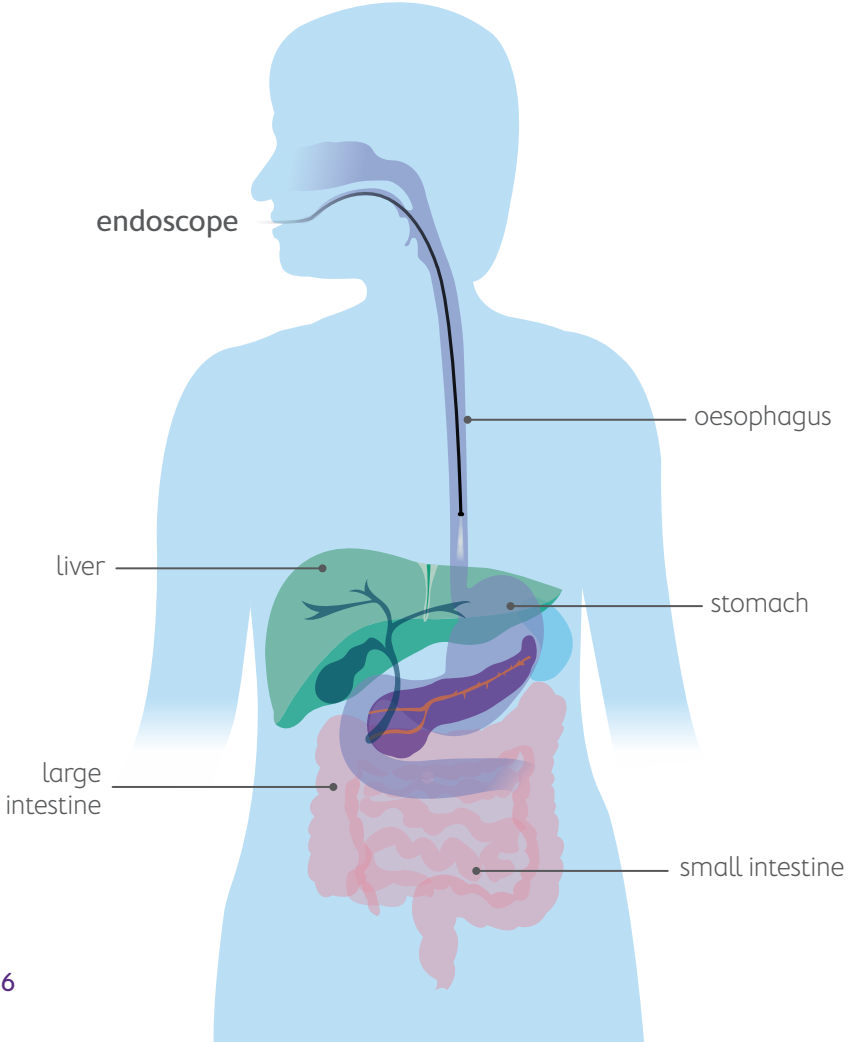
You will have blood tests as part of the initial set of tests and during ongoing health checks. Blood tests are used to check your blood count, liver and kidney function, and general health.

Endoscopy

Endoscopy is used to diagnose oesophageal cancer. Your doctor may also call it an oesophagoscopy or gastroscopy.

An endoscope is a thin, flexible tube with a small video camera on the end. While you are sedated (asleep), the doctor will slide the endoscope down your oesophagus to look for signs of cancer (*Figure 3*). The doctor may also take a biopsy (a small sample) of oesophageal tissue during the procedure. The biopsy will be sent to a pathologist to look for signs of cancer or other disease.

Figure 3: Endoscopy for diagnosing oesophageal cancer



Staging tests

If you have been diagnosed with oesophageal cancer, you may need to have more tests to help the doctor work out the size of the cancer and whether it has spread elsewhere. To find out more about the stages of oesophageal cancer, see *'Stages of cancer'* on page 19.

Endoscopic ultrasound (EUS)

You may need to be booked for an EUS after your initial endoscopy to see whether the cancer has spread to the surrounding lymph nodes, or deeper into the oesophagus or stomach tissue. EUS uses an endoscope like the endoscopy procedure, but instead of having a camera on the end of the endoscope, an ultrasound probe is attached. This probe uses soundwaves to create a picture of the inside of the body. The doctor may also take a biopsy of oesophageal tissue during the procedure. The biopsy will be sent to a pathologist to look for signs of cancer or other disease. The result from the EUS can help doctors better assess the cancer.

Biopsy

A tissue biopsy is needed to confirm the diagnosis of cancer and to get as much information as needed for treatment planning. Tissue samples for examination under a microscope can be taken during an endoscopy procedure or during a laparoscopy (see *'Laparoscopy'* on page 18). A biopsy may not be performed in certain cases when surgical removal is planned up front.

Computerised tomography (CT) scan

A CT scan uses X-rays to build a 3-dimensional picture of your oesophagus and the organs around it. Your CT scan will probably also include the chest area around the oesophagus and the abdomen, to check for any signs of cancer outside the oesophagus.

Positron emission tomography (PET)-CT scan

A PET-CT scan combines a CT scan with a PET scan. For a PET scan, a small amount of radioactive dye is injected into a vein. On the scans, the injected substance shows areas where the cells are more active in the body. This type of scan can pick up very small areas of active cells, so it can help to give a clearer picture of the cancer.

Magnetic resonance imaging (MRI)

MRI uses magnets and radio waves to build a detailed cross-sectional picture of the oesophagus, stomach and surrounding areas.

Laparoscopy

This is a small operation done under general anaesthetic. A long tube with a camera at one end (a laparoscope) is inserted through a small cut in your abdomen to see the cancer, and check whether it has spread to other parts of the body. Other small cuts may be made so instruments can be inserted to take a biopsy. Sometimes an ultrasound probe is used (laparoscopic ultrasound). Laparoscopy is sometimes called keyhole surgery.

Even if you have had an urgent referral for a test, you may have to wait days or weeks for your appointment. It is also common to have to wait for test results. Waiting can be frustrating and worrying, especially if you are already unwell. However, it is unlikely that your cancer will grow enough during this waiting period to cause you further harm if your symptoms are otherwise stable. It is still a good idea to ask your doctor how long you may have to wait. If you think you have been waiting too long or have any concerns, check with your doctor.

If your symptoms get worse or you start to feel more unwell while you are waiting, it is important to get in touch with your doctor. If you can't see your doctor, and you can't control your symptoms at home, you may need to go to the emergency department. If you have to go into hospital for any reason, you can ask whether any tests you are waiting for can be done while you are there.

Stages of cancer

Your test results will give your doctors a detailed diagnosis and tell them what stage your cancer is at.

Staging is working out the size of a cancer and whether it has spread near the tumour site or to other areas of the body. It is an important part of the assessment and treatment planning. Sometimes, staging can only be done after the cancer has been removed during surgery.

There are different ways to stage cancer. In Australia, the common ones are:

- numbered cancer stage system (*Figure 4, page 20*)
- tumour-node-metastases (TNM) system (*Figure 5, page 20*).

Figure 4: Numbered cancer stage system

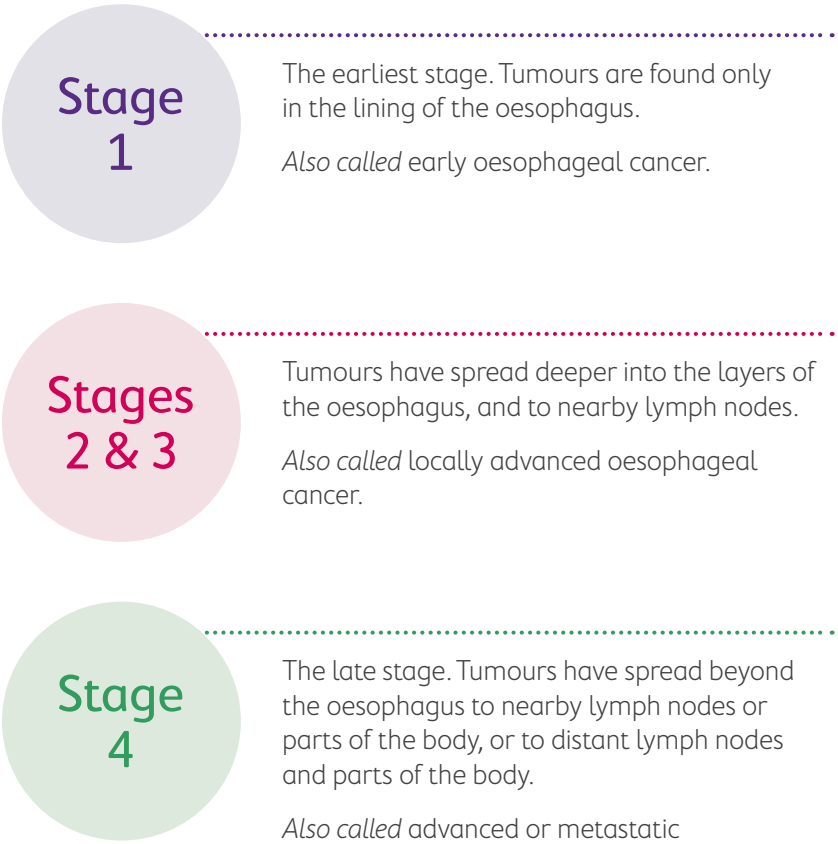


Figure 5: TNM (tumour-node-metastasis) system

T (tumour)	The size and depth of the tumour
N (node)	Indicates whether the cancer has spread to the lymph nodes
M (metastasis)	Indicates if the cancer has spread to other parts of the body (metastatic cancer)

Treatment journey

After your tests are complete, a team of doctors will design a treatment journey that is specific to you. You should receive high-quality care that aligns with your treatment goals and personal choices. The Cancer Council has developed detailed cancer care pathway guides to help health professionals provide an optimal standard of cancer care.

Based on the *Optimal care pathway for people with oesophagogastric cancer*, anyone diagnosed with oesophageal cancer should have their case reviewed at a specialist health centre, where a specialist multidisciplinary team of health professionals can assess and treat the disease. There should be one key point of contact at every step of your treatment journey.

Who in the multidisciplinary team will treat my cancer?

You will have a main doctor who will be managing your care, and they will consult with different doctors and other health professionals who are specialists in your cancer. This is called a multidisciplinary team, and may include:

- doctors from the radiology, pathology, surgery and oncology departments
- specialist nurses and other allied health professionals.

Once you have had all your tests and investigations, your specialist team will meet to discuss the results. The multidisciplinary team will use their expert knowledge to review your case and agree on the best treatment options for you.

Rural and regional hospitals are often part of a network linked to metropolitan specialist centres. This ensures that the best treatment and care are available to all patients, regardless of where they live in Australia.

Treatments for oesophageal cancer

Surgery is often used to treat oesophageal cancer. The type of surgery depends on the location of your cancer. Other options for treatment include radiation therapy, chemotherapy and immunotherapy.

The order and type of treatment you will receive depend on your individual situation. You might have one or more of these treatment options. You may have chemotherapy or radiation therapy before or after surgery, or you might not have surgery at all. The order of the treatment options in this handbook is not necessarily the order you will receive them.

Prehabilitation

Prehabilitation (prehab) means getting ready for cancer treatment in whatever time you have before treatment starts. This includes increasing your awareness of what you are eating, doing regular physical activity and looking at ways to improve your mental wellbeing through mindfulness. If you can stop smoking and cut down on your alcohol intake, it will benefit your cancer treatment, recovery and overall health.

Prehabilitation can be a program with your healthcare team (including doctors, nurses, dietitians, exercise physiologists and psychologists) or something you do by creating your own plan at home by yourself.

By getting support early to change health habits and ensure that you are as healthy as possible before treatment, you are more likely to:

- leave hospital sooner after surgery
- cope better with the side effects of cancer treatment
- have fewer side effects
- have more treatment choices
- have better long-term health.

Prehabilitation continues as rehabilitation to help you recover from cancer treatment.

Surgery

If you have been told that surgery to remove your cancer is possible, you may have been diagnosed with a cancer that has not spread to other organs and is not significantly attached to major vessels. Your doctor may call your cancer operable or resectable.

If the tumour partly surrounds some major vessels, it may be referred to as borderline operable. You may be offered surgery in these cases, depending on the vessels involved, but it is more likely that you will be offered preoperative treatment, such as chemoradiotherapy or chemotherapy alone, before surgery is considered.

Endoscopic resection

If the oesophageal cancer is quite small when detected and has not spread, the surgeon may be able to do an endoscopic resection. This is where the surgeon removes the tumour through endoscopy. This type of surgery does not need as much recovery time as an oesophagectomy.

Oesophagectomy

Surgery to remove all or part of your oesophagus is called an oesophagectomy (*Figure 6, page 25*). The amount of oesophagus that needs to be removed depends on the size and location of the cancer. The surgeon will also remove the surrounding lymph nodes so they can be examined for cancer cells.

If you need a large part of your oesophagus removed, or if you need the upper part of your oesophagus removed, it may be hard to reattach the stomach. The surgeon might use a piece of your intestine to extend the remaining oesophagus to reach your stomach.

An oesophagectomy is a complex surgery, and you may need to stay in hospital for 7 to 14 days. It may take 6 to 12 months for you to fully recover from the procedure.

Oesphago-gastrectomy

Surgery to remove the lower part of your oesophagus and top part of your stomach is called an oesophago-gastrectomy (*Figure 7, page 25*).

As part of the oesophago-gastrectomy, the surgeon will connect the lower part of your stomach to the healthy part of your upper oesophagus to make a new oesophagus.

An oesophago-gastrectomy is a complex surgery, and you may need to stay in hospital for 7 to 14 days. It may take 6 to 12 months for you to fully recover from the procedure.

Figure 6: Oesophagectomy

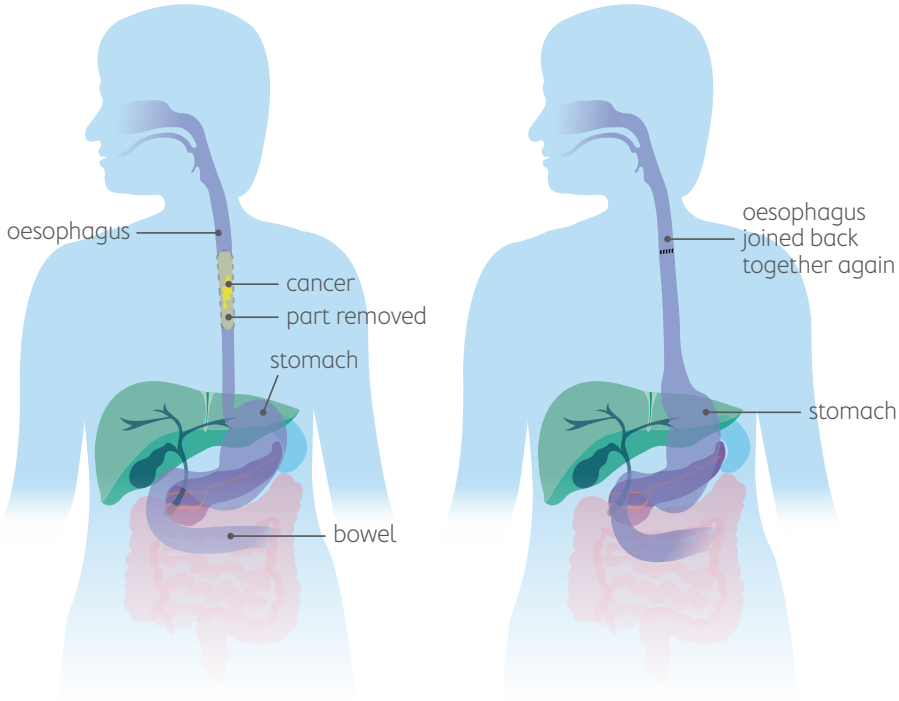
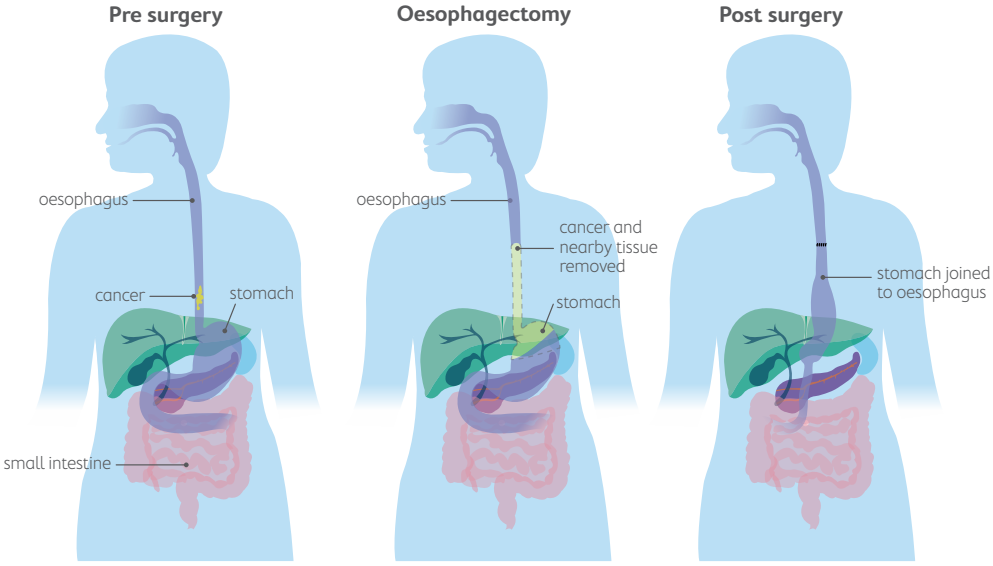


Figure 7: Oesophago-gastrectomy



Parts of the body removed

Oesophageal stents

If you have a blockage in your oesophagus, you might need to have an oesophageal stent placed.

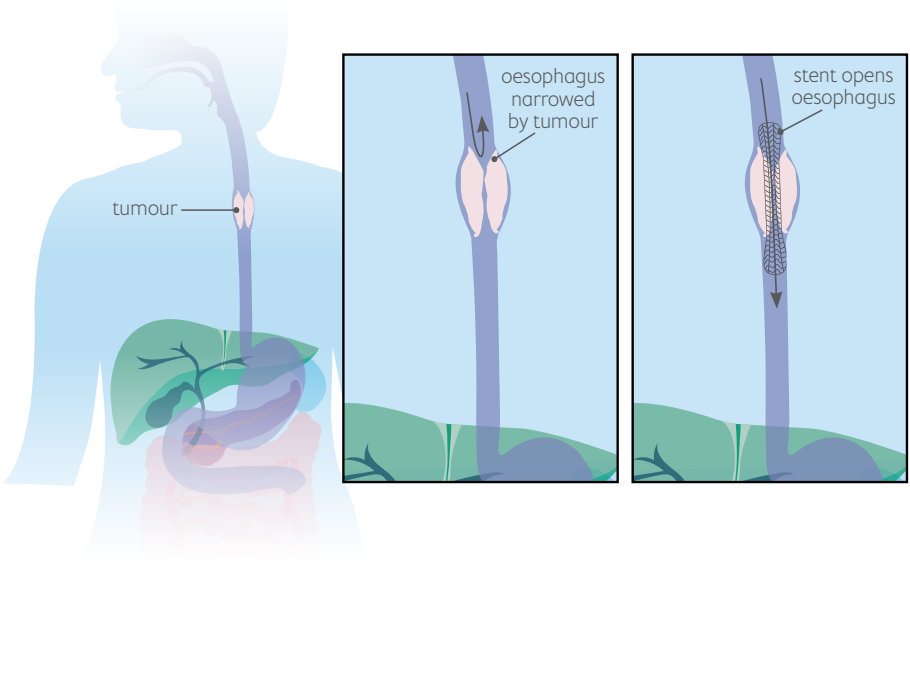
A stent won't treat the cancer, but it will help to relieve blockage of the food passage caused by the cancer so that you are more comfortable.

A stent is a flexible tube that sits in the oesophagus. It helps keep your oesophagus open so you can eat, drink and swallow better (*Figure 8*). Stents can be temporary or permanent. While you are sedated, your doctor will use a gastroscope to insert the stent.

A stent might be used:

- if your doctor thinks surgery is not an appropriate option for you, but the cancer is causing a blockage
- after surgery, when there is a narrowing of your oesophagus (called a stricture) or your oesophagus is leaking.

Figure 8: Placement of an oesophageal stent



Radiation therapy

Radiation therapy may be used by itself or combined with chemotherapy to reduce the chances of oesophageal cancer returning locally. Radiation therapy can be used to try to shrink the tumour before surgery, to increase the chance of successful surgical removal. It may also be offered to kill any cancer cells that are left after the tumour has been surgically removed.

Radiation therapy can sometimes be helpful when cancer has spread to other parts of the body (advanced or metastatic cancer).

Radiation therapy uses high-energy X-rays to destroy cancer cells. Modern radiation techniques target the cancer cells precisely, so it is called a localised treatment. Normal cells around the cancer cells can also be affected, which is why radiation therapy can cause side effects such as fatigue, nausea and swallowing difficulties.

Chemotherapy

Chemotherapy may be offered to patients with oesophageal cancer, either alone or in combination with other therapies such as radiation therapy. For oesophageal cancers that have spread and are not surgically resectable, chemotherapy on its own or in combination with immunotherapy (see *'Targeted therapy and immunotherapy'* on page 32) may improve symptoms and quality of life, and extend life expectancy. You should consider being involved in clinical trials if they are available. Ask your oncologist whether a clinical trial for treatment of oesophageal cancer is available in your region (see *'Clinical trials'* on page 42).

Depending on the type of oesophageal cancer, chemotherapy may be the only treatment used, or it could be given at different times, including:

- before surgery (known as neoadjuvant chemotherapy) – in these cases, the chemotherapy is given with the aim of shrinking the tumours or controlling the cancer growth for some time, to make surgical treatment more feasible or beneficial
- after surgery (known as adjuvant chemotherapy) – this has been shown to reduce the risk of cancer recurrence and is routinely offered after surgery
- both before and after surgery.

Chemotherapy is usually given intravenously (through a drip into the veins) at a hospital or cancer clinic, or can be given orally (swallowed as a pill or tablet). Because chemotherapy medicines travel throughout the bloodstream (systemic treatment), side effects can affect many parts of the body. For someone with advanced oesophageal cancer, chemotherapy can also be used for palliative treatment, to relieve symptoms and slow progression of the disease.

Often, patients are fitted with a temporary catheter that allows chemotherapy and other medicines to be administered intravenously without the need for multiple needle sticks. The most frequently used are either a PICC (peripherally inserted central catheter) line or a chemo port (see information boxes for more details). These may remain for several weeks, even months, with regular monitoring and care.

What is a PICC line?

A PICC is a peripherally inserted central catheter. It is used to give treatments, fluids, medicines or blood transfusions into your bloodstream and to take blood samples. A PICC is used instead of intravenous (IV) cannulas (needles in your arm) for your treatments. IV cannulas are put in for each treatment, but a PICC stays in for the duration of your treatments. This makes having frequent, repeated, continuous or at-home cancer treatments easier.

A PICC is a long, flexible, hollow tube. The tube is called a catheter. All PICCs have one end that goes through a vein in your upper arm up to a large vein near your heart (*Figure 9, page 30*). Outside your body, the PICC divides into 1, 2 or 3 smaller tubes, called lumens. Each lumen may have a small clamp and has a cap on the end. A length of the PICC stays on the outside of your inner upper arm and is covered by a dressing. Your nurse will give your treatment, or take blood from you, through the lumen. Your treatment travels through the tube straight into your bloodstream.ur PICC line will be put in by a specially trained member of your healthcare team. This can happen in a day unit or in the radiology department. A dressing keeps the area clean and dry, which is very important. A member of your healthcare team will advise of any restrictions on your activities.

Your PICC line can stay in as long as it is needed. This can be weeks, months or longer.

Figure 9: PICC line (peripherally inserted central catheter line) placement

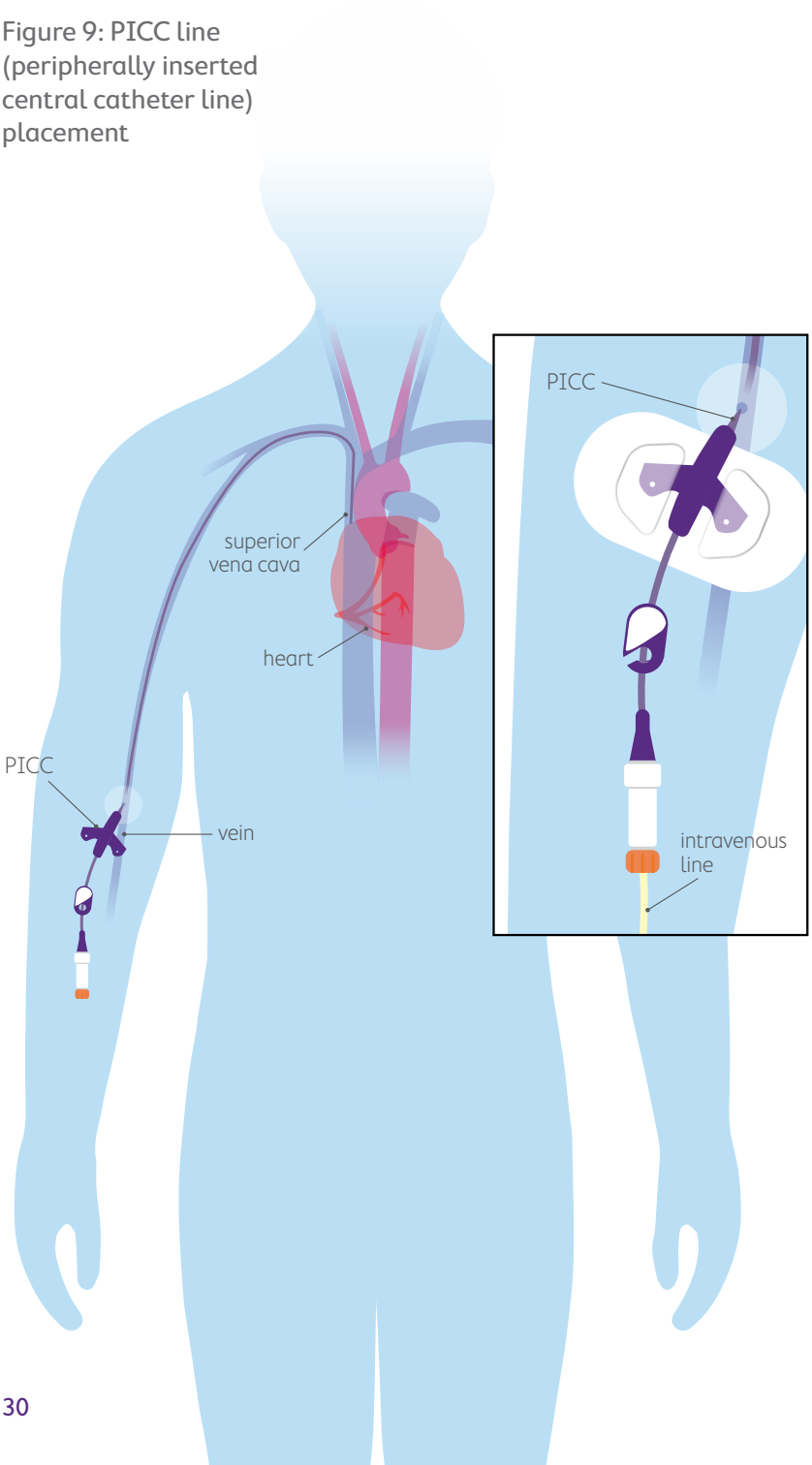
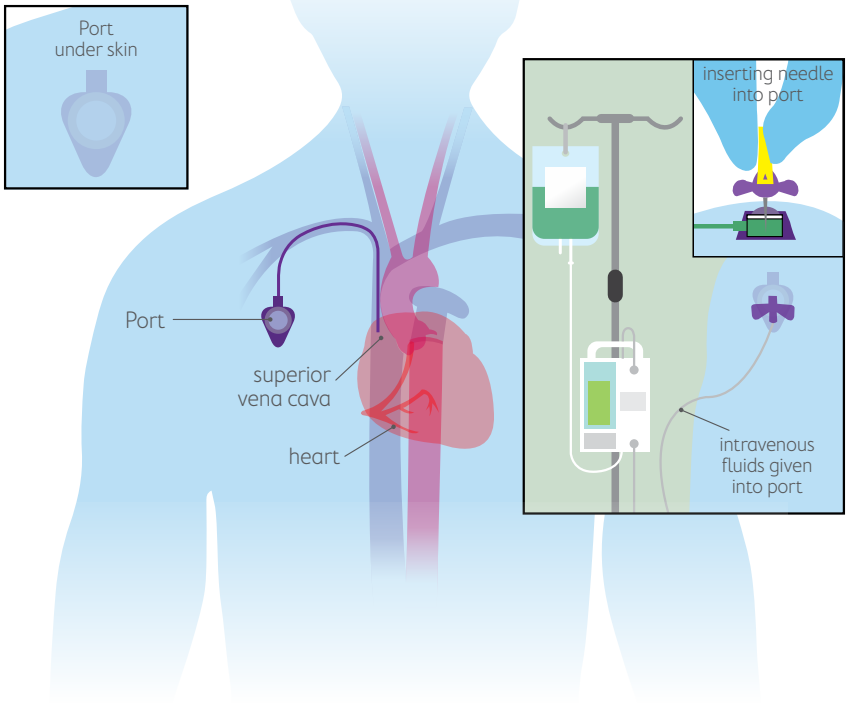


Figure 10: Chemo port placement



What is a Chemo Port?

A chemotherapy (chemo) port is a small device that is implanted under the skin, usually on the right side of the chest. It has a thin tube that is guided into a large vein above the heart (*Figure 10*). Chemotherapy medicines can be delivered straight into the port.

A port will make a visible 'bump' under the skin, but this can be easily covered with regular clothing. Many people who receive chemotherapy choose to have a port implanted, if recommended by their treatment team.

Targeted therapy and immunotherapy

Targeted therapies are drugs that target specific genes and proteins involved in cancer growth. Immunotherapies are one type of targeted therapy.

Targeted therapies are only effective for some cancers, so you may need to undergo pathology testing to see if they will benefit you.

Immunotherapy has been shown to work well with chemotherapy for certain types of oesophageal cancer. Immunotherapies are usually delivered as a single injection or infusion per session, and often there are several sessions.

Immunotherapies and other targeted therapies are rapidly evolving, with the Therapeutic Goods Administration (TGA) approving new therapies all the time. The costs of these therapies are also changing, as some get listed on the Pharmaceutical Benefits Scheme (PBS).

Your doctor will let you know which therapies are available at the time of your treatment, and which might suit you.

Managing symptoms and treatment side effects

Because oesophageal cancer affects the digestive system, your eating and drinking will be affected. Managing these changes is important for your recovery, and will make you feel better in general. Treatments can affect people differently. You might have no side effects, or some or all of them, but there are plenty of things you can do to improve your general wellbeing.

Table 1 lists the most common side effects from the most common treatment options for oesophageal cancer: surgery, radiation therapy, chemotherapy, and targeted therapy and immunotherapy.

Rare, but serious, side effects can also occur with immunotherapies, such as immune-related symptoms, hormone changes and inflammation (swelling) of organs. It is important to contact your doctor and report these symptoms as soon as you are aware of them.

Table 1: Common side effects of oesophageal cancer treatments

Surgery	Radiation therapy	Chemotherapy	Targeted therapy and immunotherapy
• Fatigue • Pain • Diarrhoea and malabsorption • Weight loss • Loss of appetite • Feeling full quickly • Difficulty swallowing and reflux	• Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea or constipation • Fatigue • Weight loss • Skin changes in the area (redness or peeling) • Increased mucus production • Difficulty swallowing and reflux	• Nausea and vomiting • Loss of appetite • Diarrhoea or constipation • Fatigue • Fever • Weight loss • Higher risk of infections • Sore mouth or throat • Taste changes • Burning or prickling feeling in the fingers and toes • Weakness, numbness and pain in the hands and feet	• Skin rash • Flu-like symptoms • Abdominal pain • Diarrhoea • Weight changes • Joint pain

A range of options can help you manage any symptoms or side effects, including:

- anti-sickness medication or complementary therapies to help with nausea
- pain medication
- seeing an oncology dietitian, who can help with diet-related side effects
- complementary therapies such as aromatherapy, reflexology and relaxation therapy
- coping strategies, as discussed with a psychologist or social worker.

If you are in hospital, your care needs should be assessed before you leave. These may include a referral to a community-based healthcare team (for example, community palliative care and a GP) who have expertise in managing pain and other cancer symptoms.

Pain relief

If pain is your main issue, you may be referred to a pain specialist to help manage it. Your GP should be sent a letter explaining your condition, and you should be given the name of a person at the hospital to contact if you have any concerns or need additional support.

Pain relief may include:

- medication
- surgery, radiation therapy or chemotherapy, to remove a tumour that is pressing on nerves or another organ.

Pain medication includes over-the-counter medicines such as paracetamol. The doctor may also prescribe anti-inflammatory medicines to help manage your pain. If your pain is severe, you may need strong pain medicines such as opioids.

Nutritional support

Oesophageal cancer and its treatment can place extra demands on your body, greatly increasing your nutrient and energy (caloric) needs, which can lead to weight loss. Weight loss can contribute to fatigue, delay and lengthen recovery, and negatively affect your quality of life. Also, because the cancer affects the digestive system, you might find it even more difficult to get enough nutrition to meet your needs and maintain weight.

You will probably have many questions about your diet and physical activity, and whether you should use dietary supplements or nutritional complementary therapies. You might seek or receive advice from family, friends, healthcare providers, the media, health food stores, magazines, books or the nutritional supplement industry. There are many claims about the use of dietary and nutritional supplements as alternatives to standard therapy. Making an informed choice can be difficult.

You should always tell your doctor or oncology dietitian if you intend to use any supplements, as they may cause certain side effects, interactions or interference when combined with standard therapies (including surgery, radiation therapy, chemotherapy and targeted therapies) and medications.

A dietitian can provide advice and information on managing your diet and symptoms. You can also read Pancare Foundation's *Diet and nutrition for people living with oesophageal cancer*, available at **www.pancare.org.au/cancer/oesophageal-cancer/oesophageal-cancer-diet-nutrition**.

Tips to help you maintain your weight and muscle mass

Try to eat nourishing foods and fluids, such as those high in protein and energy.

Include regular sources of protein-rich foods, such as chicken, fish, meat, eggs, tofu, legumes, dairy products, nuts and seeds. Aim to base each main meal around a high-quality protein. You may need to cook and prepare these foods so they are soft and gentle – for example, soups and stews, scrambled eggs, yoghurt, milk drinks, hummus dip and smooth nut butters.

Try to eat the most nourishing part of the meal first.

Take advantage of when your appetite is the strongest. This might mean having a larger meal in the morning and a smaller meal in the evening.

Ask about using nutritional supplement drinks. When choosing a nutritional supplement for your needs, consider the different options, including milk based, juice flavoured, powder, yoghurt style and soups. You may need to try different products until you find one you prefer or tolerate better. Your dietitian can guide you.

Make sure you are eating a variety of healthy foods and maintaining a good weight.

Physical wellbeing

Many people find that relieving dietary-related symptoms makes the biggest difference to how they feel. For example, if you can eat and maintain your weight, you will feel better and cope better with treatment.

Feeling sick (nauseous) is a common side effect of cancer treatment, but your doctor can prescribe you anti-nausea medication to help you feel better. You can also try remedies such as ginger, peppermint or acupressure bracelets.

You will feel other physical effects from the cancer and its treatment. As with dietary-related symptoms, managing these can play a big part in how well you feel.

Physical activity can make you feel better. The amount of activity you can tolerate will depend on how you feel and whether you are having treatment or recovering from it. Even a walk around the block or 10 minutes of stretching each day can help.

You may lose interest in sexual activity during cancer treatment, at least for a while. Talking to your partner or doctor, and sometimes seeing a relationship therapist, may help you find ways of overcoming difficulties.

Emotional wellbeing

As time passes from your initial diagnosis, you will find yourself dealing with the wider emotional impacts of oesophageal cancer and its treatment. Everyone finds their own ways of coping, but, whatever you do, it is important to take care of yourself.

Everyone will feel and react differently to treatment. What works for someone else may not always work for you. It is important to keep this in mind during your treatment.

Simple relaxation techniques can help you cope with stress, pain and anxiety. Having a warm bath, deep breathing or listening to soothing music are easy things to do at home.

You may want to try complementary therapies such as reflexology or aromatherapy massage. Ask your doctor or specialist nurse about services available in your area. Be sure to speak with your doctor, dietitian or pharmacist before taking any supplements, herbal remedies, powders, teas or tonics.

Over time, you may go through a range of emotions, from feeling positive and determined to beat the cancer to feeling low or despairing about the future. A cancer counselling service may support you with different strategies to help you cope.

If you feel overwhelmed by your cancer experience, you may find it valuable to focus some attention to other areas of your life. Making plans to do things you enjoy, spending time with loved ones, working or socialising as much as you feel able, and intentionally focusing some energy on things other than your diagnosis, treatment and recovery can help to bring some balance.

Communication is essential for everyone's emotional wellbeing. Try to make time for talking and listening, because your close relationships are important.

Your treating team will want to know how they can help, so please talk to them about your feelings.

Feeling anxious or stressed is perfectly normal. One of the best ways to deal with these feelings is by talking to family, friends or a trained counsellor. If the feelings become overwhelming and you have episodes of depression, talk to your doctor about managing this with psychological care and counselling. In some cases, antidepressant medicines may be recommended.

Pancare's Counselling Program provides free access to a trained counselling therapist. They can help you cope with a diagnosis, or support you in caring for loved ones. Learn more about cancer counselling support at **www.pancare.org.au/living-well/emotional-support/counselling-support**.

Support for people with oesophageal cancer and their families

You can find support from others who are going through a similar experience. You may want to join a local cancer support group, which can provide a safe place for you to share your feelings and experiences, and connect with others.

Pancare's PanSupport has several support services available, including patient and carer support groups. Learn more about them at **www.pancare.org.au/living-well/support-groups**.

Practical support

You are bound to feel tired or exhausted sometimes, so be kind to yourself. Make sure you rest, prioritise what you want or need to do, accept offers of help, and ask for help if you need it.

Practical issues won't have been the first things you thought about when you were diagnosed, but it is important to deal with things like your work or financial situation so that they don't become a source of stress.

Your diagnosis will affect your ability to work, even if only temporarily (for example, when having treatment). Talk to your employer, human resources department or union representative about taking sick leave, reducing your hours or working from home. Being unable to work can lead to financial problems, so ask about any financial help or benefits you may be entitled to.

States and territories offer financial assistance for people who need to travel for medical tests and treatment. You may be able to get financial help for interstate travel, or to travel from regional areas to cities within the same state or territory. For more information, go to **www.healthdirect.gov.au/travelling-to-your-healthcare-appointment**.

Clinical trials

Clinical trials for oesophageal cancer look at different treatment options, with the aim of finding more effective treatments to improve survival and quality of life.

You may be eligible to take part in a clinical trial, so it is always a good idea to ask your specialist whether there is a trial suitable for your condition.

Before you decide whether to take part in a trial, you need to know exactly what is involved. Talk to your specialist and ask as many questions as you need to. If you decide to take part in a trial, you will have to sign a form saying you understand and agree to what is involved (this is called informed consent). If you change your mind, you can withdraw from the trial at any time – withdrawing won't affect your care.

The benefit of being involved in a clinical trial is that you can access the latest treatments before they are widely available. Often, your care and condition are also more closely monitored.

Several current clinical trials are looking at different ways to treat oesophageal cancer, especially advanced oesophageal cancer. Some trials are looking at new therapies, while others are combining various therapies to see whether they work better.

Clinical trials are medical research studies involving people.

Doctors may use cancer clinical trials to:

- test new treatments to see whether they work better than current treatments
- find which treatments have fewer side effects
- find new ways to combine treatments to see whether they work better
- test new cancer medicines to find out more about them and their side effects
- improve the way treatments are given to try to reduce side effects.

Results from clinical trials can improve cancer treatments and help people live longer. Trials can also look at improving things like diagnosis and symptom management.

For more information about current Australian cancer clinical trials, go to:

- the Australian Cancer Trials website at **www.australiancancertrials.gov.au**
- the Australasian Gastro-Intestinal Trials Group website at **www.gicancer.org.au/community-clinical-trials**.

What to ask your medical team

Your medical team is made up of highly qualified people who specialise in different aspects of health care. This multidisciplinary team will likely include oncologists, nurses, surgeons, pharmacists, and allied health professionals including dietitians, physiotherapists and/or exercise physiologists. Some people may require support from counsellors or psychologists during this challenging time.

Ask your medical team any questions you may have. If you don't understand the answer, don't be afraid to ask them again.

There are some key questions that you should ask your medical team:

- What is my diagnosis?
- What treatments are available?
- What is my prognosis? Will it change if I do or don't have a particular treatment?
- What kind of surgery have I had? How much of my oesophagus or stomach remains? Did you have to use part of my intestine to form my new oesophagus or stomach? What sphincters have been removed (if any)?
- What side effects can I expect? Can I have medications to manage these (such as anti-nausea drugs)?
- Are there any concerns about my weight or muscle mass (see *Diet and nutrition for people living with oesophageal cancer*, available at **www.pancare.org.au/cancer/oesophageal-cancer/oesophageal-cancer-diet-nutrition**)?
- How can I make an appointment with a dietitian (see *Diet and nutrition for people living with oesophageal cancer*, available at **www.pancare.org.au/cancer/oesophageal-cancer/oesophageal-cancer-diet-nutrition**)?

Glossary

Adjuvant treatment is additional treatment, such as chemotherapy or radiation therapy, given after surgery.

Advanced cancer is when cancer cells have spread from where they first grew to other parts of the body. Advanced cancer is also known as metastatic or secondary cancer.

Allied health professionals are trained professionals who work with others in the multidisciplinary team to support cancer patients.

Biopsy is when tissue is removed so it can be examined under a microscope.

Caloric need is the amount of energy that the body needs from food each day to maintain weight.

Chemotherapy is treatment that uses toxic medicines to destroy cancer cells.

Diagnosis is working out what condition you have based on test results – in this case, whether you have oesophageal cancer. Diagnosis also includes working out the exact location of the tumour, and its grade and stage.

Dietitian is someone who specialises in promoting health through food and nutrition.

Exercise physiologist is someone who specialises in clinical exercise interventions for people with health issues.

Gastroenterologist is someone who specialises in diseases and disorders of the digestive system, including the oesophagus, stomach, intestines, liver and pancreas.

Gastrointestinal is a term used to describe anything that has to do with the digestive system (for example, gastrointestinal tract).

Gastro-oesophageal junction see *Oesophagogastric junction*.

Immunotherapy is treatment that activates the immune system to find and attack cancer cells. The immune system protects the body against illness and infection. See also *Targeted therapy*.

Localised treatment is treatment that affects only a certain area of the body, such as radiation therapy.

Locally advanced cancer is when cancer cells have spread from where they first grew in the oesophagus to structures around it, such as blood vessels.

Lymph nodes are tiny oval structures throughout the body that contain lymph fluid. Lymph fluid is part of the immune system. Cancer often spreads to lymph nodes.

Metastatic cancer see *Advanced cancer*.

Multidisciplinary team is a team of health professionals with different skills who plan cancer treatment and provide ongoing care; this ensures that all your needs will be considered.

Neoadjuvant treatment is treatment given before surgery, such as chemotherapy or radiation therapy.

Nutritional supplements are specially formulated drinks, powders or foods to increase calorie intake and help you maintain weight.

Oesophagogastric junction is where the oesophagus connects to the stomach.

Oesophagus is the tube that starts at the back of the mouth and ends in the stomach. After swallowing, food and liquids go down the oesophagus and into the stomach. It is sometimes known as the 'food pipe' or 'gullet'.

Oncologists are specialists in treating cancer. The main types of oncologists are:

- surgical oncologists, who specialise in operating on tumours
- medical oncologists, who specialise in chemotherapy and other systemic therapies (such as immunotherapies and targeted therapies)
- radiation oncologists, who specialise in radiation therapy.

Oncology nurses are nurses who work with you to identify and assess your supportive care needs, monitor your condition, give you medication and develop care plans. Oncology nurses also answer your questions and work closely with other members of the healthcare team to ensure that you receive the highest quality of care. See also *Supportive care*.

Palliative treatment is treatment that controls symptoms, relieves pain where possible, and slows down the progression of an illness when a cure is no longer possible.

Pathology involves looking at samples from the body to work out whether someone has a disease, and the nature of the disease. Pathology includes looking at tissue and cells from a biopsy under a microscope; testing blood, urine or stool samples; and genetic testing. A pathologist is a doctor specialising in pathology.

Prognosis is the expected outcome for you based on the most up-to-date evidence. It depends on your diagnosis and treatment, and can change over time.

Radiation therapy is treatment that uses high-energy X-rays to destroy cancer cells.

Recurrent is when cancer comes back, even after responding to treatment previously.

Supportive care is improving comfort and quality of life by preventing, controlling or relieving disease complications and side effects. Supportive care includes psychological, social and spiritual needs

Systemic treatment is treatment that travels throughout the body in the bloodstream (for example, chemotherapy).

Targeted therapy is treatment that blocks pathways that cancer cells need to grow and survive. A targeted therapy might work for one person but not another. You will likely need pathology tests to work out whether a targeted therapy will work for you. Immunotherapies are a type of targeted therapy.

Upper gastrointestinal refers to the upper part of the digestive system, including the oesophagus, stomach, liver, pancreas, gallbladder and bile ducts.

Further information and support

Best-practice care differs around the world, so this handbook focuses on resources and information available in Australia.

Pancare Foundation

Our Pancare Foundation website has information that complements what is in this handbook. You can get in touch with our specialist support team, find out more about clinical trials, learn about joining a support group and access other resources.

For information on oesophageal cancer, go to **www.pancare.org.au/cancer/oesophageal-cancer**.

Also available on our website is *Diet and nutrition for people living with Oesophageal Cancer*.

Cancer Council

Working with Cancer Australia, the Cancer Council developed the *Optimal care pathway for people with oesophageal cancer* to improve patient outcomes. It is a standardised pathway of cancer care that is consistent, safe, high quality and evidence based.

The Optimal care pathway for people with oesophagogastric cancer can be found at **www.cancer.org.au/health-professionals/optimal-cancer-care-pathways**.

The Cancer Council also supports people living with cancer and their carers. Pancare has supported the development of this service.

Find help and learn more about supportive care at **www.cancer.org.au/cancercareguides/support-and-care**.

eviQ

eviQ is a free resource of evidence-based cancer information developed for Australians diagnosed with cancer and their healthcare team.

To access these free resources, go to **www.eviq.org.au/patients-and-carers**.

Other resources

The Melbourne-based Upper Gastrointestinal Cancer Support Group, led by Dr Cuong Duong, has been a leading voice for patients and carers affected by oesophageal cancer.

With the support of Western and Central Melbourne Integrated Care Service, a cancer service improvement network, the group have produced several videos to fill a gap in available patient resources.

These videos contain personal, real and relatable stories, told by Australians who have been through the many phases of oesophageal cancer. These stories may help you through your experience with oesophageal cancer.

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