

Diet and nutrition for people living with 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:

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- Pancare Foundation patient and carer advisory working group.

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Note to the Reader

The information in this handbook is appropriate to follow if you are undergoing or have recently completed treatment for oesophageal cancer and are underweight or losing weight.

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.



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**.



What is this handbook about?

Cancer is life changing, but recent advances in medicine mean that people living with cancer are now enjoying longer, fuller and healthier lives after treatment. These advances include a broader understanding of nutrition and how your diet can help you feel better.

This PanSupport handbook highlights important information about managing your diet if you have, or recently have had, oesophageal cancer.

Cancer, its treatments and side effects of treatment can affect how you live day to day. This handbook explains the function of your oesophagus, and how oesophageal cancer and its treatments may affect your body. It also provides ideas on what you can do to feel better during and after treatment.

The potential symptoms of oesophageal cancer and treatment side effects include:

- problems with maintaining or gaining weight
- · problems with eating and swallowing
- changes in taste and smell
- differences in bowel habits
- loss of appetite
- feeling full quickly
- nausea (feeling like you are going to throw up) and vomiting
- fatigue.

You may encounter all, some, or none of the above.

We share dietary tips to help manage the unpleasant effects of treatment. If you have oesophageal cancer, you should be referred to an Accredited Practisina Dietitian, who will tailor advice specifically for you. If you have not seen a dietitian and would like to, please discuss this with your treating team. Your doctor may prescribe medication, such as anti-inflammatory or anti-nausea (anti-emetic) medication, to help with some of your symptoms.



is essential to optimising your health outcomes during and after treatment. By using strategies and tips offered in this handbook, you may find eating, maintaining your weight and managing your side effects easier.

Your guide for using this handbook

This handbook contains key details in colour-coded boxes:



Additional details



Helpful tips



Patient stories



Food ideas

At the back of this handbook, you will find:

- a glossary, which explains common terms about oesophageal cancer (page 51)
- where to find further information and support (page 54).

Contents

What is this handbook about?	4		
Your guide for using this handbook	5		
How does the oesophagus work?	8		
Oesophagogastric junction and gastric reflux	10		
What therapies are used to treat oesophageal cancer?	11		
Prehabilitation	11		
Surgery	12		
Radiation therapy			
Chemotherapy	16		
Targeted therapy and immunotherapy	17		
How can I manage the symptoms of oesophageal cancer and the treatment side effects?	18		
Nutritional support after surgery	20		
Fatigue			
Mouth dryness			
Changes in taste or smell			
Throat soreness			
Swallowing problems	26		
Loss of appetite and feeling full	27		
Nausea and vomiting	28		
Reflux	30		
Weight changes	31		
Changes in bowel habits	34		
Dumping syndrome	36		
Food safety			
Oesophageal stents			

How do I maximise my nutritional intake?	39
How can I eat a healthy diet?	42
Oral health and hygiene	47
Do should I see a dietitian?	49
How do I decide which diet is right for me?	50
Glossary	51
Further information and support	54
Pancare Foundation	54
Cancer Council	54
Dietitians Australia	54
eviQ	54
Other resources	54



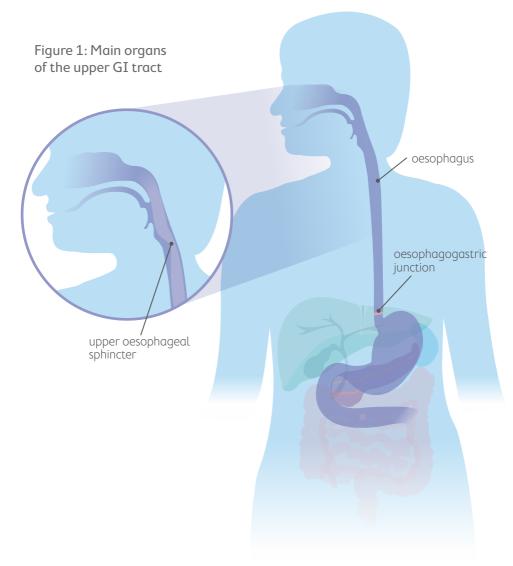
How does the oesophagus work?

People with oesophageal cancer often struggle to maintain a healthy weight. Cancer treatments and the associated side effects can also make it hard to take in, digest and absorb your food.

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.

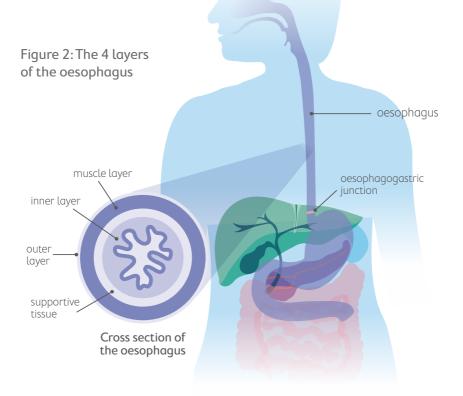
The oesophagus has muscles that squeeze and expand to move food down to the stomach. This motion is called peristalsis (per-ee-stal-sis). Nutrients are not absorbed in the oesophagus.



The oesophagus has 4 layers (Figure 2, page 10). 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.



Oesophagogastric junction and gastric reflux

The oesophagogastric junction is where the oesophagus meets the stomach (*Figure 2*). 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.

What therapies are used to treat oesophageal cancer?

Common treatments for oesophageal cancer include surgery, radiation therapy, chemotherapy and immunotherapy. You may need to have just one of these or a combination of treatments, depending on your diagnosis.

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 3, page 14*). 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 4, page 14*).

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 3: Oesophagectomy

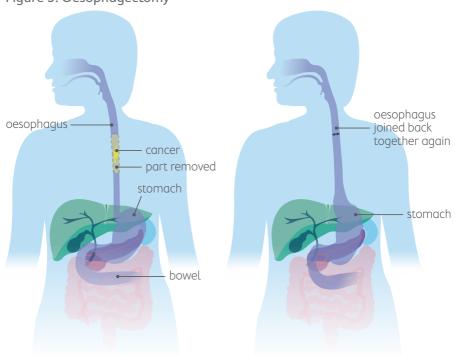
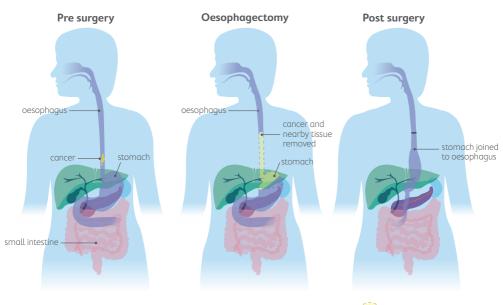


Figure 4: Oesophago-gastrectomy



Oesophageal stents

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

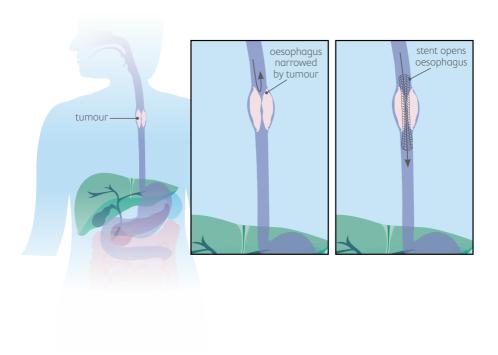
A stent won't treat the cancer, but it will help to relieve blockage of the food passage caused by the cancer so that you are more comfortable.

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 5*). 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 5: 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 17) 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 if a clinical trial for treatment of oesophageal cancer is available in your region.

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. These may remain for several weeks, even months, with regular monitoring and care.

Targeted therapy and immunotherapy

Targeted therapies are medicines that target specific genes and proteins involved in cancer growth. Immunotherapy is one type of targeted therapy.

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

Immunotherapy has been shown to work well with chemotherapy for certain types of oesophageal cancer. Immunotherapies are usually delivered as an injection or infusion, often over multiple sessions.

Immunotherapies and other targeted therapies are rapidly evolving, and the Therapeutic Goods Administration (TGA) approves new therapies all the time. The costs of these therapies can also change, if they are listed on the Pharmaceutical Benefits Scheme (PBS). Your oncologist will let you know which therapies are available at the time of your treatment, and which might suit you.

How can I manage the symptoms of oesophageal cancer and the treatment side effects?

Oesophageal cancer and the associated treatments change how you eat. Managing these changes is important for your nutritional health and recovery, and to 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.

This handbook describes several common side effects of cancer treatments, and how to manage them.

Oesophageal cancer and its treatments may impact:

- · how much you eat
- your appetite
- your ability to bite, chew and swallow food and fluids
- your ability to digest and absorb food, nutrients and fluids
- your ability to maintain your weight and muscle mass
- your energy levels and 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



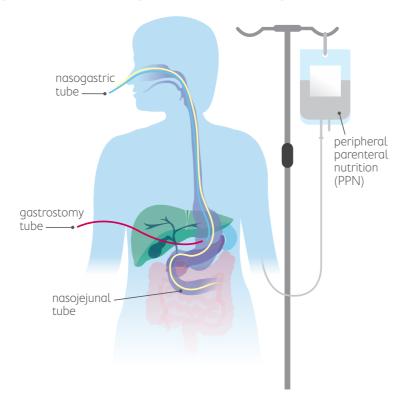
Nutritional support after surgery

Your ability to eat and drink after your operation will depend on which surgery you have had and what the hospital recommends.

It is often difficult to meet your elevated nutritional needs with food alone. Your healthcare team may recommend a feeding tube for nutrition support. You may have a feeding tube placed directly into your stomach or small intestine before your surgery (called a gastrostomy or jejunostomy). This is used to ensure that you can meet your nutritional needs. You may have a temporary feeding tube up your nose (called a nasogastric or nasojejunal tube) during or after surgery if you are struggling to eat and drink (see *Figure 6*).

Feeding tubes are an important way to ensure that your body receives the nutrition it needs to prepare for and recover from surgery. You can be given specially prepared feeding formula (called enteral formula) through this tube while the new join between the oesophagus and stomach or small intestine heals, and until you are able to eat and drink enough to meet your needs.

Figure 6: Possible feeding tube options after surgery



Once you begin eating, you may start with liquid meals such as soup or pureed foods, to avoid irritating the internal wound or stitches. Eventually, you will be able to eat soft foods for a few weeks. Your surgeon or dietitian will let you know when you can try eating solid foods.

Your surgeon or dietitian might tell you to eat several small meals or snacks throughout the day, rather than a few big meals. The hospital dietitian can prepare eating plans and work out whether you need any supplements to help meet your nutritional needs.

Fatigue

Fatigue and tiredness are common side effects of oesophageal cancer and treatment. Your food choices can help to balance your energy levels across the day.

Some tips to help optimise your energy levels include the following:

- Eat regular meals. Try six smaller meals to spread your energy across the day.
- Include complex, low-glycaemic index carbohydrates that provide you with a sustained release of energy across the day. Choose wholegrain breads and cereals, legumes, vegetables, fruit, and fullcream dairy products such as milk and Greek or natural yoghurts.
- Limit your intake of simple sugars and carbohydrates, such as soft drinks, juices, sweets, biscuits, cakes, white bread and other refined grains, cordial and sugar. These cause a spike in your energy levels, followed by a drop that leaves you feeling tired.
- Ensure that you are well hydrated, aiming for two litres of fluids per day. Water, herbal tea, milk and milk drinks are good choices.



Mouth dryness

Some chemotherapy medicines and some pain medicines can reduce the amount of saliva (spit) in your mouth and make it feel dry. This is a condition called xerostomia. A dry mouth can increase your risk of tooth decay and infections such as oral thrush, which can make eating even more difficult

Tips to help with a dry mouth

• Use mouthwash regularly to prevent infections (an alcohol-free mouthwash will reduce irritation).



- Gargle water mixed with a little salt or bicarbonate of soda.
- Use a soft toothbrush when cleaning your teeth.
- Ask your dietitian, speech pathologist, doctor or chemist about suitable mouth rinses, oral lubricants, artificial salivas and saliva stimulants.
- Moisten the inside of your mouth at night with a small amount of grapeseed oil, coconut oil or olive oil.
- Soften dry food by dipping it in milk, soup, tea or coffee, or add sauce, gravy, cream or custard.
- Cut, mince or puree food with sauce or gravy so that it does not dry out when chewed.
- Sip fluids with meals and throughout the day, or suck on ice cubes or frozen grapes to moisten your mouth.
- Chew sugar-free gum or sour drops to stimulate the flow of saliva.
- Limit alcohol and coffee, as these remove fluids from the body.
- · Avoid smoking.

Changes in taste or smell

Changes in taste and/or smell are common during cancer treatment, especially when having chemotherapy. You may find that you don't enjoy eating the foods you used to or that food has lost its taste.

Tips to help you cope with changes in taste

- If food tastes bland, try adding flavour by using herbs, lemon, lime, ginger, garlic, soy sauce, honey, chilli, pepper and other spices, sauces or pickled vegetables. You may also find that you can no longer stomach these things, and that bland food is more appetising. Do whatever works for you.
- If you have a bitter or metallic taste in your mouth, eat fresh
 fruit or suck on hard lollies. Eat your food with plastic or wooden
 (not metal) utensils, and drink out of glass or plastic cups. Don't
 store food in metal containers.
- If food is too sweet, add small amounts of lemon juice or instant coffee granules. Try plain breakfast cereals (for example, oats or wheat biscuits) that don't have any added sugar.
- Try using a straw, where possible, as this can help food bypass the taste buds.
- Continue to try different foods to assess your taste preferences. Variety is key!
- Ensure that you keep your mouth clean by cleaning your teeth and rinsing your mouth out regularly. Using mouthwash throughout the day can also help. If you use mouthwash, try to ensure that it is alcohol-free. Having a fresh, clean mouth before your meals can help.

Tips to help you cope with changes in smell



- Choose cold food or food at room temperature to minimise strong smells.
- If cooking odours make you feel unwell, ask family or friends to help prepare food for you at their house, or when you are in another room or outside.
- If you can't tolerate meat, chicken or fish, try it in different ways, such as in a mince dish, slow cooked with vegetables or blended through soups. If this doesn't help, try other protein sources, such as cheese (including ricotta and cottage cheese) and other dairy foods, eggs, nuts, tofu, or other legumes and pulses (including lentils and beans).

Throat soreness

Radiation therapy to the oesophagus and some chemotherapy can cause throat soreness, which can make eating uncomfortable or painful.

Tips to help with throat soreness





- Choose nourishing fluids that help to meet your nutrition and hydration needs.
- Cold foods and fluids may be more comfortable than hot ones.
- Avoid 'coarse' foods that can irritate your mouth or throat, such as crackers, toast, whole nuts and seeds.
- Be mindful of acidic, spicy or very hot foods as these may irritate a sore throat.
- Talk to your doctor about medication or mouthwashes to help manage the pain and allow you to eat more comfortably.
- Suck on ice cubes.
- Keep your mouth clean and healthy. See 'Oral health and hygiene' on page 47.

Swallowing problems

After oesophageal surgery, it is common to have problems swallowing. Difficulty swallowing is called dysphagia. Painful swallowing is called odynophagia, and may be a result of oesophagitis (swelling and inflammation of the oesophagus). Dysphagia and odynophagia are both common side effects of oesophageal cancer treatment. This may be because of the tumour location, or a side effect from treatment.

You may also cough while eating or feel as though food is 'going down the wrong way'. This can happen when there are changes to your oesophagus, including with oesophageal cancer, surgery or radiation therapy. If you feel as though food or fluid is going down the wrong way, or you are coughing or spluttering when eating or drinking, you should see your doctor right away, as these problems can be serious.

Tips to make swallowing easier

- Chop, mince or puree food to make smaller pieces that are easier to swallow
- Snack on soft foods between meals, such as avocado, yoghurt, custard, ice cream, diced tinned fruit and milkshakes. These are easier to swallow.
- Try eating soft, nutritious foods, such as scrambled eggs, porridge, soup and casseroles.
- Make tough food softer. Try using a slow cooker to keep food soft and moist, mash your food with a fork, or add extra gravy or sauce to your meals.
- Sit upright, and chew carefully and slowly. Avoid lying down within 30 minutes of eating or drinking.
- Wash food down with small sips of a drink.
- Make changes in texture of food and thickening of fluids as guided by your dietitian and speech pathologist.



Loss of appetite and feeling full

Loss of appetite is a common problem in people with oesophageal cancer and during treatment.

Try the following to help with loss of appetite and early satiety:

- Eat small nourishing meals, throughout the day. Try to eat every two to three hours, rather than having three large meals. Eat by the clock. Regular meals can help to stimulate your appetite.
- Try to eat the most nourishing part of the meal first (before you become full), such as high-energy and high-protein foods and fluids (see 'How do I maximise my nutritional intake?' on page 39).
- When you do feel hungry, eat! If you feel hungrier at certain times of the day or week (for example, between chemotherapy cycles), eat a bit more.
- Be mindful not to drink too much fluid during meals so you have more room for food. If you do need to drink with your meals, prioritise nourishing fluids, such as milk-based drinks, to help you get enough nutrition as well as hydration. Remember to keep hydrated by sipping on fluids between meals and snacks.
- Make your eating environment relaxed, positive and enjoyable. Distract yourself with family, friends or a good book.

Nausea and vomiting

Nausea and vomiting can be caused by oesophageal cancer and its treatments. Here are some ways to settle your stomach:

- Talk to your doctor about trying an anti-nausea medicine. Make sure
 you read the instructions on how and when to take this medicine. For
 example, metoclopramide is best taken 30 minutes before eating.
- Eat small, frequent meals throughout the day. Don't skip meals or snacks not eating can make nausea worse.
- Eat bland, starchy and salty snacks, such as dry crackers or toast with vegemite or cheese. However, you should not eat these foods if you have a dry mouth; for tips to help with mouth dryness, see page 23.
- Eat and drink slowly, and chew food well.
- Choose cold food or food at room temperature to minimise strong smells.
- Reduce fried, greasy or spicy foods if these make you feel unwell.
- Avoid strong odours and cooking smells. If possible, stay away from the kitchen if someone else is cooking. It might also be easier if you cook and/or eat outside.
- Suck on hard lollies, especially those flavoured with ginger, peppermint or lemon.
- Try ginger-based foods and drinks, such as candied ginger, ginger beer, ginger ale or ginger tea. Talk to your dietitian, doctor or pharmacist about ginger supplements.

Vomiting is more serious than nausea. Vomiting can cause dehydration and increase the risk of malnutrition. See a doctor if you are vomiting for more than one day, especially if you can't keep water down.

Tips for managing vomiting

• Take small sips of water or clear liquids, such as ginger ale, soda water, or sports drinks like Gatorade® or Hydralyte®. Dilute sweet drinks. If you feel like a fizzy drink, open it and let it sit for 10 minutes or so, and drink it when it's a bit flat.



- Once you can keep clear liquids down, try adding different liquids such as smoothies and milkshakes. Have small amounts of these frequently throughout the day.
- When you are ready to try solid foods, start with bland, starchy foods, and other foods that are easy to eat – for example, plain biscuits, bread or toast with honey or jam, peanut butter, rice, yoghurt and fruit. Try to have small, frequent servings.
- Gradually increase your intake until you are eating a well-balanced diet.



Reflux

You may have some reflux after your treatments. Reflux can cause heartburn, nausea and discomfort in your chest.

After an oesophagectomy, the stomach has less capacity to hold your food and fluid. The valve that prevents the backflow of food and fluid from the stomach may also have been removed. You may feel full more quickly or be more likely to regurgitate or vomit after eating.

Tips for managing reflux

- Limit spicy foods, fatty foods, fizzy drinks and alcohol.
- Chew foods well, and eat slowly.
- After an oesophagectomy, remain upright for at least 30 minutes after eating. Try eating your evening meal earlier to allow more time for digestion before going to bed.
- Try eating your main meal earlier in the day and have a small snack in the evening.
- Avoid bending over or positions that worsen your reflux. Don't overexert yourself physically, as this can contribute to reflux.
- 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.
- Your doctor may prescribe medicines to reduce stomach acid, which may improve these symptoms. Over-the-counter antacids may also be helpful.



Weight changes

Cancer may result in weight changes – you may find it hard to gain weight or to keep weight on. This may be because of the treatments or the cancer itself.

It is important to maintain your weight and eat well. Maintaining your weight, particularly your muscle mass, will also help you to cope better, recover faster, feel less tired, and reduce the likelihood and severity of side effects. If you struggle to keep weight on, it is important to seek support from a dietitian.

Assess your risk of malnutrition

1. Have you lost weight recently without trying?

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No = 0
Unsure = 2
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Yes, how much (kg)?

2. Have you been eating poorly because of a decreased appetite?

No
$$= 0$$

Yes $= 1$

If you scored 2 or more, you should visit a dietitian for a full assessment

Speak to your treating team or see 'Tips to finding an Accredited Practising Dietitian' on page 50.



Tips to help you maintain your weight and muscle mass



- Try to eat nourishing foods and fluids, such as those that are high in protein and energy. See 'How do I maximise my nutritional intake?' on page 39.
- 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.
 See 'Swallowing problems' on page 26.
- Try to eat the most nourishing part of the meal first.
- Take advantage of when your appetite is 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. See 'When should I see a dietitian?' on page 49.

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



What if I'm putting on weight?

Although weight loss is common with oesophageal cancer, some people may find they gain weight instead. This can be caused by various factors, including:

- medicines
- fluid retention
- changes in diet and food preferences
- altered taste
- fatigue and exercising less
- hormonal changes.

If you are worried about weight gain, speak with a dietitian.



Changes in bowel habits

Living with oesophageal cancer and its treatments can result in changes to your bowel habits. This could be differences in the appearance, consistency and/or smell of your stools.

Diarrhoea

Diarrhoea is when you pass three or more loose, watery stools per day. Frequent loose stools can occur:

- because you are not digesting food or absorbing nutrients properly
- because of treatment side effects, an irritated gut lining, qastroenteritis or surgical procedures
- because of other causes, including stress and anxiety.

Diarrhoea can result in dehydration, so it's important to stay hydrated by drinking extra fluids. Every time you have a loose bowel movement, you should drink an extra cup of noncaffeinated fluid. If you have diarrhoea for several days, see your doctor so that they can determine the cause and help to manage your diarrhoea. Your doctor may prescribe you an over-the-counter anti-diarrhoea medicine.

It is best to consult your doctor or dietitian before making big changes to your diet. Some foods can make diarrhoea worse or irritate your gut if you already have diarrhoea. You may be advised to limit some of the following until the diarrhoea stops:

- foods that have a lot of insoluble fibre, such as wholegrain breads and cereals, skins and seeds of fruit and vegetables, nuts, seeds and legumes
- large quantities of foods sweetened with artificial sweeteners (also known as sugar alcohols), such as sorbitol, mannitol and xylitol.
 These are often marketed as 'sugar-free'. Be aware of foods that may contain artificial sweeteners, including diet drinks and sugar-free lollies and chewing gum.

We need to eat two types of fibre – soluble and insoluble – for a healthy diet. Both are beneficial to the body, and most plant foods contain a mixture of the two.

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Soluble fibre is found in the cells of plants. It absorbs water, acting like a sponge in your bowel, and can help reduce the amount of loose or watery stools. Soluble fibre is a source of prebiotics, which means it provides food for the healthy gut bacteria that live in our colon.

Sources of soluble fibre include:

- fresh fruit and vegetables
- legumes such as lentils and peas (but not the skins)
- wholemeal bread and cereals
- grains such as barley, flaxseed and oat bran
- psyllium
- soy products
- garlic, onions, spring onions, leeks and shallots.

Insoluble fibre is found in the structural walls of plants. It does not absorb water and adds bulk to your stools. This can help prevent constipation and associated problems such as haemorrhoids. If you have issues with inflammation or infection in your bowel, you might need to reduce your intake of insoluble fibre in the short term.

Sources of insoluble fibre include:

- skins and seeds of fruit and vegetables
- nuts and seeds, including quinoa
- wholegrains.

Some foods have been found to help reduce diarrhoea (depending on the cause of the diarrhoea) and may be worth including in your diet. These are:

- soft, well-cooked, peeled vegetables and fruit
- white bread, white rice and pasta
- corn- or rice-based cereals.

It may also help to eat small, frequent meals throughout the day, rather than three large meals.

Dumping syndrome

Living with oesophageal cancer and its treatments can result in changes to your bowel habits. This could be differences in the appearance, consistency and/or smell of your stools.

Dumping syndrome occurs when food moves from your stomach into your small bowel too quickly. This can happen after an oesophagectomy. It can cause nausea, cramps and diarrhoea about 10 to 30 minutes after eating, or sweating and dizziness 1 to 3 hours after eating.

Be sure to speak to your doctor or dietitian if you are experiencing any of these symptoms.

Some tips to prevent dumping syndrome include the following:

- Avoid large meals.
- Limit sugary drinks and sweets.
- Choose meals high in protein to slow the digestion of carbohydrates.
- Keep drinks separate from meals.

Tips for managing dumping syndrome

- Eat small meals throughout the day.
- Chew your food well.
- Keep a record of foods that cause problems, and avoid them.
- Limit foods and drinks high in sugar, such as cordial, soft drinks, cakes and biscuits.
- Eat meals high in protein, such as lean meat, fish, eggs, milk, yoghurt, nuts, seeds, legumes and beans.
- Drink between meals rather than at mealtimes.
- Talk to a dietitian, who can help you work out how to change your meals to reduce the symptoms.

Symptoms usually improve over time. If they don't, ask your doctor for advice about medicines that may help.

Food safety

If you are having chemotherapy, you will likely be immunocompromised, which means your body might not fight infection as well as before. This makes food safety important.

Check that everything you eat and drink is prepared and stored hygienically to minimise any risk of food poisoning.

You can find easy-to-read information about food safety and food poisoning on the Better Health Channel website at www.betterhealth.vic.gov.au/health/healthyliving/food-poisoning-prevention.



Oesophageal stents

If you have a stent placed, you may need to consume only liquids and pureed foods for a short period afterwards. You will be able to build up gradually to soft foods and then some normal foods.

Some foods are more difficult to chew or are more prone to getting caught if you have a stent. This could result in your food getting stuck in the mesh of the stent or blocking the stent.

You should try to avoid:

- hard, fibrous or stringy vegetables and fruit, such as celery
- dried fruit
- very soft bread (if not chewed well) toast is a better choice
- crispy foods, such as potato chips (unless chewed very well), hard biscuits and nuts (smooth nut butters are a better choice)
- skin from fruit and vegetables, such as potato skin
- tough, gristly meat that is hard to chew
- foods with large chunks in it, such as chunky soups or stews (small pieces are okay).

If you have an oesophageal stent, you should:

- drink plenty of fluids, and drink during and after your meals; a carbonated drink (such as soda or mineral water) may help to keep the stent clear
- eat small pieces of food and chew thoroughly before swallowing, making sure there are no lumps
- eat your meals slowly
- sit up during your meals and for about 1 to 2 hours afterwards.

How do I maximise my nutritional intake?

People with oesophageal cancer often struggle to maintain a healthy weight. Cancer treatments and the associated side effects can also make it hard to eat, swallow and absorb nutrients from food.

A complete, nutritionally balanced diet is essential for everyone, but it's even more important if you are going through cancer treatment. There will be many times when you don't feel like eating, but it is really important that you are well supported to maximise your intake.

A nourishing diet is one that contains enough kilojoules, protein, nutrients, vitamins and minerals to meet your needs. You may hear the term 'high-energy, high-protein diet'. By including foods rich in energy and protein, and by fortifying the food that you already eat, you can make every mouthful more nourishing. This is often easier than eating extra food if you have a poor appetite.

Good nutrition is also important for wound healing. If you have had surgery, you want to make sure the wounds heal well. Make sure you get enough energy, choose foods rich in protein, and speak to a dietitian if you are concerned about meeting your vitamin and mineral needs.



High-energy and high-protein foods

STEP 1:

Build your meal around a good source of protein, such as:

- meat, poultry and fish
- eggs
- tofu
- beans, chickpeas, lentils and legumes
- full-cream dairy such as milk, yoghurt, cheese and custard
- evaporated milk, condensed milk, skim milk powder or fortified milk (see recipe below).



Add extra kilojoules with high-energy foods, such as:

- avocado
- nuts, seeds and nut butters/pastes
- butter, margarine and oils
- · cream and creamy sauces
- gravy (made with meat juices)
- dips made with cream cheese, or hummus
- dried fruit
- honey, maple syrup, golden syrup or jam
- trail mix (a snack of mixed nuts, dried fruit and seeds, and sometimes chocolate bits).

Make your own fortified milk

Fortified milk is easy to make yourself:

- Sprinkle 2/3 cup (or 75 g) of skim milk powder onto 2 cups (or 500 mL) of full-fat milk.
- Mix until the powder is dissolved

Try to make the fortified milk 2 hours before using it and store it in the fridge. Use fortified milk whenever you'd use regular milk – on your cereal, in your tea or coffee, or to make a milkshake or smoothie.





Nutritional supplement drinks are high in energy and protein. They may also contain additional vitamins and minerals. They can help you meet your nutritional needs because:



- they're often easier to tolerate when you don't feel like eating a meal
- they can be consumed between meals for extra nutrition, or can be taken as a meal replacement
- you can buy them in powder form or ready-made, so they can be a quick and simple snack or meal for when you are feeling too unwell or tired to cook food
- you can easily make your own at home; use combinations of fruit, dairy products and sweeteners such as honey or maple syrup (for some inspiration, see 'Smoothie and milkshake ideas' on page 43).

A dietitian can provide advice on which supplement is best for you.

How can I eat a healthy diet?

We know there'll be many times when you don't feel like eating, but it is really important that you do.

Tips to help you eat a nourishing diet

- Eat a variety of foods.
- Explore your preferred foods try something new, even if it's something you didn't like before you had cancer



- Try eating six small meals spread throughout the day instead of three large main meals.
- Eat at specified mealtimes, even if you're not really hungry.
- Take snacks with you if you are not going to be at home at a mealtime.
- Make the most of when you feel well and have an appetite, even if it's not when you would usually eat.
- Figure out when you seem to have the best appetite and plan larger meals for those times. For example, plan larger breakfasts if you are hungrier in the mornings.
- Use ready-made frozen and tinned foods to reduce the need to cook, or ask family and friends to make large batches of food and freeze meals in small portions.
- If you feel full quickly, eat the most nourishing (high-energy/protein) part of the meal first and try not to drink beforehand (during the hour before eating). If you are used to drinking with your meals, make sure you sip on nourishing fluids such as a smoothie or milkshake

Smoothie and milkshake ideas

Drinking smoothies and milkshakes is an easy way to increase your energy and protein intake. They are also suitable if you have an oesophageal stent, depending on what you put in the milkshake or smoothie.

Smoothie ideas:

- Start with a base of Greek or natural yoghurt, or fortified milk (you can buy some or make your own).
- Add fruit such as bananas, berries or mango. Frozen fruit works well.
- Fortify with nuts, seeds, peanut butter, coconut, coconut cream, protein or a nutritional supplement powder.
- Add cinnamon, cocoa or cacao to taste.
- Blend together with fortified milk and ice. If you have had surgery or radiation, or have an oesophageal stent, make sure you blend your smoothie very well so there are no lumps.

Milkshake ideas:

- Start with a base of fortified milk (you can buy some or make your own).
- Add ice cream.
- Include cocoa, chocolate powder, protein/nutritional supplement powder and/or nut butter to taste.



Sample meals

The following sample meals provide tips on how to increase the amounts of energy and protein in your diet. If you have had surgery or radiation and need a soft or pureed diet, or have an oesophageal stent, you will need to consider which foods suit you best.

Breakfast

- Cereal or muesli with fortified milk, yoghurt, fruit or honey
- Eggs (poached, scrambled, fried, boiled, omelette) with cheese, plus wholegrain or rye toast



- Buttered wholegrain, rye or sourdough bread or toast, with cheese, avocado or nut butter
- Baked beans or 4-bean mix on buttered toast with grated cheese

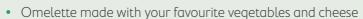
Morning tea

- Smoothie or milkshake see 'Smoothie and milkshake ideas' on page 43
- Nutritional supplement drink
- Yoghurt with fruit and nuts, or nut butter
- Fruit toast with butter or nut butter
- Boiled egg
- Bliss balls made with dates, nuts, seeds, cacao and oats (all well processed to form smooth balls)
- Wholegrain pita bread or wraps with dip, avocado, cream cheese or nut butter



Lunch

- Meat, chicken or fish with a creamy sauce or gravy
- Mashed vegetables mixed with butter, extra virgin olive oil, cream or cheese
- Wraps or sandwiches made with meat, chicken, fish, eggs, beans or lentils, avocado, mayonnaise, hummus or cheese



- Frittata made with eggs, vegetables, cheese and lentils
- Vegetable and lentil soup with grated cheese

Afternoon tea

- Smoothie or milkshake see 'Smoothie and milkshake ideas' on page 43
- Wholegrain wrap with shaved turkey breast, tuna, avocado or ricotta
- Falafel or protein ball
- Hummus or tzatziki dip with wholegrain crackers, wholemeal pita bread or vegetable sticks







Dinner

- Pasta with meat sauce, such as spaghetti bolognese with grated cheese
- Burritos with meat, beans and cheese, topped with avocado and sour cream
- Meat, chicken or fish with gravy, or cream or cheese sauce; mashed potato with butter; and vegetables or salad with a dressing made with extra virgin olive oil
- Lentil or bean salad, with cold chicken, tofu or tinned fish, avocado, corn, cheese and a dressing made with extra virgin olive oil
- Stir-fried vegetables with tofu, soy sauce and sesame seeds, served with basmati rice or soba noodles

Evening snack

- Hot chocolate or chai made with fortified milk
- Protein ball
- · Yoghurt and fruit
- Frozen yoghurt
- Crème caramel, pudding, rice pudding, ice cream or chocolate mousse



Oral health and hygiene

Some treatments for oesophageal cancer can cause side effects that affect your mouth and teeth. These conditions can make it hard to eat, and poor oral health can make them worse. It is important to have a check-up with your dentist before treatment starts so that they can check the health of your teeth and identify any problems early.

Oesophageal cancer treatments can affect the mouth in different ways:

- Some chemotherapy and targeted therapy medicines can damage healthy cells in the mouth, causing mouth sores or infections.
- Radiation therapy may injure cells in the mouth and salivary glands, cause changes to the strength of the muscles and nerves used in swallowing, or damage and affect bone strength.

Your healthcare team will talk with you about the possible side effects of treatment and how to manage them. Most mouth problems gradually improve and go away after treatment is over.

It is a good idea to visit your dentist before starting treatment, especially if you already have mouth problems or tooth decay, or are having high-dose chemotherapy or radiation therapy to the head and neck area. There is a higher risk of infection and bleeding if you have dental work during cancer treatment.

Make sure to tell your dentist about the type of treatment you will be having so that they can develop an oral health care plan. This sets out any dental work you need before you start cancer treatment, and lets you know how to look after your mouth before, during and after treatment to help prevent tooth decay and manage any side effects that affect your mouth.

Tips to help you take care of your mouth before, during and after cancer treatment



- Try to eat a balanced, nutritious diet; limit how much alcohol you drink; and quit smoking.
- Check your mouth, tongue and teeth daily during treatment for changes to the inside of your mouth. Tell your healthcare team if you notice any changes.
- Clean your teeth with a mild toothpaste and a soft-bristled toothbrush. Replace the toothbrush at least every 3 months to prevent infection.
- Rinse your mouth several times a day with an alcohol-free mouthwash (ask your doctor or nurse about what type of mouthwash to use and how often to use it). Use a mild mouthwash if your mouth is too sore or bleeds when you clean your teeth.
- Check with your dentist before flossing, as this may not be recommended during treatment. Ask your dentist if they can apply fluoride treatments to help slow tooth decay.
- If you wear dentures, make sure they fit properly, only wear them while eating, and clean them well using denture cleaning products that will not irritate your mouth.



When should I see a dietitian?

An Accredited Practising Dietitian (APD) is trained to guide your food choices. Cancer will usually affect a person's food and fluid intake, and the impact is greater for people suffering from oesophageal cancer because it is harder to take in and swallow food and fluids.

Cancer and its treatment can affect each person differently. What works well for one person may not work for another.

If you have oesophageal cancer, you should be referred to a dietitian. They will explore your unique situation, challenges and needs, and provide you with education about your current food and fluid intake.

APDs are healthcare professionals who are trained to provide evidence-based nutrition and dietary advice. APDs understand how a healthy diet can optimise health and minimise risk. They are uniquely placed to support people with complex and individual dietary needs.



Note that the term 'dietitian' is used throughout this handbook to refer to APDs. The term 'nutritionist' used on its own does not refer to a regulated profession in Australia.

If you need to see a dietitian, ensure that they are an APD.

Tips to finding an Accredited Practising Dietitian



- Request a referral to a dietitian through your treating hospital. Ask your doctor or nurse for more information.
- Find a dietitian in your local area through Dietitians Australia, at **dietitiansaustralia.org.au**.
- Request a referral to an oncology dietitian through your doctor.
- Ask the PanSupport team for more information on local services.

Talk to your doctor about arranging a Chronic Disease Management Plan to assist with Medicare rebates for dietitian services.

How do I decide which diet is right for me?

If you are already on a restricted diet because of a previous medical condition, such as a low-cholesterol or low-salt diet, or if you have multiple symptoms that require different approaches, make sure you talk to a dietitian. You will need more personalised advice than this handbook provides.

If you were following a diet for nonmedical reasons before your diagnosis (for example, if you were vegetarian or vegan), your dietitian will help you to adjust your intake to meet your needs within your personal preferences. The key goals are to eat a nutritionally balanced diet and to maintain your weight.

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.

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.

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

General wellbeing is how you feel overall, including physically, mentally and emotionally.

High-energy, high-protein diet is a diet that has foods high in energy (or kilojoules) and protein. A high-energy, high-protein diet helps you to meet your increased nutritional demands, and preserve your weight and muscle mass.

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

Kilojoules and calories are measures of how much energy is in a food. High-energy foods provide our bodies with lots of energy, and can help with managing weight loss and muscle wasting.

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

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.

Malnutrition means that a person is not getting enough nutrients, such as proteins, vitamins, minerals and energy.

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 'qullet'.

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.

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.

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

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 A guide to understanding diagnosis and treatment: 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.

Dietitians Australia

It is important that you receive nutritional advice and support from a trained health professional who understands your complex and unique dietary needs. Dietitians Australia makes it easy to search for an Accredited Practising Dietitian in your local area.

To find an Accredited Practising Dietitian near you, go to **dietitiansaustralia.org.au**.

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.





