

# Oesophagogastric cancer (oesophageal and stomach)

Your guide to best cancer care



## About this guide

Being told you have oesophagogastric cancer or could have oesophagogastric cancer can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

## Information and support

**Cancer Council:** For information and support, call Cancer Council on **13 11 20** to talk to an experienced healthcare professional or visit [www.cancer.org.au](http://www.cancer.org.au).

For more information about oesophagogastric cancer, look for Cancer Council's Understanding Oesophagogastric Cancer booklet on your local Cancer Council website.

**Translating and Interpreting Service (TIS):** If you need a translator, call TIS on **13 14 50** or visit [www.tisnational.gov.au](http://www.tisnational.gov.au).

## Initial tests and referral

### Symptoms

If you have pain in your upper stomach, have worsening reflux, are finding it hard to swallow, are vomiting blood or are experiencing unexplained weight loss, tell your general practitioner (GP) as soon as possible.

### Initial tests you may have

**Blood tests.** A sample of your blood will be collected to assess your general health.

If your GP thinks you have oesophagogastric cancer, they will send you to an endoscopist to get an endoscopy.

**Endoscopy.** A flexible tube with a camera on it (called an 'endoscope') is put inside your nose or throat. The endoscope takes images of the oesophagus and stomach.

### Referrals

If your GP has concerns, you will be referred to a specialist (upper gastrointestinal surgeon) at a public hospital or in private practice. Upper gastrointestinal surgeons are doctors who are highly trained in oesophagogastric cancer.



**You can bring a family member or friend with you to your appointments.**



### Timeframes

You should have an endoscopy and see a specialist **within two weeks** of referral.

If you can't get an appointment with your specialist or an appointment for an endoscopy within this time, follow up with your GP.



### Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?

## Diagnosis and staging

An endoscopist will talk about your test results with you and let you know if cancer is present. This is called making a **diagnosis**.

If the endoscopy shows cancer, the specialist will do more tests or procedures to see where exactly the cancer is in your body, if the cancer is growing or if it has spread. This is called **staging**. **Staging** helps to work out the best treatment for you.

You might have one test or a mix of tests or procedures:

**Computed tomography (CT) scan.** Computers and x-rays are used to make a detailed picture of the oesophagus and stomach.

**Position emission tomography (PET) scan.** A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

**Endoscopic ultrasound.** An endoscope is used to look inside your oesophagus and stomach. It uses soundwaves to make a picture of the oesophagus and stomach.

**Endoscopic resection.** An endoscope is used to take tissue from your oesophagus or stomach. This is done under anaesthetic so you cannot feel it.

**Laparoscopy.** Small cuts are made on your abdomen or stomach area. The specialist puts a small tube with a camera into your stomach through the cuts. This is called a laparoscope. This is done under anaesthetic (you will be put to sleep) so you cannot feel it. It is used to find cancers that are too small to be seen on a CT or PET scan. This test is only for stomach cancer.



### Timeframes

Results should be available **within two weeks** from when you have the tests.



### Questions you might want to ask

- What is oesophagogastric cancer?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What stage is my cancer?
- What support services are available to me?

## Treatment

There are several ways to treat oesophagogastric cancer. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

**Endoscopic treatment.** Your specialist can use an endoscope for different treatments. These treatments are used if you have early oesophagogastric cancer. They can also be used to prevent cancers from growing.

**Surgery** is where the cancer is cut out.

**Radiation therapy** uses x-rays to kill cancer cells and stop the cancer growing. It might be used with surgery or chemotherapy. It might be used if the cancer has spread.

**Chemotherapy or drug therapy** uses drugs to kill cancer and stop the cancer growing. It might be used if the cancer has spread.

**Stent.** A tube of flexible mesh is put into your oesophagus. This is called a stent. It is used to make your oesophagus wider so foods and liquids can get to the stomach more easily.

For more information visit [www.cancer.org.au/cancer-information/treatment](http://www.cancer.org.au/cancer-information/treatment).

Supportive care (treatment or services that support you through a cancer experience) are also available.



### Timeframes

Treatment should start **within two weeks** of agreeing to your treatment plan.



**You can ask your GP for a referral to another specialist for a second opinion.**

## Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit [www.australiancancertrials.gov.au](http://www.australiancancertrials.gov.au).

## Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.

## If you smoke

Stopping smoking is one of the most important things you can do to improve your health and wellbeing. Stopping smoking can improve how well the treatment works, reduce the risk of complications during surgery and improve recovery after surgery. For individual and confidential support to stop smoking call Quitline on **13 7848**, speak to your GP or specialist, and visit [www.quit.org.au](http://www.quit.org.au).



### Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- Should I see a dietitian?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?



## Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a healthcare professional about financial support.

For more information about costs, visit [www.cancer.org.au/support-and-services/practical-and-financial-assistance](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance) and [www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment](http://www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment).

## Recovery

Cancer treatment leads to a range of physical and emotional changes.

### Follow-up care plan

Your healthcare team will work with you to make a plan for you and your doctor. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- identifying and dealing with side-effects of treatment
- how to get help quickly if you think the cancer has returned or become worse.

Many people express feeling anxious that the cancer will return. Your specialist and healthcare team will talk with you about your needs and refer you to healthcare professionals and/or community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- side effects of treatment and the specialists you may need to see how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit [www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment](http://www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment).



#### Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

## Living with advanced cancer

### If cancer returns

Cancer can come back in the same place after treatment or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.



#### Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

### Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

### Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit [www.advancecareplanning.org.au](http://www.advancecareplanning.org.au).

### Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit [www.palliativecare.org.au](http://www.palliativecare.org.au).

### Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer. For more information visit [www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment](http://www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment).



#### Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Disclaimer: Always consult your doctor about matters that affect your health. This guide is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided above.

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This resource is based on information from the optimal care pathway for people with oesophagogastric cancer (2nd edition), available at [www.cancer.org.au/OCP](http://www.cancer.org.au/OCP).