HEARTBURN CANCER UK

Just been told you have

cancer of the oesophagus?

Here are some things that might be useful to know...

Heartburn Cancer UK - **Supporting your journey**

Right now, you and your loved ones are probably feeling at least a little worried and scared. You may also be confused, shocked, sad and upset. This is all completely natural and understandable.

You might not have taken in all that you've recently been told, and that's normal too.

Over the next few days, weeks, and months, you'll be given a lot of information, and you might need some support from new people in new areas.

Heartburn Cancer UK is a charity that supports people with problems with the oesophagus, also known as your food pipe or gullet. We're here to help you, your family, and friends where we can.

Our experience shows that in your situation, some basic information and advice is helpful for people, so we've put together this leaflet.

It's just a starting place. There is a lot more information available, but you can ask, or find it, when you're ready.

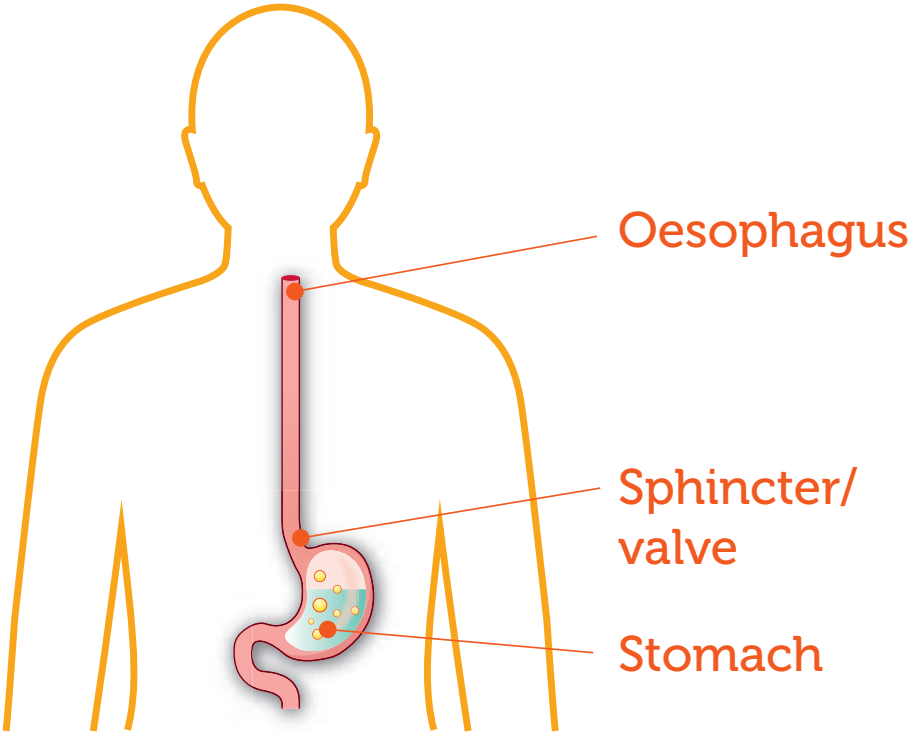
The main things you'll probably want to know now.

A quick low down on the oesophagus and where cancer can develop.

The oesophagus (sometimes known as the food pipe or gullet) connects your mouth to your stomach.

It is a hollow tube of muscle that is about 25 cm long in adults. The inside of the oesophagus is usually lined by flat "paving slab" like cells (called a stratified squamous epithelium). These cells sit on a membrane that separates the lining from the layers of muscle.

Cancer can develop at any point along its length. And because the oesophagus doesn't have an outer layer like many other organs, sometimes cancer cells can get into it or through it to other nearby organs.



What are the main types of oesophageal cancer?

Oesophageal cancer is usually one of two types:

1. Adenocarcinoma usually occurs in the lower part of the oesophagus at the point where it meets the stomach and can be linked to Barrett's oesophagus. Adenocarcinoma develops in the lining of cells that have changed shape and size due to long-term exposure to stomach and bile acids. They then go from looking like "paving slabs", under the microscope, to looking more like piled-up columns.
2. The second is squamous cell carcinoma (SCC) which tends to affect the upper part of the oesophagus and is more strongly linked to smoking and drinking alcohol.

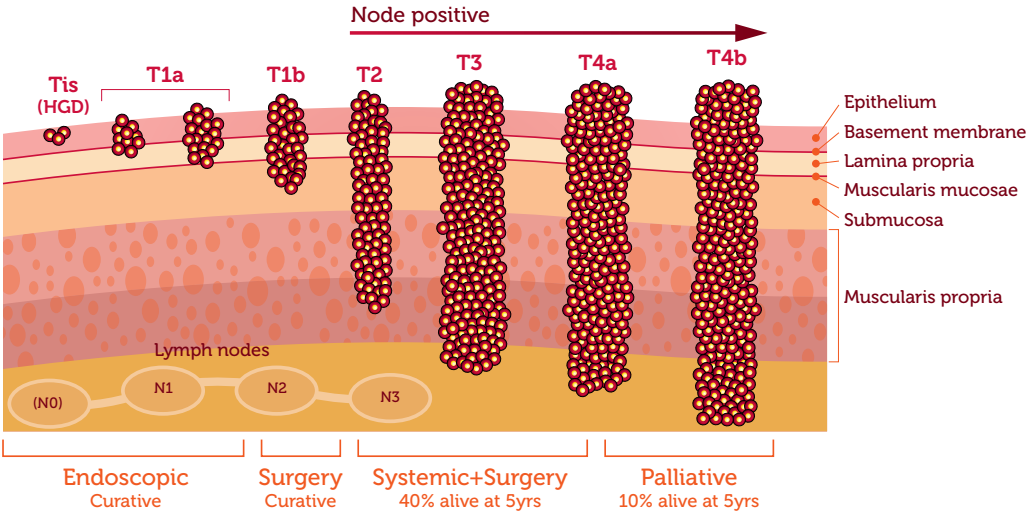
How is oesophageal cancer staged?

The stage of the cancer describes its position and whether it has spread from where it started. Knowing the stage helps doctors decide on the best treatment for you.

The TNM staging system is most commonly used for oesophageal cancer.

TNM stands for tumour, nodes, and metastasis.

- T describes how far the tumour has grown into the oesophageal wall.
- N describes whether the cancer has spread to the lymph nodes.
- M describes whether the cancer has spread to other parts of the body (metastases).



Tumour

TNM stands for tumour, nodes, and metastasis.

- T1 means the tumour has grown into the inner wall (mucosa or submucosa) of the oesophagus:
  - T1a – the tumour has grown into the mucosa.
  - T1b – the tumour has grown into the submucosa.
- T2 means the tumour has grown into the oesophagus's muscle layer (muscularis).
- T3 means the tumour has grown into the oesophagus's outer lining (adventitia).
- T4 means the tumour has grown through the outer lining of the oesophagus and into nearby structures, such as the diaphragm or a blood vessel. Doctors sometimes put the letter 'a' or 'b' after this. This gives extra detail about where the tumour is.

Nodes

- N0 means there are no cancer cells in any nearby lymph nodes.
- N1 means there are cancer cells in 1 to 2 nearby lymph nodes.
- N2 means there are cancer cells in 3 to 6 nearby lymph nodes.
- N3 means there are cancer cells in 7 or more nearby lymph nodes.

Metastases

- M0 means the cancer has **not** spread to other parts of the body.
- M1 means the cancer has spread to other parts of the body, such as the lungs or liver.

What treatment will I be offered?

There are many treatments available for oesophageal cancer. But like most cancers, the earlier it is caught, the better the outcome usually is.

You may be offered one, or more of the following treatments:

Endoscopic Mucosal Resection (EMR): A doctor will remove abnormal cells from the inside of the oesophagus in a similar way to the camera test used to look for the cancer. This may need to be done more than once.

Radiotherapy is a treatment using a high-energy beam of x-rays targeted to a precise area. It can be a stand-alone treatment or can be offered with other treatments, such as chemotherapy.

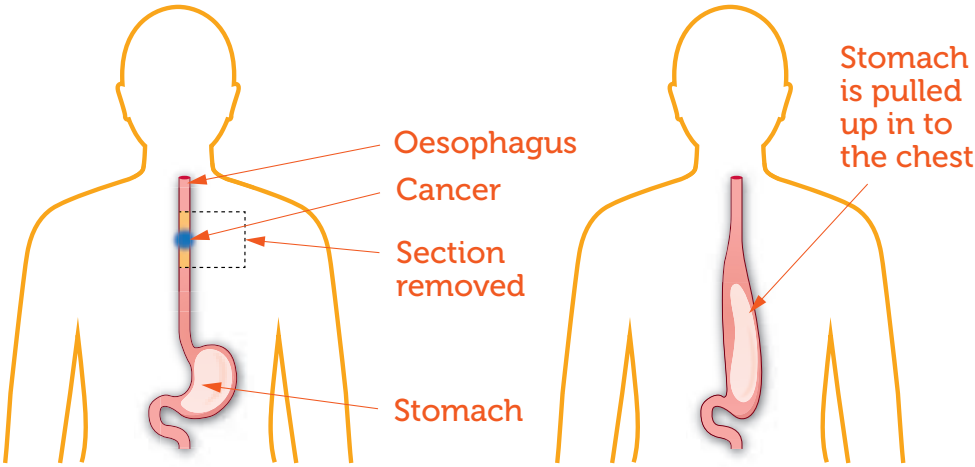
Chemotherapy could be offered before or after surgery or as a stand-alone treatment. This is a treatment where strong medicine is used to kill cancer cells. There are many types of chemotherapy, but they all work in a similar way. They stop cancer cells from reproducing, which prevents them from growing and spreading in the body.

Immunotherapy uses the body's own immune system to find and attack cancer cells. The cancer cells are tested in the laboratory for specific markers. The results will determine whether immunotherapy, or targeted therapy, could be added to the treatment options available for you.

An Oesophageal Stent is a tube fitted into the oesophagus to overcome the blockage caused by the tumour. It is placed during an endoscopy procedure.

Surgery is often needed for the oesophageal cancer to be removed completely. The aim of surgery is to remove the tumour, the oesophagus, the lymph nodes (that may contain cancer cells) and the surrounding tissue. It will try to make it so people can eat and drink normally.

The Ivor-Lewis oesophagectomy is, by far, the most performed type of surgery for cancer of the oesophagus. It involves operating in the abdomen and the chest. When the oesophagus or part of the oesophagus is removed, a tube is made out of the stomach instead, which is then drawn up into the chest or neck to where it is joined to the remainder of the oesophagus. The doctors can do this either via keyhole (using instruments fed through a small hole in your skin) or by making a larger open skin incision or using a combination of both. Robotic surgery is also starting to be used.



If your cancer is too advanced for treatment that may cure it, the doctors will try to improve the length and quality of your life, and that will often include using some of the procedures mentioned above.

How worried should I be?

Your doctors will be able to tell you more about your own situation. And although there will be common themes, and averages, your cancer or experience won't be exactly the same as anyone else.

You will have your own treatment plan. Some things that haven't helped other people may help you and there is some research that a positive outlook can reduce pain and discomfort caused by the cancer or treatment, even if it doesn't change the outcome.

During your treatment, you will be assigned a clinical nurse specialist (CNS) who will be on hand to support you. They will often be the first person to turn to if you have any questions.

It's also sometimes helpful to speak to other people in a similar position or who have been through what you are experiencing now. Ask us for information about our support groups or visit our website.

If your cancer can't be cured, you will be offered support from palliative care doctors and other health care professionals who specialise in helping you cope with your situation.

Don't be put off by the words 'palliative care', which are often confused with 'end of life' care. It is a term used to describe people living with cancer or requiring specialised medical care for example, treatment for pain, and symptom relief which can help make life easier and more comfortable.

Why me?

Like many cancers, some things increase the risk of developing oesophageal cancer, including being older, smoking, drinking alcohol and being overweight.

And for oesophageal cancer, having long-term heartburn or acid reflux - which can lead to a precancerous condition called Barrett's oesophagus which can, in some cases, put you at risk of developing cancer.

There is ongoing research into genes that can make people more prone to some cancers.

However, sometimes, someone develops cancer without having any of these things. As far as we can tell, the reason is just bad luck; a cell has changed for no apparent reason.

None of this may be much consolation right now. But it might help give you some perspective. And, although it's impossible to turn back the clock, it might be worth considering some lifestyle changes that will help you deal with the cancer's symptoms and the treatments impact.

Things to note -

'key messages I would have liked to know'

- provided by an OC patient.

- Be wary of your source of information – Doctor Google isn't always the answer. This leaflet has been fact checked and approved by medical experts and has been developed with feedback from patients.
- You will need to prepare for many tests and appointments (regardless of the treatment plan). You will have CT scans, pet scans, MRI's, placement scans etc and that is before you even start any treatment.
- Even though you are entering a bewildering and scary place, try to remember that you are in good hands and will meet warm and friendly professionals who want to help you navigate this journey.
- The role of the clinical nurse specialist (CNS) provides vital support to you and your loved ones. They are dedicated to your type of cancer and are a wealth of information. They are approachable and a good first point of contact for any questions you may have.

Where can I get more information?

- Ask your doctor, consultant, or clinical nurse specialist.
- Look on our website **www.heartburncanceruk.org** or search for Cancer Research UK or Macmillan Cancer Support.
- Join a support group of people who know what you're going through. You'll find a link to them in our '**supporting you**' section of our website**.**
- Speak to a dietician. Problems with eating and drinking are common with oesophageal cancer. At HCUK, we work with a specialist dietician, and you will find more diet and lifestyle advice in our '**supporting you**' section of our website**.**

Call 01256 338668

www.heartburncanceruk.org

HEARTBURN CANCER UK

Is it really only Heartburn?

Heartburn Cancer UK is registered in England & Wales. Company Limited by Guarantee.
Company Registration Number: 07227937. Charity Registration Number: 1136413

v1.0 January 2024