GUT CANCER FOUNDATION

A guide to understanding diagnosis and treatment:

STOMACH CANCER

Gut Cancer Foundation

The Gut Cancer Foundation funds innovative research, is the voice of cancers of the digestive system, and provides vital information and education to improve and save the lives of all New Zealanders affected by cancers of the digestive system, which is pancreatic, liver, stomach, biliary, oesophageal, bowel and anal cancers.

The information in this booklet has been repurposed from our partners at Pancare Foundation Australia. We would like to extend our sincere gratitude to Pancare for generously sharing their patient support material and providing permission for us to adapt it to support Kiwis and whānau with stomach cancer in Aotearoa New Zealand.

This booklet has been reviewed for the New Zealand system by relevant specialists in the New Zealand medical sector.

Note to the Reader

The medical profession and research community are continually updating information about stomach cancer. We have taken care to ensure that the information in this handbook is reflective of 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.

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

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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 support you, your whānau and friends.

In this booklet, you will 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 and practical ways we can support you and your whānau.

Talk to our team

To discover more or talk further with our team,
visit www.gutcancer.org.nz/support-service,
email support@gutcancer.org.nz or call 0800 112 775

Your guide for using this handbook

This handbook contains key detail in colour coded boxes.

ADDITIONAL DETAILS

PATIENT STORIES

FREQUENTLY ASKED QUESTIONS

HELPFUL TIPS

Note: At the back of this booklet you will find a list of explanations of common terms relating to stomach cancer and sources of further information and support.

Introduction

This handbook is for anyone who has recently been diagnosed with stomach cancer, and for their partners, family members and carers. It gives a general introduction to stomach 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 stomach 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 stomach cancer would not have had any idea or suspicion 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 specific situation; you may wish to discuss anything raised in this handbook with these professionals.

Contents

About the stomach

The stomach forms part of the upper gastrointestinal (GI) tract. The GI tract is a part of the digestive system. The function of the stomach is to store and break down food and fluid after being swallowed.

The stomach is a hollow sac that connects to the oesophagus at one end and the small intestine at the other. The stomach secretes acid and enzymes that help to digest food. It also has muscles that contract, which churns food into a semifluid mixture called chyme.

The stomach is divided into five regions *(Figure 1)*. These are the:

cardia – this is the part of the stomach that is closest to the oesophagus

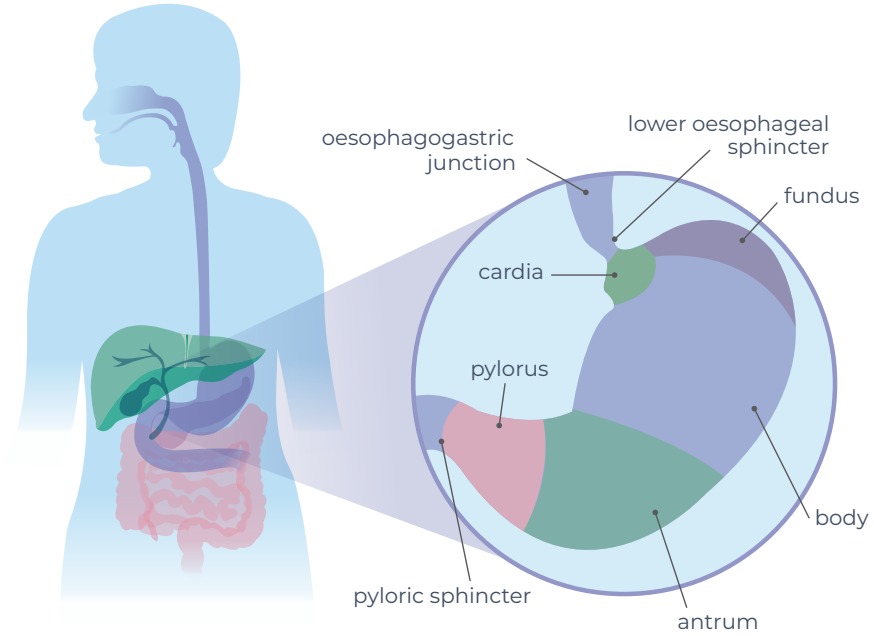
fundus – this is the upper part of the stomach, next to the cardia

body – this is the main part of the stomach, in the middle

antrum – this is the lower part of the stomach and is shaped like a funnel

pylorus – this is the narrow part of the stomach that joins the duodenum (part of the small intestine).

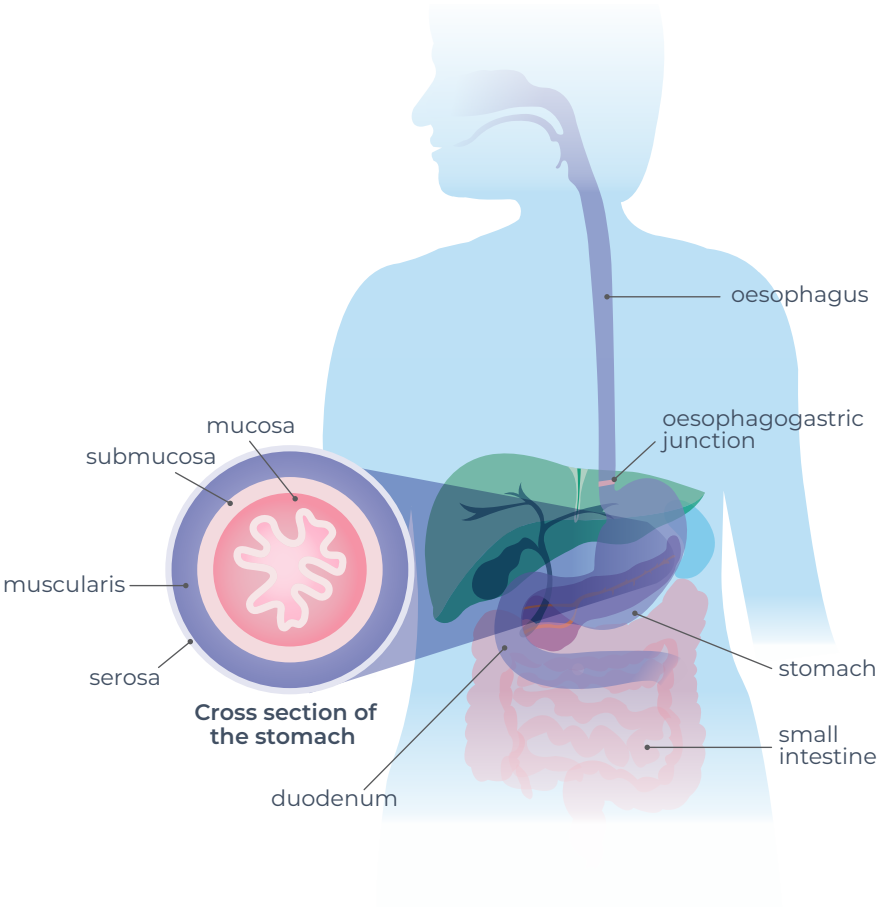
Figure 1: Parts of the stomach



The stomach also has four layers *(Figure 2)*. These are the:

- **inner layer, known as the mucosa** – this layer produces the acid and enzymes that help break down food, and mucus to protect the stomach lining
- **submucosa** – this layer supplies blood and nutrients to the stomach
- **muscle layer, known as the muscularis** – this layer contracts to help break down food and push it into the small intestine
- **outer layer, known as the serosa** – this layer wraps the stomach.

Figure 2: The four layers of the stomach



Sphincters and bile reflux

The stomach has sphincters at each end, which are muscles that allow liquids and food to move through the digestive system. Sphincters work like valves, opening and closing at the right time to control the movement of partially digested food and liquid.

The lower oesophageal sphincter is at the top of the stomach, where it joins the oesophagus. This area is known as the oesophagogastric junction. Cancers in this region are talked about in Gut Cancer Foundation's - A guide to understanding diagnosis and treatment: oesophageal cancer, available at www.gutcancer.org.nz/shop.

The pyloric sphincter is at the bottom of the stomach, where it meets the duodenum. This muscle controls the flow of chyme into the intestines. If the pyloric sphincter is removed or damaged, food and fluids can pass too quickly through to the duodenum. This can lead to a condition called dumping syndrome, and difficulty digesting and absorbing food and nutrients. For more information on dumping syndrome, see Gut Cancer Foundation's - Diet and nutrition for people living with stomach cancer at www.gutcancer.org.nz/shop

Bile is a fluid that helps digest fats in the small intestine. Bile reflux happens when the pyloric sphincter relaxes at the wrong time, allowing bile to flow up from the duodenum and back into the stomach. If the lower oesophageal sphincter is also not working properly, bile can reach the oesophagus. Bile reflux that is left untreated increases the risk of developing stomach cancer.

About stomach cancer

Stomach cancer occurs when abnormal cells in the stomach grow out of control. Stomach cancer may also be called gastric cancer.

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

- **Adenocarcinomas** (the most common type of stomach cancer) start in the cells that line the inside of the stomach (the mucosa).
- **Gastrointestinal stromal tumours** (a rare type of stomach cancer) start in special cells in the wall of the stomach.
- **Neuroendocrine tumours** start in the cells of the stomach that make hormones.
- **Lymphomas** are a cancer of the lymph system that is sometimes found in the wall of the stomach.

The main form of stomach cancer (adenocarcinomas) can sometimes be split into two sub-types; intestinal and diffuse-type however often tumours are a mix of subtypes where there is a combination of both features. A classification is made by a pathologist.

Hereditary stomach cancer is a diffuse-type stomach cancer caused by a mutation in a particular gene called CDH1, that is passed down through family and whānau. The level of hereditary diffuse-type stomach cancer (also known as Hereditary Diffuse Gastriic Cancer - HDGC) in New Zealand is much higher than in many other countries and is prevalent in some whānau Māori in New Zealand. For more on information on HDGC please visit www.gutcancer.org.nz/hereditary-stomach-cancer

Risk factors

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

Health risk factors

Long-term bile reflux can lead to inflammation and ulcers, and may change the cells lining the stomach into the same type of cells that line the intestines.

Infection with *Helicobacter pylori,* a type of bacterium that can be found in the stomach lining, causes inflammation of the stomach lining (called gastritis) and increases the production of stomach acid (also called gastric acid). This can lead to ulcers in the stomach and duodenum, which increases the risk of developing stomach cancer.

Other health risk factors for developing stomach cancer include:

- having part of the stomach removed (a partial gastrectomy) to treat non-cancerous conditions
- having low levels of red blood cells due to pernicious anaemia
- being infected with Epstein–Barr virus, which is a type of herpes virus.

Environmental and behavioural risk factors

Environmental and behavioural risk factors for developing stomach cancer include:

- smoking tobacco
- having moderate to heavy alcohol intake
- obesity
- eating a lot of processed meat, or salted or pickled foods
- being exposed to asbestos, certain dusts in the rubber industry, and airborne lead.

Hereditary risk factors

Hereditary factors that increase the risk of stomach cancer are rare. They include familial adenomatous polyposis, hereditary diffuse gastric cancer, Lynch syndrome and Peutz–Jeghers syndrome. There are currently no genetic tests available to screen for stomach cancer.

Other risk factors

Other risk factors for developing stomach cancer include being:

- over 60 years of age
- male.

Towards a stomach cancer diagnosis

Reaching a diagnosis of stomach 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 stomach cancer was considered, and you may have had the cancer for some time without knowing.

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

- difficult swallowing
- feeling full quickly
- heartburn or indigestion, especially if it is getting worse
- discomfort or bloating in the abdomen
- unexplained weight loss
- black or bloody stools
- unexplained fatigue
- blood in your vomit.

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 stomach 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 stomach 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 stomach cancer will help doctors understand your condition. You may need other tests to confirm the type of stomach 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.

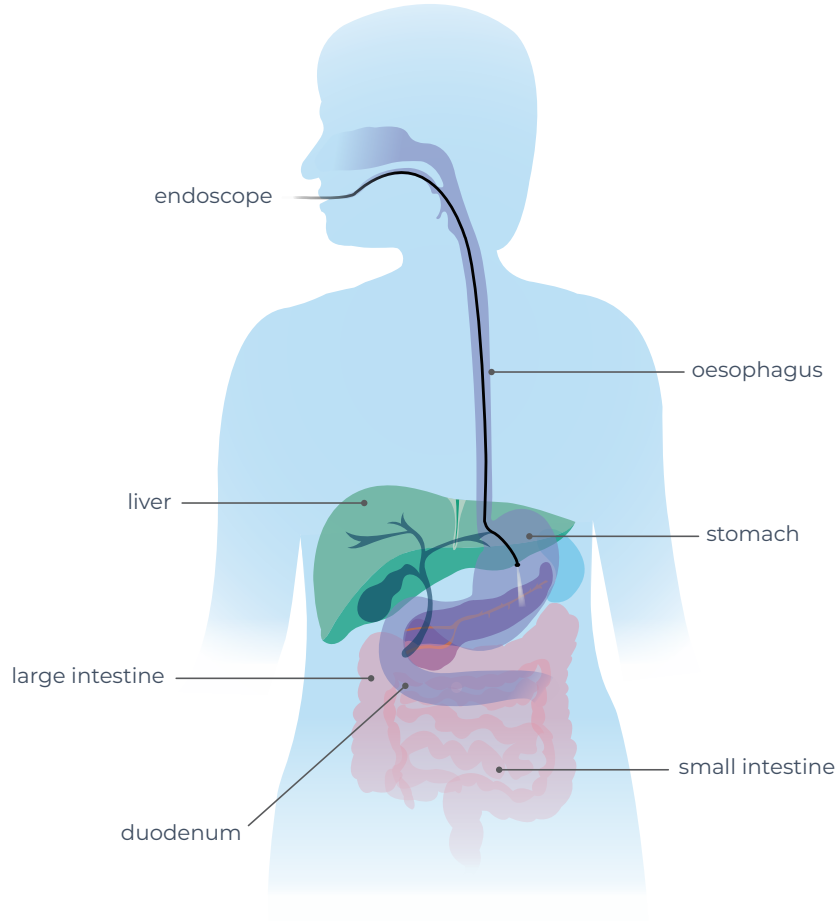
Some blood tests can also check for tumour markers, which are chemical substances produced by cancers that show up in the bloodstream. For example, CA19-9 and CEA are tumour markers linked to stomach cancer. However, other conditions can also raise the level of these markers, and some people with stomach cancer have normal levels. These markers on their own cannot be used to diagnose stomach cancer.

Endoscopy

Endoscopy is used to diagnose stomach cancer. Your doctor also may call it a gastroscopy.

An endoscope is a thin, flexible tube with a small video camera on the end. This can be performed with or without sedation. You can let your doctor know what you would prefer. The doctor will slide the endoscope down your oesophagus and into your stomach to look for signs of cancer *(Figure 3)*. The doctor may also take a biopsy (a small sample) of stomach 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 stomach cancer



Staging tests

If you have been diagnosed with stomach 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 stomach cancer, *(see 'Stages of cancer' on page 20)*.

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, an EUS or a laparoscopy *(see 'Laparoscopy' on page 19)*. A biopsy may not be performed in certain cases when surgical removal is planned upfront.

Computerised tomography (CT) scan

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

Endoscopic ultrasound (EUS)

You may have an EUS after your initial endoscopy to see whether the cancer has spread to the surrounding lymph nodes or deeper into the stomach tissue. EUS uses an endoscope with a camera and ultrasound probe at the end. This probe uses soundwaves to create a picture of the inside of the body. The doctor may also take a biopsy of stomach 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.

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 thebody. 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 stomach and surrounding areas.

Laparoscopy

A laparoscopy 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 outside of the stomach, and check whether the cancer 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.

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 New Zealand, the common ones are:

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

Figure 4: Numbered cancer stage system

Stage 1	The earliest stage. Tumours are found only in the lining of the stomach. Also called early stomach cancer.
Stage 2 & 3	Tumours have spread deeper into the layers of the stomach wall, and to nearby lymph nodes. Also called locally advanced stomach cancer.
Stage 4	The late stage. Tumours have spread to nearby lymph nodes or parts of the body, or to distant lymph nodes and parts of the body. Also called advanced or metastatic stomach cancer.

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

T (tumour)	The size of the tumour
N (node)	Indicates whether the cancer has spread to the lymph nodes
M (metastasis)	Indicates whether 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.

Anyone diagnosed with stomach 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 (oncology nurses) and other allied health professionals.

Once you have had all your tests and investigations, your multidisciplinary 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.

Treatments for stomach cancer

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

The treatments 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.

Endoscopic resection

If the stomach cancer is quite small when detected and has not spread, the surgeon may be able to perform 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 a gastrectomy.

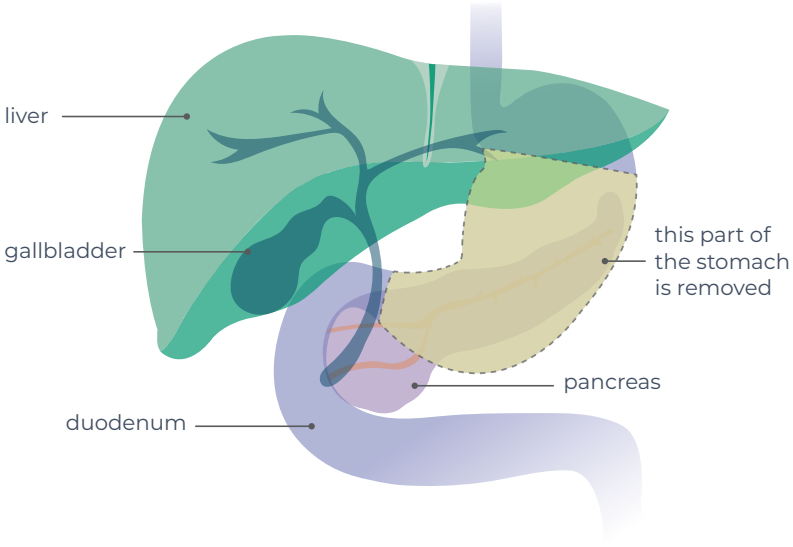
Subtotal gastrectomy

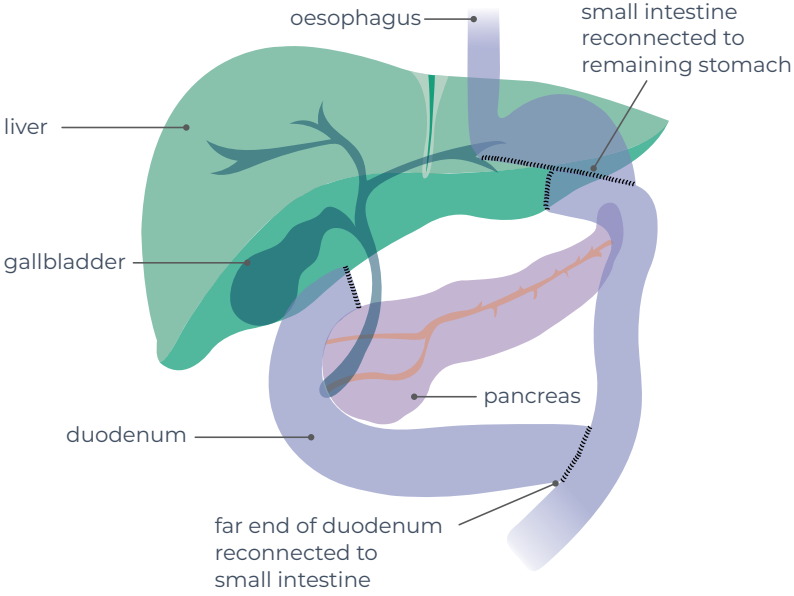
If the stomach cancer is at the lower part of your stomach, you may have surgery to remove that part of the stomach. This is called a subtotal gastrectomy. The amount of stomach that is removed depends on the size and location of the cancer. The surgeon will also remove some of the tissue that holds the stomach in place (called omentum), along with the surrounding lymph nodes so they can be examined for cancer cells.

The surgeon will attach the remaining part of your stomach and the first part of your small intestine (duodenum) to the rest of the small intestine *(Figure 6)*.

A subtotal gastrectomy can be a complex surgery, and you may need to stay in hospital for 5 to 10 days. It may take up to 3 months for you to fully recover from the procedure.

Figure 6: Partial gastrectomy





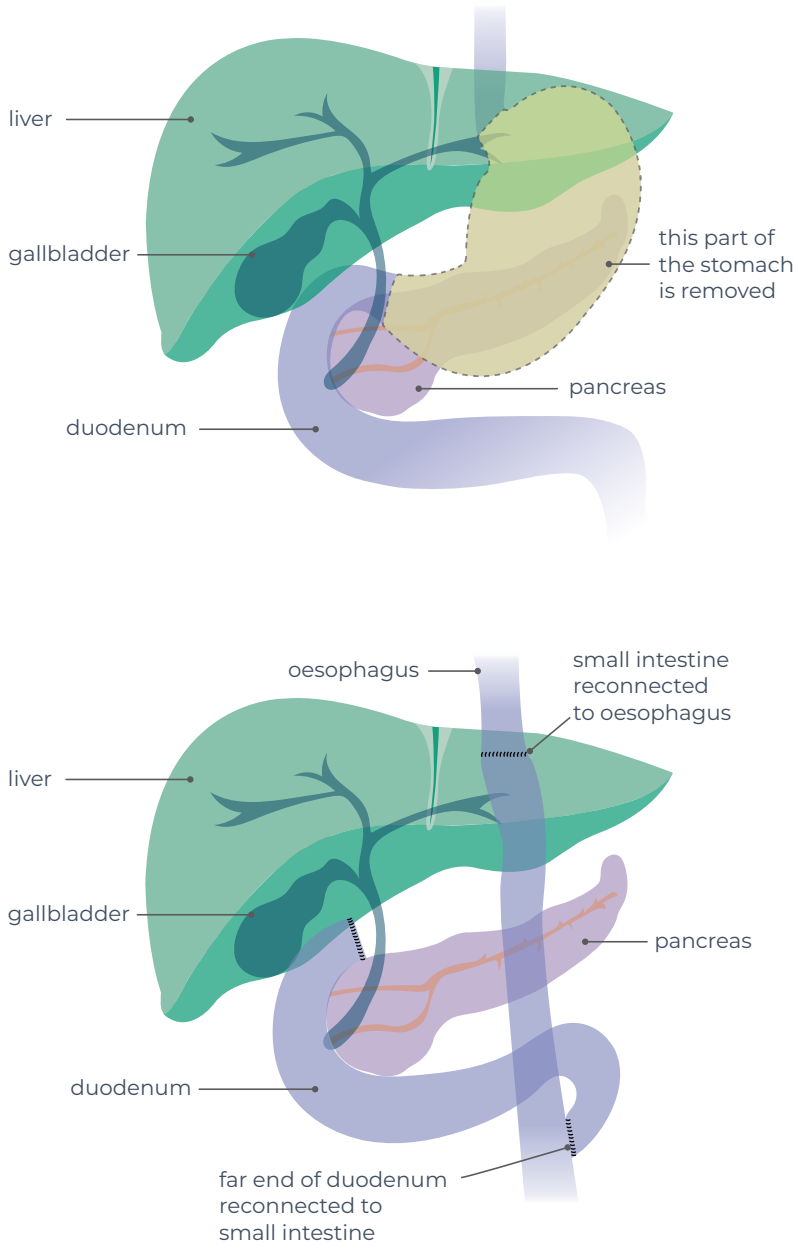
Total gastrectomy

Surgery to remove all your stomach is called a total gastrectomy. The surgeon will also remove the surrounding lymph nodes so they can be examined for cancer cells.

After your stomach is removed, the surgeon will attach your oesophagus to your small intestine *(Figure 7)*. Part of the small intestine will serve as a stomach.

A total gastrectomy can be a complex surgery, and you may need to stay in hospital for 5 to 10 days. It may take up to 3 months for you to fully recover from the procedure.

Figure 7: Total gastrectomy



Chemotherapy

Chemotherapy may be offered to patients with stomach cancer, either alone or in combination with other therapies such as radiation therapy. For stomach 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 33)* 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 stomach cancer is available in your region *(see 'Clinical trials' on page 44)*.

Depending on the type of stomach 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 stomach 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 in place for several weeks, even months, with regular monitoring and care.

What is a PICC line?

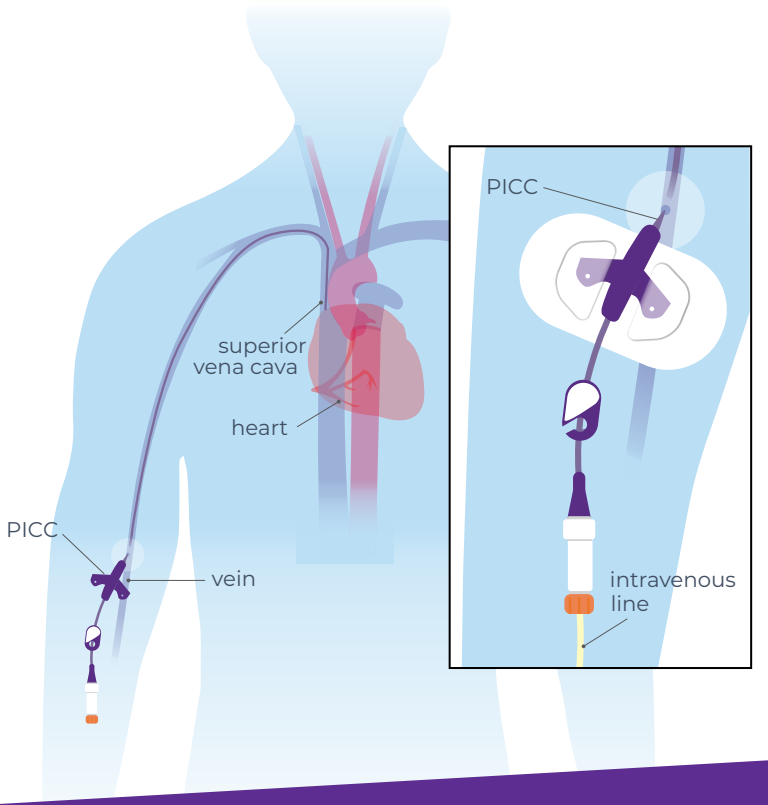
A PICC is a peripherally inserted central catheter. It is used to give treatments, fluids, medicines or blood transfusions into your bloodstream and to take blood samples. A PICC is used instead of intravenous (IV) cannulas (needles in your arm) for your treatments. IV cannulas are put in for each treatment, 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 8)***. 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.

Your 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 8: PICC line (peripherally inserted central catheter line) placement

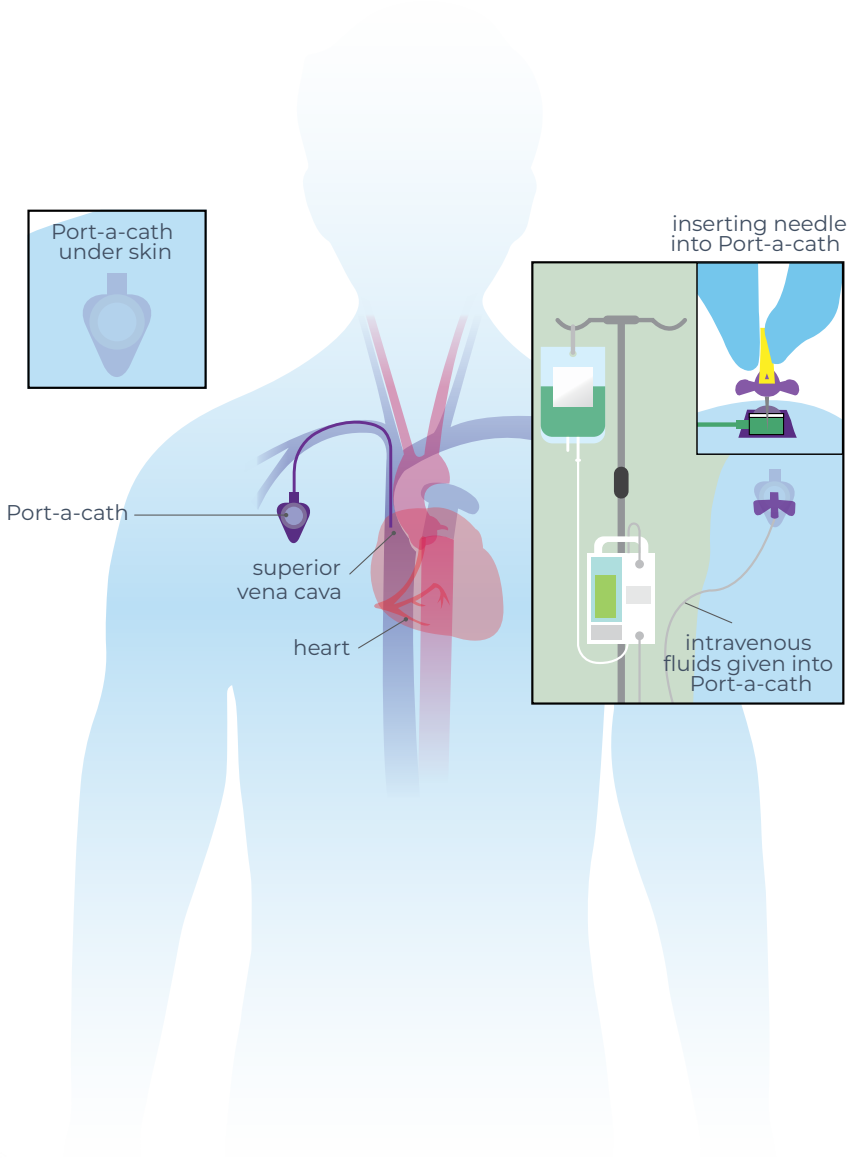


What is a chemo port?

A chemotherapy (chemo) port-a-cath 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 9)***. 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.

Figure 9: Chemo port (port-a-cath) placement



Radiation therapy

Radiation therapy may be used for bleeding stomach cancers when surgery or other treatments are not available.

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, loss of appetite and diarrhoea.

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 stomach 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.

Managing symptoms and treatment side effects

Because stomach 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 stomach cancer: surgery, chemotherapy, radiation therapy, 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 stomach cancer treatments

Surgery	Chemotherapy	Radiation therapy	Targeted therapy and immuno-therapy
• Fatigue • Pain • Reflux • Diarrhoea and malabsorption • Weight loss • Muscle loss • Malnutrition • Loss of appetite • Feeling full quickly • Gastroparesis (food moves too slowly through the stomach) • Dumping syndrome (food moves too quickly through the stomach) • Infections and wound complications.	• Nausea and vomiting • Loss of appetite • Diarrhoea or constipation • Fatigue • Fever • Weight loss • Muscle loss • Malnutrition • Hair 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.	• Nausea and vomiting • Loss of appetite • Feeling full quickly • Diarrhoea or constipation • Fatigue • Weight loss • Muscle loss • Malnutrition • Skin changes in the area (redness or peeling).	• Skin rash • Flu-like symptoms • Abdominal pain • Diarrhoea • Weight changes • Joint pain • Shortness of breath.

Various 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
- wellbeing support from a counsellor, psychologist or social worker.

If you are in hospital, your care needs should be assessed before you leave. This 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 reduce 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

Stomach 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, chemotherapy, radiation therapy and targeted therapies) and medications.

A dietitian can provide advice or supplementary information on managing your diet. You may wish to refer to the Gut Cancer Foundation's 'Diet & nutrition for people living with stomach cancer' guide.

Malabsorption and pancreatic enzyme replacement

Changes to your stomach after a gastrectomy can mean that food passes too quickly from the oesophagus to the small intestine. It can also result in your pancreas releasing fewer digestive enzymes to the stomach. This can lead to poor digestion and absorption of food, and is known as pancreatic exocrine insufficiency.

There are several symptoms of malabsorption, including:

- floating, pale, foul-smelling stools
- more frequent or loose bowel movements
- bloating or pain (because the large intestine is not used to dealing with these undigested nutrients)
- excess flatulence (passing wind)
- stools that are oily in appearance
- stools that are difficult to flush and stick to the toilet bowl
- weight loss
- not gaining weight, even if you feel you are eating enough
- fatigue and weakness.

If pancreatic exocrine insufficiency is suspected, your specialist should recommend that you take a supplement to replace the pancreatic enzymes. Creon® is the brand name of one of these supplements.

Pancreatic enzyme supplements are available in capsules. These capsules contain a mixture of three different pancreatic enzymes: lipase (to digest fats), amylase (to digest carbohydrates) and protease (to digest proteins).

Your doctor or dietitian will help you to determine the dosage you require at each meal and snack, and when to take them. The dosage is adjusted according to the type and amount of food being eaten, and whether your symptoms persist.

"What Creon has allowed me to do is to eat what I want, when I want. It's important to understand how it works. Many people are unsure how to use it correctly. My dietitian helped me to understand the correct dosage, when to take it and how to make it work best for me."

Creon (the brand name of a pancreatic enzyme supplement) may be prescribed if your body is not producing any or enough pancreatic enzymes, or if you are displaying symptoms of malabsorption. More information about Creon can be found in the Diet & Nutrition Booklet, for people living with pancreatic cancer.

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 eating smaller, more frequent meals and snacks to prevent weight loss.

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 stomach 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 and one of the best ways to help is by talking to family, friends or a trained counsellor. If the feelings become overwhelming and there are episodes of depression, talk to your doctor about managing this with antidepressant medications or counselling.

For more ideas and support,
visit www.gutcancer.org.nz/emotional-health

Support for people with stomach 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.

For more ideas and support,
visit: www.gutcancer.org.nz/patient-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.

You may be able to get financial help for travel, or to travel from regional areas to cities. For more information, go to www.gutcancer.org.nz/travel-and-accommodation.

Clinical trials

Clinical trials for stomach 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.

Some trials are looking at new therapies, while others are combining various therapies to see whether they work better together.

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 together
- 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 clinical trials, please visit www.gutcancer.org.nz/cancer-research-and-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, specialist 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 (expected outcome)? Will it change if I do or don't have a particular treatment?
- What kind of surgery have I had? How much of my stomach remains? Did you have to attach my oesophagus to my small intestine? 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 stomach cancer, available at www.gutcancer.org.nz/shop)
- Do I need to take vitamin supplements or pancreatic enzyme supplements (Creon®)? How long will I need to take them for? How do I take them?
- How can I make an appointment with a dietitian (see Diet and nutrition for people living with stomach cancer, available at www.gutcancer.org.nz/shop)

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.
- **Bile** is a fluid that is made in the liver, stored in the gallbladder and secreted into the small intestine. Bile is transported through bile ducts. Bile is made from cholesterol, water, bile salts and bilirubin (a yellow pigment that is formed when red blood cells break down), and is used to help digest fats.
- **Biomarker** is a chemical substance in the bloodstream that a pathology lab can test for. See also Pathology
- **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 stomach 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).
- **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 only affects 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 stomach 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 and foods that increase calorie (energy) 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:
  - 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.
- **Pernicious anaemia** is a condition where the body is unable to make enough red blood cells. Pernicious anaemia happens when the body cannot absorb vitamin B12 from food or oral supplements.
- **Prognosis** is the expected outcome for you based on the most up-todate 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.
- **Recurrence** 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

There are a range of international organisations that Gut Cancer Foundation is collaborating with. Due to differences in best practice care around the world, we have focused on resources and information available in New Zealand.

Our website has information that complements what is in this booklet. 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.

www.gutcancer.org.nz/stomach-cancer

To maximise your nutritional needs and learn more about pancreatic enzyme supplements, we have developed a booklet specially to focus on the topic of diet and nutrition. You can download these booklets at www.gutcancer.org.nz/shop.

There are organisations that can support you with counselling to help patient and whānau work through a diagnosis.

Cancer Society: www.cancer.org.nz/how-we-can-help/support-we-offer/psychology-and-counselling

Healthpoint: www.healthpoint.co.nz/community-health-and-social-services/cancer-support/cancer-counselling


Making a difference to the
lives of people with cancers
of the digestive system.

A guide to understanding diagnosis and treatment of stomach cancer.

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