Understanding Pancreatic Cancer

Whaimōhiotanga mō te matepukupuku repetaiaki huka

A guide for people with pancreatic cancer

Cancer Society

Te Kāhui Matepukupuku o Aotearoa

Published by:
Cancer Society of New Zealand Inc
PO Box 12700
Wellington 6011

First edition

978-0-9951486-5-9 (print)

978-0-9951486-6-6 (online)

Thanks to our supporters who make it possible for us to produce this resource.
If you would like to support the Cancer Society you can donate at cancer.org.nz.

About this booklet

This booklet provides you with information on how pancreatic cancer is diagnosed, the different stages of pancreatic cancer, how it is treated, and living well during and after treatment.

Information is summarised in the **'Key points'** at the start of each section of the booklet. The key points are also translated into te reo Māori.

You may like to ask your cancer treatment team which sections you may find most useful. You can phone the **Cancer Information Helpline 0800 CANCER (226 237)** to talk with our friendly staff.

You can get copies of Cancer Society booklets and information sheets from your local Cancer Society, by phoning the Cancer Information Helpline, or by downloading them from our website: www.cancer.org.nz

We would value your feedback on this booklet. Please email any comments or suggestions to admin@cancer.org.nz

Ngā kōrero kei roto

Ka whakarato tēnei puka i ngā pārongo mō te āhua o te whakatau i te matepukupuku repetaiaki huka, ngā wāhanga rerekē o te repetaiaki huka, pēhea te whakamaimoa, me te noho ora i te wā o te maimoatanga me te wā whai muri mai.

Kua whakarāpopotohia ngā pārongo ki raro i 'Ngā kōrero matua' i te tīmatatanga o ia tekiona o te puka. Kua whakamāoritia anō hoki ngā korero matua.

Tērā pea ka hiahia koe ki te uiui i tō rōpū whakamaimoa matepukupuku mō ngā tekiona ka whai kiko mōu. Ka āhei hoki koe ki te waea atu ki te **Cancer Information Helpline (226 237)** kī te kōrero kī ngā kaimahi hoahoa.

E āhei ana hoki koe ki te rapu kape o ngā puka a te Kāhui Matepukupuku me nga whārangi pārongo mai i tō Kāhui Matepukupuku ā-Rohe, mā te waea atu ki Cancer Information Helpline, mā te tiki ake rānei mai i tō mātou paetukutuku: www.cancer.org.nz

Ka tino whai hua ki a mātou mehemea he whakaaro ōu mō tēnei puka. Tēnā koa īmēratia mai ōu whakaaro, ōu huatau rānei, ki admin@cancer.org.nz.

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Section One: Understanding pancreatic cancer (cancer of the pancreas)

Tekiona tahi

Whakamōhiotanga mō te matepukupuku repetaiaki huka

Key points:

- The pancreas is part of your digestive system and sits behind your stomach. It has three parts: the head, the body, and the tail.
- The pancreas has two jobs.
  - It makes digestive juices (enzymes) that help to break down the food you eat.
  - It helps to make the hormones, insulin and glucagon, that control the level of sugar in your blood.
- Pancreatic cancer is cancer that starts in the pancreas. There are two types of pancreatic cancer: pancreatic adenocarcinoma and pancreatic neuroendocrine cancer. The most common type is adenocarcinoma (95% of all pancreatic cancer).
- Pancreatic cancer is hard to diagnose early. Symptoms often do not occur until the cancer has become large or has spread to other parts of the body.

- Symptoms may include:
    - pain or discomfort in your tummy (abdomen) that may spread to your back
    - unexplained weight loss
    - jaundice (yellowing of skin and/or whites of eyes, dark pee [urine] and itchy skin)
    - fatigue (no energy)
    - a new diagnosis of diabetes without weight gain
    - changes to bowel habits (pale poos [faeces] that float)
    - feeling and being sick (nausea and vomiting)
    - loss of appetite.
- These symptoms can be caused by conditions other than cancer. That is why it is important to have your GP or whānau doctor check any of these symptoms.

Ngā kōrero matua:

- He wāhanga te repetaiaki huka o te pūnaha kūnatu me tana noho ki muri i tō puku. E toru ngā wāhanga: te upoko, te tinana, me te whiore.
- E rua ngā mahi a te repetaiaki huka.
    - he mahi i ngā tarawai (pūmua whākōkī) e āwhina ana i te wāwāhitanga o ngā kai ka kainga e koe
    - he āwhina ki te mahi i ngā taiaki, me te kurukakona e whakahaere ana i te rahi o te huka kei roto i tō toto.
- He momo matepukupuku te matepukupuku repetaiaki huka ka tīmata ki roto i te repetaiaki huka. E rua ngā momo matepukupuku repetaiaki huka: te matepukupuku repetaiaki huka pukumarere me te matepukupuku repetaiaki huka iotaiaki. Ko te matepukupuku e kitea nui ana ko te Matepukupuku repetaiaki huka pukumarere (e 95% o ngā matepukupuku repetaiaki huka katoa).
- He uaua ki te whakatau moata i te matepukupuku repetaiaki huka. Kāore ngā tohumate e tino puta kia rahi rā anō te matepukupuku, kia hōrapa rānei ki wāhi kē o te tinana.

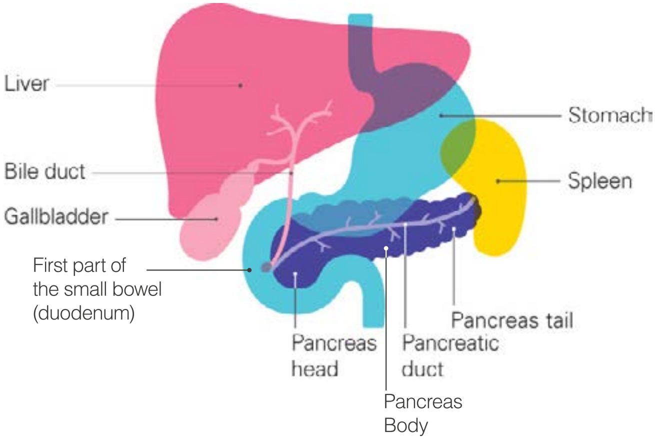
- Tērā pea ka puta ko tētahi o ēnei tohumate:
    - He mamae, he auhi rānei ki roto o tō puku tērā pea ka hōrapa ki tō tua
    - He ngaronga taumahi tinana,
    - hūhunu (ka kowhai haere te kiri, ngā wāhi mā o te whatu rānei, ka pāpango te mimi, ka māeneene te kiri),
    - ka ngenge (kore kaha)
    - he whakatau mate hou o te matehuka engari kīhai he pikinga taumaha
    - rerekētanga ki ngā mahi tiko (horotea te tae o te hamuti me tōna taupua haere)
    - te rongo i te hia ruaki (te whakapairuaki me te ruaki)
    - kore hiakai

What is the pancreas?

The pancreas is part of your digestive system and sits behind your stomach. It has three parts: the head, the body, and the tail.

The pancreas has two jobs.

- It makes digestive juices (enzymes) that help to break down the food you eat.
- It helps to make the hormones, insulin, and glucagon that control the level of sugar in your blood.



This image was produced by Pancreatic Cancer UK and is reused with permission.

What is pancreatic cancer?

Pancreatic cancer is cancer that starts in the pancreas. There are two main types of pancreatic cancer.

- Pancreatic adenocarcinoma. Cancer starts in the cells that help to break down food. This is the most common type of pancreatic cancer (95% of all pancreatic cancers).
- Pancreatic neuroendocrine cancer. Cancer starts in the cells that make hormones. These are known as pancreatic NETs (neuroendocrine tumours) (5% of all pancreatic cancer).

The two types of pancreatic cancer are treated differently and have different outlooks (prognoses).

This booklet provides information about pancreatic adenocarcinoma. You can find more information on pancreatic neuroendocrine cancer on the Neuroendocrine/Unicorn Foundation website: www.unicornfoundation.org.nz

Your specific type of pancreatic cancer needs to be diagnosed to help you decide on the best treatment for you.

What are the risk factors for pancreatic cancer?

Anything that can increase your chance of cancer is called a risk factor.

Some risk factors, such as smoking, can be changed. However, some risk factors cannot be changed, such as having a strong family history of cancer.

Having one or more risk factors does not mean that you or your whānau will develop cancer. Most of us have at least one risk factor but never develop cancer. Others with cancer may have no known risk factors.

Risk factors for pancreatic cancer that we know make some people more at risk include:

- Smoking tobacco, including, cigarettes, cigars and pipes
- A history of diabetes
- Being overweight
- Chronic pancreatitis
- Workplace exposure to certain chemicals
- Older age
- Male gender
- Family history
- Inherited syndromes.

Symptoms of pancreatic cancer

Pancreatic cancer is hard to diagnose early. The pancreas is deep inside the body, and most of the time small pancreatic cancers do not cause any signs or symptoms. Symptoms often do not occur until the cancer has become large or has spread to other parts of the body.

Symptoms may include:

- pain or discomfort in your tummy (abdomen) that may spread to your back
- unexplained weight loss
- jaundice (yellowing of skin and/or whites of eyes, dark pee [urine] and itchy skin) (see page 40)
- fatigue (no energy)
- a new diagnosis of diabetes without weight gain
- changes to bowel habits (pale poos [faeces] that float)
- feeling and being sick (nausea and vomiting)
- loss of appetite.

These symptoms can be caused by conditions other than cancer. That is why it is important to have your GP or whānau doctor check any of these symptoms.

Section Two: Diagnosing pancreatic cancer

Tekiona Rua

Te whakatau i te matepukupuku repetaiaki huka

Key points:

- If your GP or whānau doctor is concerned that your symptoms may be signs of pancreatic cancer, they will recommend further tests.
- These tests aim to find out the type of pancreatic cancer you have and if the cancer has spread to other parts of your body. The results of any tests you have will help your treatment team to decide on the best treatment options for you.
- Common tests include:
    - blood tests
    - imaging tests (scans)
    - ultrasound and endoscopic ultrasound (EUS)
    - endoscopic retrograde cholangiopancreatography (ERCP)
    - biopsy
    - laparoscopy.

Ngā kōrero matua:

- Mehemea kei te māharahara tō GP, tō rata rānei, he tohu pea o tohumate o te matepukupuku repetaiaki huka, ka taunaki rātou kia whāia anō he whakamātautau ake.
- Ko te whāinga o ēnei whakamātautau, ko te rapu ko tēwhea matepukupuku repetaiaki huka kai te whai koe, me te tiro mehemea kua hōrapa ki wāhi kē o te tinana. Ka āwhina ngā hua o ngā whakamātautau ka whai koe i tō rōpū whakamaimoa ki te whakatau ko tēwhea te kōwhiringa maimoa pai mōu.
- Ko ngā whakamātautau auau ka whāia, ko ēnei:
    - whakamātautau toto
    - whakamātautau ata (ngā mātāwai)
    - orotarapī me te karu tirowhakaroto orotarapī
    - unuhanga
    - unuhanga
    - pūtirohanga puku.

Diagnosing pancreatic cancer

If you have noticed any of the symptoms of pancreatic cancer, you will usually see your GP or whānau doctor first. They will talk to you about your symptoms, examine your abdomen, and ask you about your family history of cancer and any risk factors you may have.

If your GP or whānau doctor is concerned that your symptoms may be signs of pancreatic cancer, they will recommend further tests.

These tests aim to find out the type of pancreatic cancer you have and if the cancer has spread to other parts of your body. The results of any tests you have will help your treatment team decide what the best treatment options are for you.

Blood tests

Your doctor or specialist may suggest some blood tests to check your general health and how well your body is working. Blood tests may include:

- tests to check your general health
- liver-function tests to see how well your liver is working

- a specific test to check for pancreatic cancer markers in the blood. These are chemicals that are produced by the cancer that show up in a blood test, such as CA 19-9 and CEA.

CT, MRI, and PET-CT scans

CT, MRI, and PET-CT scans are different imaging tests that are used to build a detailed picture of the inside of the body, looking for the size, location, and possible spread of any cancer.

Ultrasound and endoscopic ultrasound (EUS)

Ultrasound can be done from either outside your body using a hand-held ultrasound probe, or inside your body using an endoscopic ultrasound (EUS). An endoscope is a thin, flexible tube that is put in your mouth and down your throat with a small ultrasound probe at the end of it. The endoscope can be moved through your stomach and into the first part of your small bowel (duodenum) as needed. Both of these ultrasound techniques can show the size and position of a cancer and the surrounding lymph nodes.

ERCP

Endoscopic retrograde cholangiopancreatography, or ERCP, is used to diagnose and treat problems in the liver, gallbladder, bile duct, and pancreas. It combines x-ray and the use of an endoscope (a thin, flexible tube) that is put in your mouth and down your throat, past your stomach and into the first part of your small bowel (duodenum) to check for problems.

Biopsy

A biopsy removes small samples of tissue from your pancreas. The tissue samples are looked at under a microscope to see if there are any cancer cells present. If cancer cells are seen in your biopsy sample, the information will help your treatment team to learn more about the type of pancreatic cancer you have. A biopsy can be taken during an EUS or ERCP, or as a fine needle biopsy through the skin.

Laparoscopy

If you are diagnosed with pancreatic cancer, you may have a small operation called a laparoscopy. This is done to check if the cancer has spread outside the pancreas to other parts of the body.

A laparoscopy is often done as a day surgery. The surgeon makes two or three small cuts near your belly button to insert a laparoscope (a thin tube with a light and camera on the end). During the laparoscopy the surgeon can take samples to send to the laboratory to check for cancer cells.

Section Three: Staging pancreatic cancer

Tekiona Toru

Te whakawāhanga matepukupuku repetaiaki huka

Key points:

- Staging describes:
  - the size of the cancer
  - if there is cancer in your lymph nodes
  - if the cancer has spread to other parts of your body.
- Pancreatic cancer is given a number from stage 1 to stage 4. The lower the number, the less the cancer has spread.

Ngā kōrero matua:

- Whakamārama ai te whakawāhanga:
  - i te rahi o te matepukupuku
  - mehemea he puku kei roto i ngā tīpona waitinana
  - mehemea kua hōrapa ki wāhi kē o te tinana
- Hoaturia ai he tau mai i te 1 ki te 4 ki te matepukupuku repetaiaki huka. Mehemea he iti ake te tau, kua iti ake te hōrapa o te matepukupuku.

Staging pancreatic cancer

Staging describes:

- the size of the cancer (T)
- if there is cancer in your lymph nodes (N)
- if the cancer has spread to other parts of your body (M).

Your treatment team will use this TNM information to give the cancer stage a number from 1 to 4. In general, the lower the number, the less the cancer has spread. A higher number, such as stage 4, means a more serious cancer.

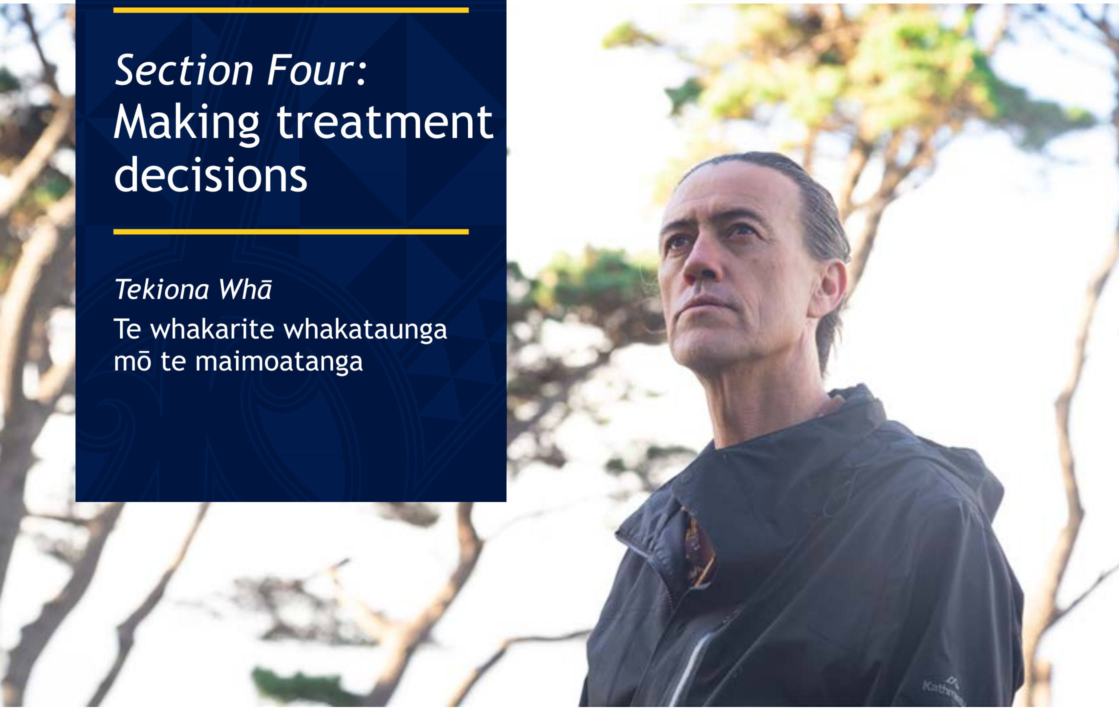
Stages of pancreatic cancer		
Stage 1	The cancer is small and only in the pancreas.	Early pancreatic cancer
Stage 2	The cancer can be different sizes. It may have spread to nearby lymph nodes.	Early/Locally advanced pancreatic cancer
Stage 3	The cancer can be any size and has usually spread to lymph nodes. It may also be growing into major blood vessels nearby.	Locally advanced pancreatic cancer
Stage 4	The cancer can be any size and has spread to other parts of the body, such as the liver and lungs.	Advanced pancreatic cancer

Simplified version of pancreatic cancer staging

Section Four: Making treatment decisions

Tekiona Whā

Te whakarite whakataunga
mō te maimoatanga



Key points:

- The treatment choices you are offered will be based on all the information available about the cancer and your general health.
- Recommendations will depend on:
    - the type of pancreatic cancer and its stage
    - your general health
    - your personal wishes.

- You will be cared for by a team of health professionals that may include:
  - your GP or whānau doctor
  - oncology nurses and cancer care coordinators
  - a gastroenterologist
  - a surgeon (gastrointestinal)
  - a medical oncologist
  - a radiation oncologist
  - a dietician
  - a palliative care team.
- Before you visit your treatment team, think about any questions you would like to have answered.
- You can ask another doctor for a second opinion about the cancer or treatment options if you want to.

Ngā kōrero matua:

- Ka hāngai ngā kōwhiringa maimoatanga ka whakaratoa ki a koe i runga anō i ngā pārongo e wātea ana mō te matepukupuku me tō oranga whānui.
- Ka hāngai ngā taunaki ki:
  - te momo matepukupuku repetaiaki huka me te wāhanga kua eke
  - tō oranga whānui
  - Ōu ake tino hiahia
- Ka tiakina koe e tētahi rōpū ngaio hauora, kei roto pea ko ēnei tāngata:
  - tō GP, tō rata whānau rānei
  - ngā tapuhi mātai mate pukupuku me ngā kairuruku mātai kōpiro
  - he mātanga (puku mātai kōpiro)
  - he mātai mate pukupuku
  - he kaimātai matepukupuku hauora
  - he mātanga kaimātai matepukupuku hauora iraruke
  - he mātanga kaiwhakatinana rārangi kai
  - he rōpū whakaora atawhai taurima

- I mua o tō haere ki te kite i tētahi rōpū maimoatanga, ata whakaarotia ētahi pātai e hiahia ana koe kia whakautua.
- E āhei ana koe ki te torotoro i tētahi atu rata mō he kōrero tuarua e pā ana ki te matepukupuku, ki ngā maimoatanga rānei, mēnā e pīrangi ana koe.

How treatment decisions are made

The treatment choices you are offered will be based on all the information available about the cancer and your general health.

Recommendations will depend on:

- the type of pancreatic cancer and its stage
- your general health
- your personal wishes and goals of care.

The treatment team

From the time you are diagnosed with pancreatic cancer, you will be cared for by a team of health professionals, including:

- your GP or whānau doctor, who will often be the first person you see
- oncology nurses and cancer care coordinators, who specialise in the care of people with a cancer diagnosis
- a gastroenterologist, who specialises in diseases of the digestive system
- a surgeon (gastrointestinal), who specialises in pancreatic cancer surgery
- a medical oncologist, who specialises in the use of different medications to treat cancer
- a radiation oncologist, who specialises in the use of radiation treatment
- a dietician
- a palliative care team.

Your treatment team may include other health care professionals such as a social worker, psychologist, physiotherapist, practice nurse, community health nurse, pharmacist, or occupational therapist.

Talking to your cancer treatment team

When you first learn you have pancreatic cancer, you may have many questions. We suggest that, before you visit your cancer treatment team, you think about the questions you would like them to answer and if there is anything you do not want to be told. There is a lot of information to take in, so it can be helpful to have a support person with you when you visit. See page 49 for some questions you may wish to ask your treatment team.

It is useful to ask your treatment team who to contact, and how, if you have any questions outside your appointment times.

Asking for a second opinion

You may want to ask another doctor about your cancer or treatment to help you feel more confident about your treatment decision. You can ask your cancer doctor or GP to refer you to another cancer doctor to get a second opinion if you want one.

Your rights — Health and Disability Commissioner

Your rights as a health and disability service consumer are protected by the Code of Health and Disability Services Consumers' Rights. If you have concerns about a health and disability service, independent advocates are available to support and guide you, or you can complain directly to the Health and Disability Commissioner.

You can find more information on this website:
www.hdc.org.nz/your-rights/the-code-and-your-rights

Interpreting services

The Code of Health and Disability Services Consumers' Rights states that everyone has the right to have an interpreter present during a medical consultation. If you do not speak English as your first language or you are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. Speak to a member of your health care team about arranging interpreters in your local area.

Talking to others

When you have talked about your treatment options with your treatment team, you may want to discuss these options with other people. Talking it over can help you decide what is right for you. You may want to talk to your whānau or friends, specialist nurses, your GP or whānau doctor, the Cancer Society, a hospital social worker, or a spiritual advisor.

Coping with waiting

Waiting is a big part of receiving your diagnosis and starting treatment. It can take several days, or even weeks, for your treatment team to review your test results before they can discuss treatment options with you.

If you are finding the waiting difficult, contact your treatment team.

You can find more information on coping with waiting on our website: www.cancer.org.nz/coping-with-waiting

Taking part in a clinical trial

People all over the world have taken part in clinical trials that have improved cancer treatments. There are many new and emerging treatments for cancer, and clinical trials are a vital part of the search to find better treatments.

Clinical trials test new and modified treatments to see if they are better than existing treatments. In a randomised clinical trial, you will receive either the standard treatment currently available or the new treatment being tested. Neither you nor your doctor can decide which treatment you get.

If you are asked to take part in a clinical trial, make sure you fully understand the reasons for the trial and what it means for you. It is your decision whether you take part in a trial or not.

Section Five: Pancreatic cancer treatments

Tekiona Rima

Maimoatanga matepukupuku repetaiaki huka

Key points:

- Your cancer treatment team will advise you on the best treatment for pancreatic cancer.
- Depending on the stage of the cancer, treatment may include:
  - surgery
  - radiation treatment
  - chemotherapy
  - palliative care
  - or a combination of these.
- If you are thinking about using complementary, traditional Māori, or Pacific therapies, please talk about them with your cancer treatment team.

Ngā kōrero matua:

- Mā tō rōpū atawhai koe e kōrero mō te maimoatanga pai rawa mō te matepukupuku repetaiaki huka.
- E ai ki te wāhanga kua eke tō matepukupuku, tērā pea ka mahia ko ēnei maimoa
    - te hāparapara
    - te maimoatanga iraruke
    - te mahi hauhau
    - te whakaora atawhai taurima
    - he whiriwhiringa rānei o ēnei.
- Mehemea e whakaaro ana koe ki te whakamahi haumanu tautoko, haumanu Māori taketake, haumanu Moana-nui-ā-Kiwa, kōrero mō ēnei ki tō rōpū maimoa matepukupuku.

Treatment options

Your treatment team will advise you on the best treatment for your pancreatic cancer. Depending on the stage of the cancer, it may include surgery, radiation treatment, chemotherapy, or palliative care, or a combination of these.

Sometimes treatment will be offered with the goal of curing the cancer. Your treatment team will talk with you about how likely the treatment is to be successful.

Even when treatment to cure the cancer is not possible, your treatment team may recommend treatment options to reduce the symptoms of the cancer and improve your quality of life.

Stage of pancreatic cancer	**Main treatment options**
Early (Stages 1 and 2)	• Surgery to remove the cancer • Chemotherapy (with or without radiation treatment) before surgery to try to shrink the cancer (neo-adjuvant treatment) • Chemotherapy after surgery (adjuvant treatment)
Locally advanced (Stages 2 and 3)	• Chemotherapy using a combination of medications • Sometimes radiation treatment can be used after chemotherapy • Clinical trials
Advanced (Stage 4)	• Chemotherapy using a combination of medications • Targeted therapy can be effective for people with advanced cancer who have specific gene changes • Clinical trials • Palliative treatment and supportive care

Surgery

If pancreatic cancer is early stage (stage 1 or 2), you may be able to have surgery to remove it (potentially curative surgery).

If the cancer cannot be removed, you may be offered surgery to help control some of the symptoms of pancreatic cancer (palliative surgery).

Surgery to treat pancreatic cancer

There are different surgeries used to treat pancreatic cancer. All surgeries remove part (or sometimes all) of the pancreas. Other organs around the pancreas may also be removed. The most common type of surgery is called the Whipple procedure.

People having surgery to treat pancreatic cancer need to be otherwise fit and well, as this is major surgery and it takes a long time to recover.

The Whipple procedure

The Whipple procedure removes the head, and sometimes the body, of the pancreas. The surgeon also removes:

- the first part of the small bowel (duodenum)
- part of the bile duct
- the gall bladder
- lymph nodes near the pancreas
- sometimes part of the stomach.

The end of the bile duct and what is left of the pancreas are reattached to the small bowel. This means that bile and digestive juices can still enter the small bowel to help with the breakdown of food (digestion).

The ends of the small bowel (or the stomach and small bowel) are also reattached so that food can pass through the stomach into the small bowel.

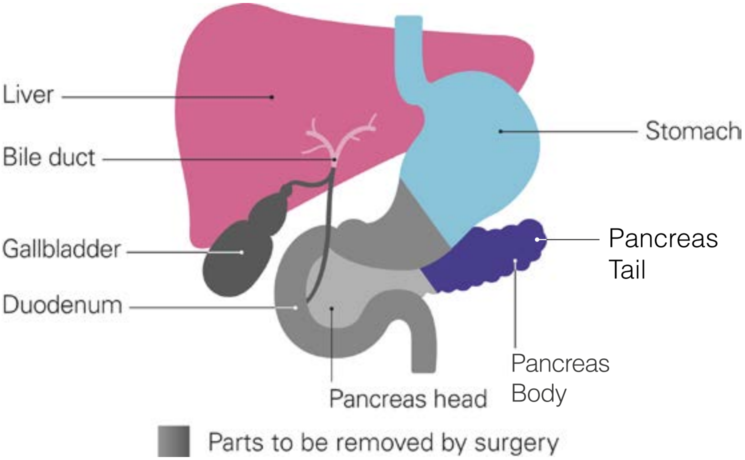
You can find more information on pancreatic cancer surgery and the Whipple procedure on the following websites:

Pancreatica
https://pancreatica.org/pancreatic-cancer/pancreatic-cancer-surgical-treatment

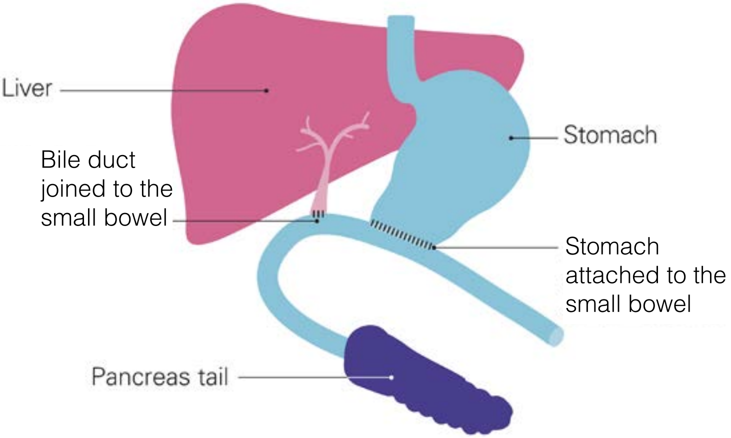
Waitematā DHB
www.waitematadhb.govt.nz/assets/Documents/clinics-services/upper-gi/TheWhippleAguideForPatientsJun14.pdf

Pancreatic Cancer UK
www.pancreaticcancer.org.uk/information/treatments-for-pancreatic-cancer/surgery-for-pancreatic-cancer

This diagram shows the parts of the body removed by the Whipple procedure:



This diagram shows the pancreas and surrounding organs after the Whipple procedure:



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Distal pancreatectomy

A distal pancreatectomy removes the body and tail of the pancreas.

Sometime the spleen is removed at the same time. This is called a splenectomy.

Total pancreatectomy

A total pancreatectomy removes the whole pancreas. Depending on where the cancer is, the surgeon may also remove:

- the first part of the small bowel (duodenum)
- the gall bladder
- part of the bile duct
- sometimes part of the stomach
- sometimes the spleen.

You can find more information on surgery for pancreatic cancer on this website: www.pancreaticcancer.org.uk/information/treatments-for-pancreatic-cancer/surgery-for-pancreatic-cancer

Recovery after surgery

Your recovery after surgery will depend on many factors. Here are some things you can do to help.

- Try to eat as well as possible in the weeks before your surgery.
- Stay active.
- If you have lost weight, you may need to gain some weight before surgery. Your treatment team will guide you on this.

Side effects of surgery

Your treatment team will talk to you about the benefits and side effects of surgery.

Surgery to remove pancreatic cancer may cause problems with digesting your food. It can also cause diabetes.

If your spleen is removed during surgery to treat pancreatic cancer, you will need to have a course of immunisations and antibiotics as part of your recovery.

Food digestion

Having part of your pancreas removed will affect how well the pancreas makes pancreatic enzymes that help digest the food you eat. After surgery, some people need medication (pancreatic enzyme replacement therapy) to help them digest food (see page 42).

Ask if you can see a dietician before and after your surgery. They can give you advice on managing symptoms after surgery, eating well and putting on weight, and taking pancreatic enzymes.

Stents or bypass surgery to help control symptoms of pancreatic cancer

Stents and bypass surgery can be used to help control the symptoms of pancreatic cancer. Stents are usually inserted as a day surgery using endoscopy. Bypass surgery is a more complex operation that requires a hospital stay.

These procedures aim to help reduce any symptoms you may be experiencing. They do not cure the cancer.

Common surgical procedures to control symptoms

Symptom	**Surgery (procedure)**
Jaundice (see page 40)	Placing a small tube (stent) in the bile duct to unblock the duct or stop it getting blocked. Day surgery using endoscopy.
Feeling or being sick	Placing a small tube (stent) in the first part of the small bowel (duodenum) to unblock it or stop it getting blocked. Day surgery using endoscopy.
Jaundice and feeling or being sick	Bypassing a blockage in the bile duct or small intestine to make a new path for food or bile to move around the cancer. Larger operation that requires a hospital stay.

Placing a stent

A stent is a small tube that is put into your bile duct or the first part of your small bowel (duodenum) to unblock it or stop it getting blocked. Your symptoms should improve soon after you have a stent put in.

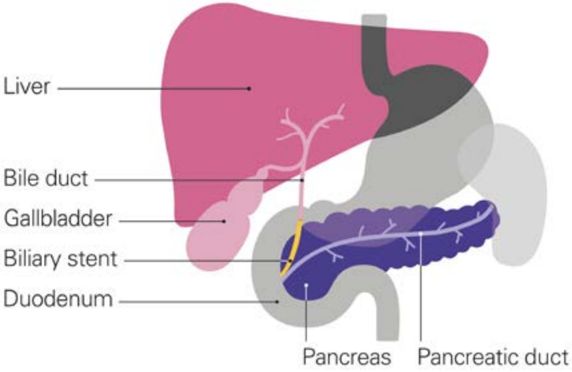
A stent placed in the bile duct helps to relieve jaundice. A stent placed in the small intestine can help to improve symptoms of nausea and vomiting.

There is a chance that the stent will get blocked or move once it has been put in. If this happens, the stent may need to be replaced.

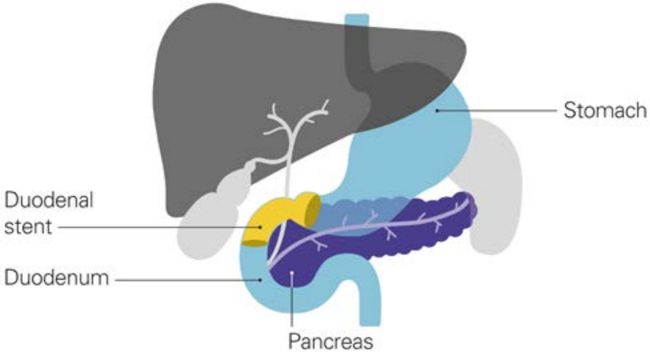
Sometimes the bile duct gets infected (cholangitis). This will need treatment in hospital.

If your symptoms return or you feel unwell (such as with a high temperature or shivering) at any time after you have had a stent put in, you need to contact your treatment team straight away.

Bilary Stent: A stent placed in the bile duct



Duodenal Stent: A stent placed in the first part of the small bowel (duodenum)



These images were produced by Pancreatic Cancer UK and are reused with permission.

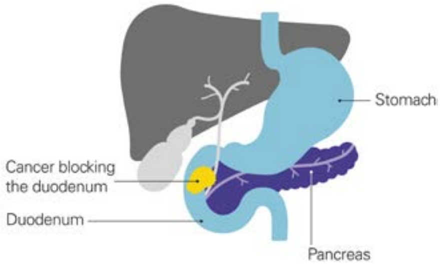
Bypass surgery

If the cancer has blocked the first part of your small bowel (duodenum) or bile duct, you may need bypass surgery to treat your symptoms (jaundice and nausea/ vomiting). It does not remove the cancer.

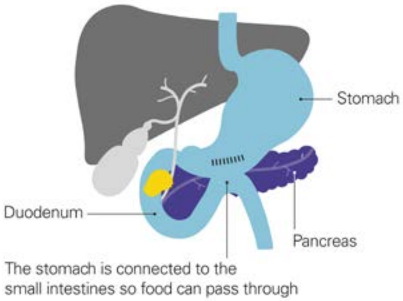
Bypassing a blockage in the bile duct or small intestine makes a new path for food or bile to move around the cancer.

Bypass surgery is a big operation. Your treatment team will talk to you about the advantages and disadvantages of having this surgery.

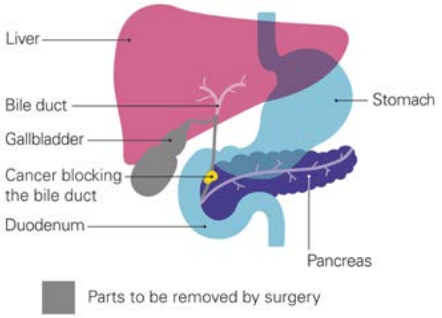
You can find more information on bypass surgery on this website: https://cdn.shopify.com/s/files/1/0424/0949/2641/files/211021PC01_PCUK_Bypass_Surgery_2021_Factsheet_Download.pdf?v=1637425744



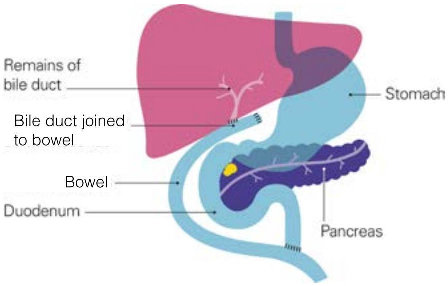
Before bypass surgery for a blocked duodenum



After bypass surgery for a blocked duodenum



Before bypass surgery for a blocked bile duct



After bypass surgery for a blocked bile duct

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Chemotherapy treatment

Chemotherapy uses medication to kill cancer cells or slow their growth. It affects cells throughout the body and is used to reduce the risk of cancer returning to the pancreas or growing in other parts of the body.

You can find more information on chemotherapy in our *Chemotherapy, Immunotherapy and Targeted Treatment booklet*, available on our website: www.cancer.org.nz/chemotherapy

When chemotherapy treatment is given

Chemotherapy may be given:

- before surgery to try to make the cancer smaller
- after surgery to reduce the chances of the cancer coming back
- to improve symptoms if you are unable to have surgery
- as palliative treatment for cancer that has spread beyond the pancreas, to reduce symptoms and improve your quality of life or extend your life.

In Aotearoa New Zealand the chemotherapy medication nab-paclitaxel (ABRAXANE) has been approved for use (but not funded) for some advanced pancreatic cancers (2022). You may like to ask your oncologist if there are any unfunded treatments available that may be beneficial for you. Your oncologist can give you an estimate of the cost involved if you choose to fund your own treatment.

How chemotherapy is given

Chemotherapy is given as tablets (oral chemotherapy) or into a vein (intravenously).

If chemotherapy is given intravenously, it may be through a cannula. A cannula is a small tube that is put into a vein in your arm or the back of your hand and is removed after each treatment. Intravenous treatment is usually given to you at your local treatment centre.

Some people may need a central venous access device such as a portacath or a peripherally inserted central catheter (PICC), which stays in place for the whole of your treatment. This is a fine tube placed in your arm or chest that ends in the large veins inside your chest.

Intravenous treatment is usually given to you as an outpatient at your local treatment centre, at regular intervals over several months. It may be helpful to know that not all people with pancreatic cancer receive the same treatment.

Side effects of chemotherapy

Chemotherapy side effects vary depending on the combination of medications you receive.

You can ask your treatment team to provide you with some written information on the side effects that are most likely to affect you.

Common side effects that you may experience include:

- increased risk of infection
- hair loss

- infertility
- fatigue
- forgetfulness and concentration problems (chemo brain)
- nausea and vomiting
- constipation or diarrhoea
- sore mouth and ulcers.

Your treatment team will provide you with the contact phone numbers you need — keep this information somewhere you can easily find it.

Some side effects of chemotherapy can be life threatening. If you develop any of the following symptoms you must contact your treatment team, or go immediately to your nearest hospital emergency department and tell them you are receiving chemotherapy treatment.

- Fever – a temperature over 38˚C
- Chills – shivers or shakes, feeling hot or cold
- Chest pain
- Difficulty breathing
- Vomiting that continues after taking anti-sickness medication
- Diarrhoea
- Gum or nose bleeds, or bleeding that does not stop
- Pain or burning when passing urine, or blood in urine

It is important that you do not wait to seek assistance until the next morning or after the weekend.

Radiation treatment

Radiation treatment is the use of x-ray beams to destroy cancer cells or slow their growth. Radiation treatment only affects the part of the body that the beams are aimed at.

You can find more information on how radiation treatment works in our *Radiation Treatment/Haumanu Iraruke booklet*, available on our website: www.cancer.org.nz/radiation-treatment

When is radiation treatment offered?

Radiation treatment is not often used to treat pancreatic cancer. But you may have radiation treatment:

- to treat early-stage pancreatic cancer if you are not able to have surgery. It is usually combined with chemotherapy (chemoradiation)
- with chemotherapy before surgery to try to make the cancer smaller
- to reduce symptoms of advanced pancreatic cancer, improve your quality of life or extend your life (palliative treatment).

How radiation treatment is given

External beam radiation treatment

External beam radiation treatment is given from outside the body by a machine called a linear accelerator (LINAC). This is the most commonly used type of radiation treatment for pancreatic cancer.

Treatment is given daily (Monday to Friday) and your treatment team will give you information on how long you will have treatment for. The LINAC is on for only a few minutes and the total amount of time spent in the treatment room is usually 10 to 20 minutes.

Treatment is carefully planned to do as little harm as possible to your normal body tissue.

OncoSil

A newer form of radiation treatment, called OncoSil, is available for people who meet specific treatment criteria. It is currently only available in Waikato (2022). The radiation is placed directly into the pancreatic tumour using an endoscope (a telescope placed into the bowel via the stomach).

This treatment is not funded in Aotearoa New Zealand. However, you may want to ask your treatment team if this treatment is suitable for you.

Where radiation treatment is provided

Radiation treatment is available at specialist treatment centres in Auckland, Hamilton, Tauranga, Palmerston North, Wellington, Christchurch, and Dunedin (2022).

If you need to be away from home for your treatment, help may be available for transport and accommodation costs through the National Travel Assistance Scheme (NTA).

Your treatment centre, hospital social workers, the travel office at your local hospital, or your local Cancer Society can advise you on what help may be available.

You can find more information on the National Travel Assistance Scheme on our website: www.cancer.org.nz/nta

Side effects of radiation treatment for pancreatic cancer

People react in different ways to treatment. These are the common side effects that you may experience.

- Fatigue (tiredness) – can occur during and after treatment
- Red and dry skin in the area being treated
- Nausea (feeling sick) or vomiting
- Loss of appetite

The availability of targeted treatment and immunotherapy for pancreatic cancer

There have been recent advances in pancreatic cancer treatment. Unfortunately, these treatments are expensive and Pharmac is not able to provide funding for all the treatments that might be helpful for the management of cancer. You may like to ask your oncologist if there are any unfunded treatments available that may be beneficial for you. Your oncologist can give you an estimate of the cost involved if you choose to fund your own treatment.

Targeted treatment

What is targeted treatment?

This type of treatment targets the damaged genes or proteins of cancer cells to stop cancer growing and spreading. It is sometimes called biological therapy.

How targeted treatment works

Targeted treatment medication travels through the bloodstream. Each medication blocks a specific target, for example a damaged gene or protein, on or within a cancer cell. Blocking these targets can kill cancer cells or slow their growth. The signs and symptoms of cancer reduce or disappear, and damage to healthy cells is minimal.

Why you might be offered targeted treatment

If the cancer contains a change in a specific gene or protein that is helping it to grow, you may benefit from targeted treatment.

To find out if the cancer contains these gene or protein changes, your doctor will take a tissue sample from the cancer and send it to a laboratory for testing. It may take anywhere from a few days to a few weeks to receive the results.

In Aotearoa New Zealand, targeted treatments olaparib (Lynparza) and erlotinib (Tarceva) have been approved for use for some people with advanced pancreatic cancer.

Palliative treatment and supportive care

Palliative treatment is for people with advanced cancer (stage 4) and focuses on improving quality of life. Depending on the cancer, radiation treatment, chemotherapy, targeted treatments, and immunotherapy can be used to slow the growth of the cancer and relieve symptoms you may be experiencing.

Everyone with advanced cancer needs supportive care. Supportive care will mostly be provided by your primary health care team and palliative care team. It includes the management of physical symptoms, cultural, emotional, and spiritual support, and guidance to help you plan ahead.

It is a good idea to ask for palliative care early. Being able to manage problems or issues early, rather than waiting until they become difficult to cope with, can help reduce stress for both you and your whānau.

In general, palliative care services are free. There may be a charge for hiring some equipment for home care. Palliative care and hospice services are funded by both the government and voluntary donations.

Advance care planning

An important part of planning ahead is preparing an advance care plan. Advance care planning helps you, and the people important to you, to talk about the treatments and care you might want towards the end of your life. It will guide your whānau and doctors when you can no longer tell them yourself.

Advance care planning is voluntary – no one can force you to do it.

You can find more information on our website:
www.hqsc.govt.nz/our-programmes/advance-care-planning

Other treatments

It is important to discuss any additional treatments you are using or thinking of using with your treatment team. Some treatments may be harmful if they are taken at the same time as medical treatments, so it is advisable to discuss the benefits, medicine interactions, and any safety concerns.

Complementary treatment

Complementary treatments (sometimes called integrative therapy) are healing practices and products that are not usually part of standard medical care. A number of practices are now being used to complement medical treatments. Examples include massage, meditation, and acupuncture, which are sometimes used to lessen the side effects of treatment.

Alternative treatments

When these treatments are used instead of medical treatment, they are considered alternative treatments. Some alternative therapists may claim their treatments are cancer cures — this is very unlikely to be true.

You can check for warnings on natural and herbal products on the Medsafe website: www.medsafe.govt.nz

You can find more information on complementary and alternative medicines in our *Complementary and Alternative Medicine booklet*, available on our website: www.cancer.org.nz/complementary-therapy

Traditional treatments

Traditional Māori healing

Traditional healing has been a central part of Māori culture for generations. Values, belief systems, and teachings from kaumātua and tohunga have seen Māori focus on total wellbeing, which includes taha tinana, taha hinengaro, taha wairua, and taha whānau (the physical domain, the domain of the mind and behaviour, the spiritual domain, and the whānau or social domain).

Traditional healing methods can include rongoā Māori, romiromi or mirimiri. These therapies are based on the use of native plants, massage therapy, and spiritual healing.

You can find more information on rongoā Māori and providers on our website: www.cancer.org.nz/traditional-healing

Hauora Māori

Mai rā anō te hauora Māori i noho ai hei wāhanga ō te ahurea Māori. Nā ngā uaratanga, te pūnaha whakapono me ngā akoranga a ngā kaumātua me ngā tohunga i kitea ai te arotahi a te Māori ki te oranga kotahi e rarawhi ana i te taha tinana, te taha hinengaro, te taha wairua me te taha whānau.

Ka whai wāhi te rongoā Māori, te romiromi, te mirimiri rānei, hei tauira atu. Ka hāngai katoa ki tarutaru otaota whenua me ngā rākau, te haumanu romiromi me te whakaoranga ā-wairua.

Ka taea etahi atu mōhiohio e pa ana ki te rongoā Māori me ngā kaiwhakarato i runga i tō mātou paetukutuku: cancer.org.nz/traditional-healing/

Traditional Pacific healing

Traditional healing is also important to Pacific peoples, to help in their recovery. It takes a holistic approach to treating the person, where mental, emotional, physical, and spiritual needs are looked after together, rather than as separate parts. The therapy offered to each person depends on their specific needs. Medicinal plants and herbs may be used during the treatment process, as well as stones and massage.

If you are thinking about using Māori or Pacific traditional healing, please discuss them with your treatment team. Both traditional healers and your treatment team aim to provide you with the best possible care that has minimal side effects. If you have difficulty expressing your needs to your treatment providers, find someone to advocate on your behalf. The traditional healers and hospital treatment specialists can then work together to support you on your cancer journey.

Section Six: Managing pancreatic cancer symptoms

Tekiona Ono

Te whakahaere i ngā tohumate matepukupuku repetaiaki huka

Key points:

- Pancreatic cancer can cause problems with digestion, weight loss, fatigue (no energy), and pain. You may have jaundice (yellowing of the skin), which is caused by a high level of bilirubin in the liver and blood.
- Your treatment team may recommend options to reduce the symptoms of the cancer and improve your quality of life. These may include:
    - dietary changes
    - the use of prescription medications
    - procedures such as inserting a stent or having bypass surgery (to reduce jaundice)
    - complementary therapies.
- Talk to your treatment team about any symptoms you may be experiencing. As well as providing cancer treatments, they may be able to refer you to a palliative care service to help you manage the cancer symptoms.

Ngā kōrero matua:

- Tērā pea ka puta he raruraru ki te pūnaha nakunaku nā te matepukupuku repetaiaki, te ngaronga taumaha, te māuiui, me te mamae. Tērā pea ka puta te huhunu, (ka kowhai te kiri), nā runga i te kaha piki o te bilirubin i roto i te ate me te toto.
- Tērā pea ka taunaki tō rōpū maimoa i ngā kōwhiringa hei āwhina ki te whakaheke i ngā tohumate me te whakapai ake i tō toioranga. Tērā pea ko ētahi o ēnei:
  - whakarerekētanga rārangi kai
  - te whakamahi rongoā whakahaunga
  - manatūnga pērā ki te whakauru ngongo roa, te whai hāparapara ara karo (hei whakaiti i te huhunu)
  - ngā haumanu tautoko.
- Kōrero ki tō rōpū maimoa e pā ana ki ngā tohumate tērā pea kai te rongo koe. I tua atu i te hoatu maimoa matepukupuku, tērā pea ka āhei rātou ki te tono i a koe ki tētahi ratonga atawhai taurima ki te āwhina i a koe ki te whakahaere i ngā tohumate matepukupuku.

Ways of managing pancreatic cancer symptoms

Talk to your treatment team about any symptoms you may be experiencing. As well as providing cancer treatments, your doctor may be able to refer you to a palliative care service to help you manage the cancer symptoms.

Pain

Not everyone with pancreatic cancer has pain. If you do have pain, you may not be in pain all the time and it can usually be well managed.

There is a range of prescription medications and complementary therapies to help with pain caused by pancreatic cancer.

Pain-relief medication works best when it is taken regularly. Tell your treatment team if your prescribed medications are not easing your pain, as there are likely to be other pain-relieving medications you can try.

Radiation treatment and chemotherapy can also be used to treat pain caused by cancer. Many people find a combination of more than one treatment helps, and it may take a little time to find the most effective pain control for you.

Fatigue (no energy)

Fatigue can be described in many ways, including feeling exhausted, extremely tired, sleepy, or drowsy, or finding it difficult to concentrate. Fatigue can appear suddenly and rest may not help. Here are some ideas to help you cope with fatigue:

- Let people help you. Whānau, friends, and neighbours may offer to help with tasks such as shopping, childcare, housework, and driving.
- Take a few weeks off work during or after treatment, or work fewer hours. You may be able to work from home.
- Do light exercise such as walking, and keep up your normal exercise routine if approved by your GP or whānau doctor. Do not start any new exercise routine until you feel better after treatment.
- Try to eat a healthy, well-balanced diet. Some people find small, frequent snacks more appealing than meals. If you have nausea, have your meals when you feel like eating.
- Fatigue may be caused by specific things that can be found in blood tests and may be improved by treatment.

Jaundice

Understanding jaundice

Jaundice is caused by a high level of bilirubin in your liver and blood.

Bilirubin is made when old red blood cells break down. Usually it is processed in the liver, where it is mixed into bile. The bile goes from the liver through the bile duct and into the small intestine, where it helps to digest the food we eat.

If pancreatic cancer blocks the bile duct, the bilirubin (in the bile) cannot leave the liver. This causes the levels of bilirubin in your liver and blood to rise, and this in turn causes the symptoms of jaundice.

Bilirubin is often yellow in colour. This is why when the level of bilirubin in your blood is high, your skin and the whites of your eyes often look yellow.

Common symptoms of jaundice include:

- yellow-coloured skin
- yellow-coloured whites of your eyes
- itchy skin
- pale or white-coloured poo (faeces)
- dark-coloured pee (urine)
- pain in your tummy (abdomen)

Treating jaundice

Your treatment team may recommend a procedure, such as a stent or bypass surgery, to restore the flow of bile and help reduce the symptoms of jaundice (see page 28).

Coping with itchy skin

Some people with jaundice experience itchy skin, which is caused by high levels of bilirubin in the skin. If you are experiencing this, you might find some of the following suggestions useful.

- Wash in warm water instead of hot water.
- Place cool, damp cloths on your skin.
- Use unperfumed soaps, soap substitutes, and moisturisers.
- Pat your skin dry with a soft towel instead of rubbing.
- Wash clothing and bedding in mild (hypoallergenic) detergents.
- Wear loose-fitting clothing made from natural fibres such as cotton. These do not irritate the skin as much as synthetic materials like nylon do.
- Keep your fingernails short and clean (to prevent infection if scratching breaks the skin).
- Talk to your treatment team about medications to help relieve the itching.

Trouble sleeping

Some people with pancreatic cancer have trouble sleeping or have problems falling asleep, which can affect how well they feel during the day. If you are in pain, this may also affect your sleep.

If you are having difficulty sleeping, these ideas may help.

- Try to wake up at the same time each day and go to bed at the same time each night.
- Create a quiet, dark, and restful place for sleeping. Sleeping in a more upright position or in a recliner chair may be useful if lying flat makes you feel breathless or causes you to start coughing.
- Reduce caffeinated drinks like tea and coffee, soft drinks, and alcohol. These may give you energy but leave you unable to sleep.
- Use your pain medication as prescribed if pain is keeping you awake.

You can find more information in our information sheet, *If you have difficulty sleeping*, available on our website: www.cancer.org.nz/sleep-problems

Nausea (feeling sick)

If you have pancreatic cancer it is common to feel sick at some point. This can be caused by many things, including the cancer itself and cancer treatments.

People have found the following suggestions helpful.

- Try to eat small meals at frequent intervals.
- Avoid fatty and fried foods.
- Rest before and after eating.
- Do not lie flat during or after eating.
- Drink plenty of fluids.
- See a dietitian or nurse for dietary advice.
- Try relaxation or mindfulness exercises.
- Do something enjoyable as a distraction from feeling sick.

Anti-sickness medications work in a range of ways, depending on the cause of your nausea. Let your GP or whānau doctor know if you feel sick or if the medication you are using is not working — there may be something else you can try.

You can find more information on nausea on our website:
www.cancer.org.nz/eating-well-with-cancer

Weight changes

It is important to try to maintain your weight and eat well during and after treatment for pancreatic cancer. Eating small, frequent meals high in energy (calories), fat, carbohydrates (sugars), and protein may help you maintain a stable weight.

To help maintain your weight, you could try:

- eating nourishing foods that are high in energy and protein, such as poultry, fish, meat, eggs, tofu, legumes, dairy products, nuts, and seeds
- eating the most nourishing part of a meal first
- taking advantage of times when your appetite is the best. This might mean having a larger meal in the morning and smaller snacks or meals during the rest of the day.

If you have tried increasing your energy intake but still struggle to eat enough, you may benefit from a nutritional supplement drink or pancreatic enzyme replacement therapy (PERT) (see page 43). Talk with a dietitian or your treatment team about the right supplements for your needs.

You can find more information about managing weight on our website:
www.cancer.org.nz/managing-your-weight

Problems with digestion

Many people with cancer of the pancreas have problems with digestion. The pancreas makes enzymes that help to break down (digest) the food you eat. Nutrients from the food are then absorbed into the blood and used by the body for energy. Pancreatic cancer, and surgery to remove the cancer, can reduce the amount of enzymes made by the pancreas.

Without enough pancreatic enzymes in your body, the food you eat cannot be digested or absorbed properly (malabsorption). Common symptoms include:

- loss of appetite
- weight loss
- bloating and farting (wind)
- loose poo (diarrhoea)
- poo that floats and smells bad
- pain after eating.

These digestion problems can be managed by medication that replace the enzymes your pancreas would normally make. This is called pancreatic enzyme replacement therapy (PERT).

Pancreatic enzyme replacement therapy (PERT)

PERT is the use of medication to replace the enzymes that your pancreas is not making. Taking this medication can help to manage the symptoms caused by digestion problems. The replacement enzymes are normally given as capsules, which you swallow with food.

The dose of enzymes you need will depend on the type and amount of food you are eating. It is important to make sure that your treatment team includes a dietician. They will help you to understand how PERT works and support you in balancing the amount of food you eat and the dose of enzymes you need to manage your symptoms.

When you start using PERT, you may find it helpful to keep a diary of what you eat, the enzyme doses you take, and if it reduces your symptoms. This can help you work out if you are taking enough enzymes.

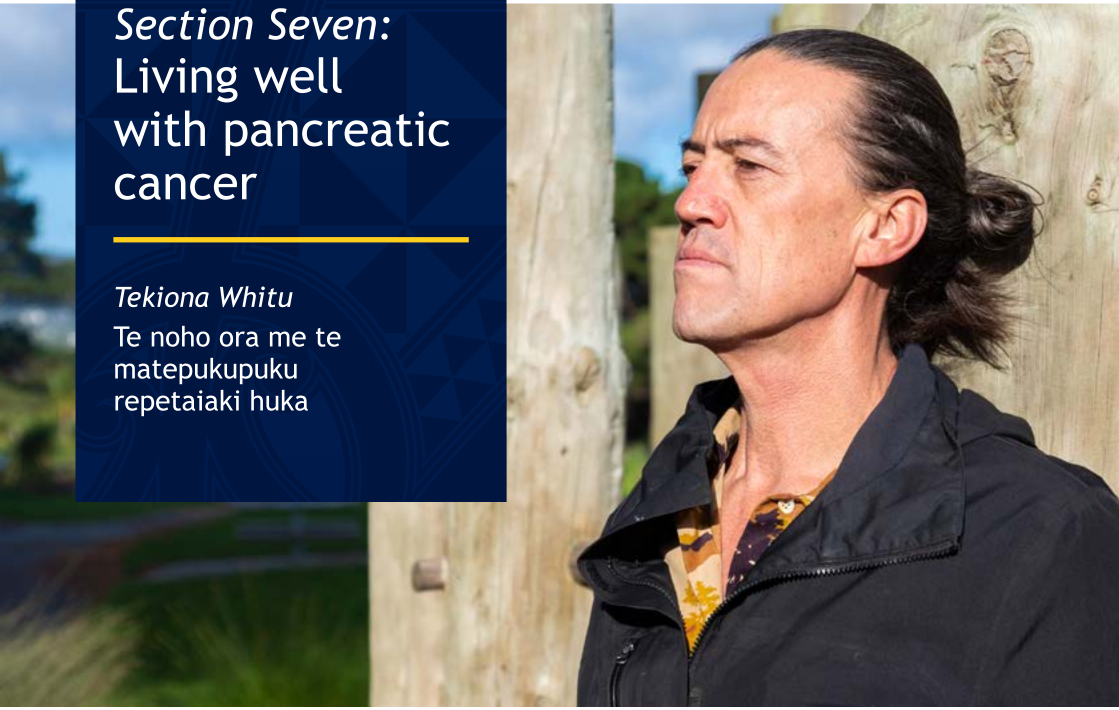
All PERT enzymes are made from pork products. Talk to your treatment team if you are a vegetarian or follow a religion that avoids pork products. Many organisations representing these communities have said these treatments are acceptable to use as there is no alternative.

You can find more information on PERT on this website: https://cdn.shopify.com/s/files/1/0424/0949/2641/files/210429PC01_PCUK_PERT_Factsheet_RGB_Web.pdf?v=1621341525

Section Seven: Living well with pancreatic cancer

Tekiona Whitu

Te noho ora me te matepukupuku repetaiaki huka



Key points:

- Finding ways to focus positively on your body – such as by eating well, starting a new exercise programme like yoga, and making positive lifestyle changes – can help you live well with pancreatic cancer.
- Keeping active will help you to maintain a healthy weight and can reduce stress and tiredness. It will also help to keep your bones strong and your heart healthy.
- If you are unable to work for a period of time because of the effects of pancreatic cancer, you and/or your carer may be entitled to receive income support from the Ministry of Social Development – Work and Income.
- It is also a good idea to check your personal insurance policies, as you may qualify for an early payment. Speak to your insurance agent to find out if you are covered.
- A counsellor can help you to talk about your thoughts and feelings after a diagnosis of pancreatic cancer.

- Hospitals throughout Aotearoa New Zealand have trained health workers available to support your spiritual, cultural, and advocacy needs.
- Talk to your GP or whānau doctor, or contact your local Cancer Society, about the support services available for you and your whānau.

Ngā kōrero matua:

- Mā te rapu huarahi ki te arotau pai ki tō tinana – pērā ki te kai tika, te whai hōtaka korikori hou pērā ki te yoga, me te mahi panoni ki tō āhua noho – e āwhina i a koe ki te noho ora me te matepukupuku repetaiaki huka.
- Mā te noho kakama tonu e āwhina i a koe ki te mau tonu ki tō taumaha, me tana whakaiti ake i te ahotea me te hiamoe. Ka āwhina hoki kia noho kaha tonu o kōiwi, kia pakari hoki tō manawa.
- Mehemea kīhai koe e kaha ki te mahi mō tētahi wā, nā runga i nga papātanga o te matepukupuku repetaiaki huka, ka āhei koe me tō kaitiaki hoki, ki te whiwhi tautoko mai i te Manatū Whakahiato Ora – Te Hiranga Tamariki.
- He whakaaro pai ki te arowhai i ō kaupapa inihua whaiaro, i te mea tērā pea ka āhei koe ki ētahi utu moata. Kōrero ki tō māngai inihua ki te rapu mehemea kai te pai tō inihua.
- Tērā pea ka āwhina tētahi Kaitautāwhi i a koe ki te kōrero mō ōu whakaaro, ōu kare-ā-roto whai muri i tētahi whakatau mate mō te matepukupuku repetaiaki huka.
- Kai ngā hōhipera huri noa i te motu ngā kaimahi hauora kua whakangungutia, hei tautoko i ōu hiahia ā-wairua, ā-ahurei, me ōu hiahiatanga whaitaua.
- Kōrero ki tō GP, ki tō rata whānau rānei, me whakapā atu rānei ki ngā ratonga tautoko e wātea ana ki a koe me tō whānau.

Adjusting to change

Finding ways to focus positively on your body — such as by eating well, starting a new exercise programme like yoga, and making positive lifestyle changes — can help you live well with pancreatic cancer.

Keeping active will help you to maintain a healthy weight and can reduce stress and tiredness. It will also help to keep your bones strong and your heart healthy.

You can find more information on living well with cancer on our website: www.cancer.org.nz/living-with-cancer

Financial and legal support

Financial support — benefits and entitlements

If you are unable to work for a period of time because of the effects of pancreatic cancer, you and/or your carer may be entitled to receive income support from the Ministry of Social Development — Work and Income.

Depending on your situation, financial help may be available. Talk to a social worker, Work and Income, or Senior Services if you are 65 and over, to find out about the types of support you may be able to receive.

You can find more information on returning to work on financial support on our website: www.cancer.org.nz/supporting-you/financial-impacts-of-cancer/financial-assistance-and-benefits

The Cancer Society has partnered with Sorted to produce a life guide to help you navigate finances during a difficult time. The guide is available here: https://sorted.org.nz/seriousdiagnosis

Talking to your bank

If you have a mortgage or other financial commitments, talk to your bank as soon as possible about how they can support you if you are unable to work for a period of time.

You can find more information on these websites.

- Applying for KiwiSaver hardship withdrawal: https://sorted.org.nz/must-reads/applying-for-kiwisaver-hardship
- Our information sheet Benefits and entitlements: available at www.cancer.org.nz/assets/Downloads/Info-sheet-applying-to-work-and-income.pdf

Personal insurance benefits

It is also a good idea to check your personal insurance policies, as you may be eligible for an early payment. Speak to your insurance agent to find out if you are covered.

Power of attorney

A power of attorney is a legal document giving one person the power to act for another person. There are two types of power of attorney.

- An Ordinary Power of Attorney
- An Enduring Power of Attorney (EPA)

It is a good idea to have your advance care planning (see page 35) done before you choose who you will give your powers of attorney to. A person cannot act on your behalf if they do not know what your wishes are. The person (or people) you choose should be someone you trust, a member of your whānau, or a friend.

Ordinary Power of Attorney	**Enduring Power of Attorney**
This is used when you are still able to manage your own affairs	There are two types of EPA. • Property • Personal care and welfare You must set them up while you are able to manage your own affairs.
The person you choose to act on your behalf has the power to act on specific issues only (such as managing your bank account while you are overseas).	**Property** - authority can start immediately. You can nominate more than one person to manage your property.
You can have one or more people acting in your behalf.	**Personal care and welfare** - the person you nominate can only act on your behalf when you

You can find more information on these websites.

- Community Law: www.communitylaw.org.nz
- Citizens Advice Bureau: www.cab.org.nz/article/KB00001276

Finding support

For some people, meeting others who are in similar situations can help to decrease feelings of anxiety, isolation, or fear. Support groups and online forums offer you the opportunity to share your experiences and learn different ways of dealing with problems.

The Cancer Society offers support groups that you may find helpful. You can phone the Cancer Information Helpline (0800 CANCER 226 237) for further information.

Counselling

A counsellor can help you to talk about your thoughts and feelings after a diagnosis of pancreatic cancer. Counselling can be very useful to help you and your whānau understand feelings and develop coping strategies. To find a counsellor, talk to your GP or whānau doctor, your local Cancer Society, or your treatment team.

You can find more information on counselling on our website: www.cancer.org.nz/emotions-and-cancer

Cultural and spiritual support

Hospitals throughout Aotearoa New Zealand have trained health workers available to support your spiritual, cultural, and advocacy needs. They may include Māori and Pacific health workers who will work with you and your whānau.

Hospital chaplains are available to offer support through prayer and quiet reflection. Community-based health workers at your local marae and Pacific health services may also be good sources of support.

You can find more information on cultural and spiritual support on our website: www.cancer.org.nz/spirituality-and-cancer

How whānau can help

As a friend or whānau member of someone diagnosed with pancreatic cancer, you are learning to cope with your own feelings and emotions. You may want to help but not know what to do. Here are some suggestions that might be useful.

Learn about pancreatic cancer and its treatment. This will help you understand what the person you are supporting is coping with.

Be thoughtful about offering advice. Listening while they talk or just being there with them are good ways to show you care.

Talk about your feelings together and be honest about what worries you.

Offer to go to appointments with them. You can be there for support, to take notes or, when appropriate, to take part in the discussions.

Respect that your whānau member or friend may want to talk to their treatment team alone.

The Cancer Society offers a range of resources to support you. You can find more information on how whānau can help in our *Supporting Someone with Cancer booklet*, available on our website: www.cancer.org.nz/supporting-someone-with-cancer

We also have an online tool — Support Crew — to help you coordinate offers of help such as meals, childcare, and cleaning. You can also use it as a secure online channel to send updates to whānau members and friends. It is free to use.

You can find more information at www.supportcrew.co.nz

Questions you may wish to ask

When you hear you have pancreatic cancer, you and your whānau may feel understandably frightened and you may have many questions. Here is a list of questions you may want to ask to help you make the most of your time with your doctor.

Let your doctor know if there are things you do not want to be told.

- What type of pancreatic cancer do I have?
- How far has my cancer spread? What stage is it?
- What scans do I need?
- What treatment do you advise for my cancer and why?
- Are there any private treatments available that you would advise for my cancer, and why?
- Are there other treatment choices for me?
- What are the risks and possible side effects of each treatment?
- Will I have to stay in hospital, or will I be treated as an outpatient?
- How long will the treatment take?
- How much will it affect what I can do?
- How much will the treatment cost?
- If I need further treatment, what will it be like and when will it begin?
- How often will my check-ups be and what will they involve?
- Are there any problems I should watch out for?
- If I choose not to have treatment either now or in the future, what services are available to help me?
- When can I return to work?
- When can I drive again?
- Will the treatment affect my sexual relationships?
- Is my cancer hereditary (passed on by my parents)?
- Is the treatment attempting to cure the disease or not?
- What is my prognosis (future outlook)?
- I would like to have a second opinion. Can you refer me to someone else?

If there are answers you do not understand, feel comfortable saying:

- “Can you explain that again?”
- “I am not sure what you mean”
- “Could you draw a diagram or write it down?”

You can find more information in our *Questions You May Wish to Ask booklet*, which has general questions and spaces in which you or your doctor can write answers. You can also phone the Cancer Information Helpline (0800 CANCER 226 237) for further information or visit our website: www.cancer.org.nz/questions-to-ask

Section Eight: Resources

Tekiona Waru

Rauemi

What is cancer?

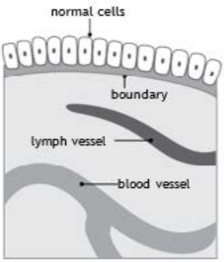
Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells, or heal damaged cells after injury.

The process of making new cells is controlled by certain genes – the codes that tell our cells how to grow and behave. Cancers are caused by damage to these genes. These changes usually happen during our lifetimes.

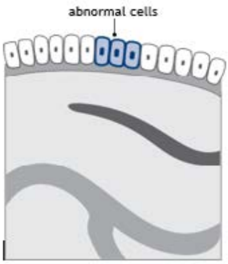
In a very small number of families, damaged genes are passed through generations. While these people will have an increased risk of developing cancer, it does not mean they will definitely get cancer.

How cancer starts

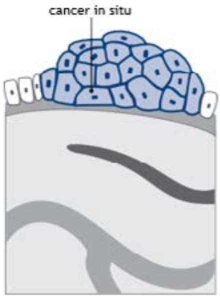
Tumours can be benign (not cancerous) or malignant (cancerous). Benign tumours do not spread to other parts of the body.



1. Normal cells



2. Abnormal cells



3. Abnormal cells multiply

4. Malignant or invasive cancer

How cancer spreads

A malignant tumour is made up of cancer cells. When it first develops, a malignant tumour is usually confined to its original site. This is known as the primary site. Some tumours can become quite large within their organs of origin, for example the lung or breast. With growth, the tumour may spread beyond the original organ boundaries and into surrounding tissues. This is called locally advanced cancer.

Sometimes cells move away from the original (primary) cancer through the bloodstream or lymphatic systems and start to grow in other body organs. When these cells reach new sites, they may form more lumps or masses. This is called secondary cancer or metastasis. For example, if lung cancer spreads to the bone, it is called a bone secondary (or metastasis).

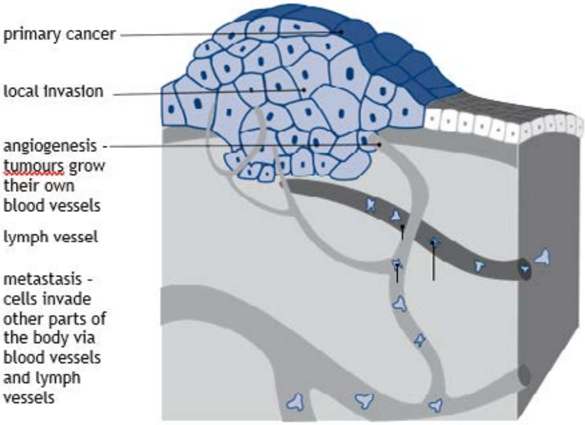
If the only place of spread is nearby lymph nodes, it is called regional nodal spread. Your cancer doctor will still refer to it as lung cancer even though it has spread to another part of your body.

The sort of treatment you are offered for cancer will depend on the type of cancer, where it began, and whether it has spread. Your cancer doctor will also take into account other things about you, such as your age and general health.

Treatment for cancer includes surgery, radiation treatment and chemotherapy (drug treatment). Immune therapy or targeted treatments, which are now used to treat some cancers, will become more important in the future.

Sometimes only one of these types of treatment is used for a cancer. Sometimes more than one is used.

How cancer spreads



Suggested websites

You may be interested in looking for information about pancreatic cancer on the internet. While there are very good websites, be aware that some websites may provide incorrect information.

We recommend that you begin with the Cancer Society's website (www.cancer.org.nz) and use our links to other good cancer websites, or visit the following websites:

MacMillan Cancer Support
www.macmillan.org.uk/cancer-information-and-support/stories-and-media/booklets/understanding-cancer-of-the-pancreas

Pancreatic Cancer UK
www.pancreaticcancer.org.uk

American Cancer Society
www.cancer.org/cancer/pancreatic-cancer/if-you-have-pancreatic-cancer.html

Pancare Foundation
www.pancare.org.au

Pancreatica
https://pancreatica.org

Gut Cancer Foundation (New Zealand)
www.gutcancer.org.nz

The suggested websites are not maintained by the Cancer Society of New Zealand. We only suggest sites we believe offer credible and reliable information, but we cannot guarantee that the information on these websites is correct, up to date, or evidence-based medical information.

Suggested resources

Information sheets

Applying to work and income

Cancer Society/Sorted NZ financial and legal guide

Cancer and insurance, employment and legal issues

Coping with waiting

Healthy eating and cancer treatment

Making decisions about treatment

Searching the internet

Sex and cancer

Spirituality, wairuatanga and cancer

Supporting young adult children when you have cancer

Telling others about your diagnosis

Your cancer treatment team

Booklets

Cancer in the Family

Eating Well with Cancer

Emotions and Cancer

Living Well with Cancer

Sex and Cancer

Supporting Someone with Cancer

Acknowledgements

The Cancer Society would like to thank the following people for their reviews, advice, and contributions.

- **Jonathan Koea** - Professor of Surgery, North Shore Hospital.
- **Kate Clark** - Medical oncologist.
- **Katie Whytock** - Cancer Care Coordinator.
- **Hohepa McDougall** - Maori translator
- **Eileen Brown, Julie Holt, Kate Velenski** – Cancer Society Editorial Team
- **Dr George Laking** - Cancer Society Medical Director
- **Dr Kate Gregory** - Cancer Society Medical Director

Also a big thank you to the volunteers who reviewed the booklet and shared their experiences with us.

Cancer Society information and support services

The Cancer Information Helpline is a Cancer Society phone line where you can talk about your concerns and needs with trained health professionals. Phone the Cancer Information Helpline (0800 CANCER 226 237).

Your local Cancer Society offers a range of services for people with cancer and their families/whānau. These may include:

- information and support
- volunteer drivers providing transport to treatment
- accommodation while you are having treatment away from home.

The range of services offered differs in each region, contact your local Cancer Society to find out what is available in your area.

Auckland/Northland

Auckland
09 308 0160
Domain Lodge
1 Boyle Crescent
Grafton

Whangarei
09 437 5593
Daffodil House
73 Kamo Road
Kensington

information@akcansoc.org.nz
Northland@akcansoc.org.nz

Central Districts

Palmerston North
06 356 5355
Young House (District office)
127 Ruahine Street

Whanganui
06 348 7402
3 Koromiko Road

New Plymouth
06 757 3006
TSB Cancer Support Centre
71 Lorna Street
Westown

Gisborne
06 867 1795
Morris Adair Building
Gisborne Hospital

Hastings
06 876 7638
310 Orchard Road

Palmerston North
06 356 355
Addis House
135 Ruahine Street

Waikato/Bay of Plenty

Hamilton
07 838 2027 or 0800 22 77 44
Divisional Office (Hamilton)
511 Grey Street
admin@cancersociety.org.nz

Rotorua
07 349 4556 or 0800 22 77 44
1235 Ranolf Street
rotorua@cancersociety.org.nz

Tauranga
07 571 2035 or 0800 22 77 44
111 Cameron Road
tauranga@cancersociety.org.nz

Wellington

Wellington
04 389 8421
52-62 Riddiford Street

Paraparaumu
04 298 8514
27 Kāpiti Road

Masterton
06 378 8039
37 Te Ore Ore Road

Nelson
03 539 1137
102 Hardy Street

Blenheim
03 579 4379
The Forum Building
Market Street

info@cancersoc.org.nz

Canterbury-West Coast

Christchurch
03 379 5835
97 Fitzgerald Avenue

Greymouth
03 768 9557
98 High Street

Timaru
03 688 0124
32 Memorial Avenue

Rolleston
03 925 9708
6B Kidman Street

Ashburton
03 307 7691
122 Kermode Street

contact@cancercwc.org.nz
info@cancercwc.org.nz

Otago and Southland

Dunedin
03 477 7447
283 Great King Street
SupportiveCare@cansoc.org.nz

Oamaru
03 434 3284 or 027 674 4200
Waitaki District Community House
100 Thames Street

Balclutha
03 418 3916 or 027 277 7632
Arcade 84
5/37 Clyde Street

Alexandra
03 440 0754 or 027 580 0640
Alexandra Community House Office
14-20 Centennial Avenue

Wanaka
Wanaka Community House
40 McDougall Street

Queenstown
03 442 4281 or 027 536 0066
112B Aurum House
1092 Frankton Road

Southland
149 Spey Street

Invercargill
03 218 4108

National Office
04 494 7270
39 The Terrace
Wellington
admin@cancer.org.nz

Cancer Society

Te Kāhui Matepukupuku
o Aotearoa

☎ Cancer Information Helpline **0800 CANCER (226 237)**

Cancer Society of New Zealand Inc - Te Kāhui Matepukupuku o Aotearoa
Level 6 Ranchhod Tower | 39 Terrace | Wellington
Phone (04) 494 7270 | PO Box 651, Wellington 6140

www.cancer.org.nz @NZCancerSo @cancersocietynz

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