Understanding Lung Cancer

Matepukupuku pūkahukahu

A guide for people with lung cancer

Cancer Society

Te Kāhui Matepukupuku o Aotearoa

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

Sixth edition:
ISBN I978-0-9951486-1-1 (print)
ISBN 978-0-9951486-2-8 (online)

Cover image and images on page 11, 17, 34 and 40 are stock images used with paid actors (Truestock)

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 about how lung cancer is diagnosed, the different stages of lung cancer, how it can be 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: cancer.org.nz.

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

Ngā kōrero mō tēnei puka

Ka hoatu tēnei puka i ngā pārongo mō te mōhio pēhea te whakatau i te matepukupuku pūkahukahu, ngā wāhanga rerekē o te matepukupuku pūkahukahu, pēhea maimoatia ai, me te noho ora i te wā o te maimoa.

Kua whakarāpopotohia ngā pārongo mā ngā Kōrero Matua kei te tīmatatanga o ia tekiona o tēnei puka. Kua whakamāoritia anō hoki ngā Kōrero Matua i te tīmatatanga o ia tekiona.

Tērā pea, ka hiahia koe ki te uiui i tō rōpū maimoa matepukupuku, ko ēhea ngā tekiona tērā pea whai kiko mōu. Ka āhei koe ki te waea atu ki te **Cancer Information Helpline 0800 CANCER (226 237)** ki te kōrero me ō mātou kaimahi ratarata.

Contents

Section One: Understanding lung cancer

Tekiona Tahi
Kia mārama ki te matepukupuku pūkahukahu

Key points:

- Lung cancer is cancer of some of the cells in part of the lungs, usually beginning in the lining of the airway.
- Secondary cancer in the lungs is common. This is cancer that has started somewhere else in the body (for example, bowel or breast) and spread to the lungs.
- There are two main types of lung cancer:
  - Small cell lung cancer (SCLC)
  - Non-small cell lung cancer (NSCLC) – adenocarcinoma, squamous cell carcinoma and large cell carcinoma
- Tobacco smoking is the greatest risk factor for lung cancer.
- The symptoms of lung cancer can be different from person to person. It is important to have your GP or whānau doctor check any symptoms:
  - A cough that doesn't go away or a change in a cough you have had for a long time

- Loss of voice or a change in voice (hoarseness)
- Feeling breathless or wheezy without exercising, or becoming unable to do your usual activities
- A chest infection that doesn't improve with treatment, or frequent chest infections
- Chest, upper back or shoulder pain that does not go away
- Coughing up blood
- Weight loss for no reason, or loss of appetite
- Feeling very tired

Ngā kōrero matua:

- Ko te matepukupuku o ētahi pūtau kei ētahi wāhi o te pūkahukahu te matepukupuku pūkahukahu. I te nuinga o te wā, tīmata ai ki te whakapaparanga ngongo hau.
- E rua ngā momo matepukupuku pūkahukahu matua:
  - Matepukupuku pūkahukahu pūtau iti
  - Matepukupuku pūkahukahu pūtau iti-kore – adenocarcinoma, squamous matepukupuku kiri me te matepukupuku kiri pūtau nui
- Ko te momi tupeka te take mōrearea rawa atu mō te matepukupuku pūkahukahu.
- He rerekē ngā tohumate o te matepukupuku pūkahukahu mai tēnā tangata, ki tēnā tangata. He mea nui kia arowhaitia ngā tohumate ka puta, e tō Tākuta Whānau:
  - maremare e kore e pai ake, he panoni rānei ki te āhua o tō maremare kua roa nei e mau ana ki a koe
  - ngaronga reo, panonitanga rānei o te reo (whango)
  - kua hēmanawa te mahi hā, kua tīmohu rānei ahakoa kīhai koe i korikori, te kore rānei ōu e āhei ki te whai i āu mahi aua
  - He whakapokenga poho e kore e pai ake ahakoa ngā maimoa, he nui rawa rānei ngā wā puta ake ai te whakapokenga poho
  - he mamae poho, mamae tuarā whakarunga, mamae pokohiwi rānei, e kore e mutu
  - te maremare toto
  - he ngaronga taumaha mō te kore noa iho, ngaronga hiakai rānei
  - kua tino pokea e te hiamoe

What is lung cancer?

Primary lung cancer is cancer of some of the cells in the lungs, usually beginning in the lining of the airways. Primary lung cancer can spread as secondaries (metastases) to any other part of the body.

Secondary cancer in the lungs is common. This is cancer that has started somewhere else in the body (for example, bowel or breast) and spread to the lungs.

This booklet is about primary lung cancer.

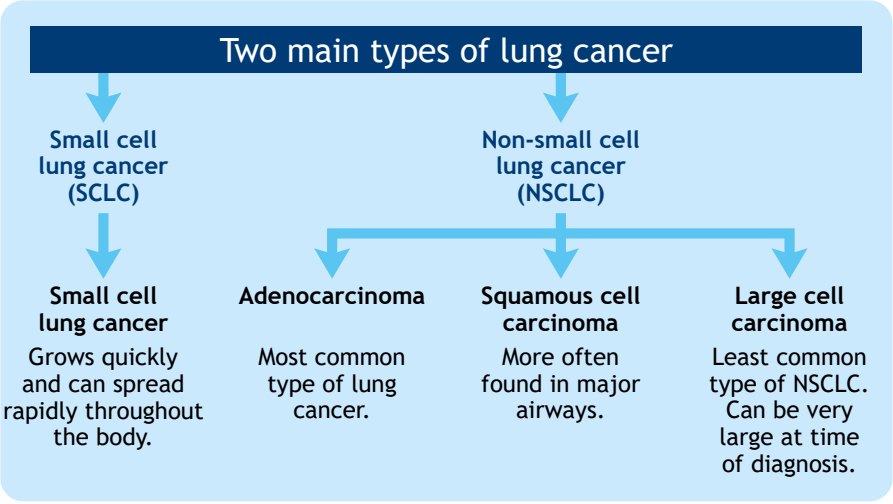
For more information on cancer that has spread to the lung, see to the Cancer Society's *Living Well with Advanced Cancer* booklet, available on our website: cancer.org.nz/advanced-cancer

Types of lung cancer

Although there are many types of lung cancer, there are two main types:

- Small cell lung cancer (SCLC) makes up about 15-20 percent of lung cancers.
- Non-small cell lung cancer (NSCLC) is the most common type and makes up about 80 percent of all lung cancers. NSCLC is divided into several specific types.

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



Mesothelioma is a rare cancer that occurs in the outer lining of the lung (pleura) but it is not the same as lung cancer. This type of cancer is most often linked with asbestos exposure.

You can find more information on mesothelioma on our website: cancer.org.nz/mesothelioma

What are the risk factors for lung cancer?

Anything that can increase your chances of developing cancer are called risk factors. Tobacco smoking is the greatest risk factor for lung cancer. Exposure to asbestos also increases the chance of developing lung cancer.

Some risk factors, such as smoking, can be changed. Some risk factors can't 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 may never develop cancer. Others with cancer may have no known risk factors.

Risk factors that we know make some people more at risk than others for lung cancer include:

Tobacco *(smoking)* Smoking tobacco is the number one risk factor for lung cancer. This includes smoking cigarettes, cigars and pipes. And the more you smoke, the bigger the risk. People who do not smoke can also get lung cancer, but their risk is much lower.

Smoke *(second-hand)* Passive or second-hand smoking (breathing in other people's smoke) can slightly increase your risk of lung cancer. In New Zealand, smoking is now banned in most public places.

Ageing *(senescence)* Lung cancer is more common in older people (aged over 65). Younger people do get lung cancer, but it is rare.

Asbestos *(silicates)* People who have worked with asbestos have a higher risk of getting lung cancer.

Genetics *(family history)* People with a parent, brother or sister with lung cancer have a higher risk of developing it themselves. This may be because families often have shared risk factors such as smoking or it may more rarely be caused by a lung cancer gene that runs in the family.

Occupation *(eg miners)* It is rare, but sometimes contact with certain chemicals and substances through workplaces can increase the risk of lung cancer.

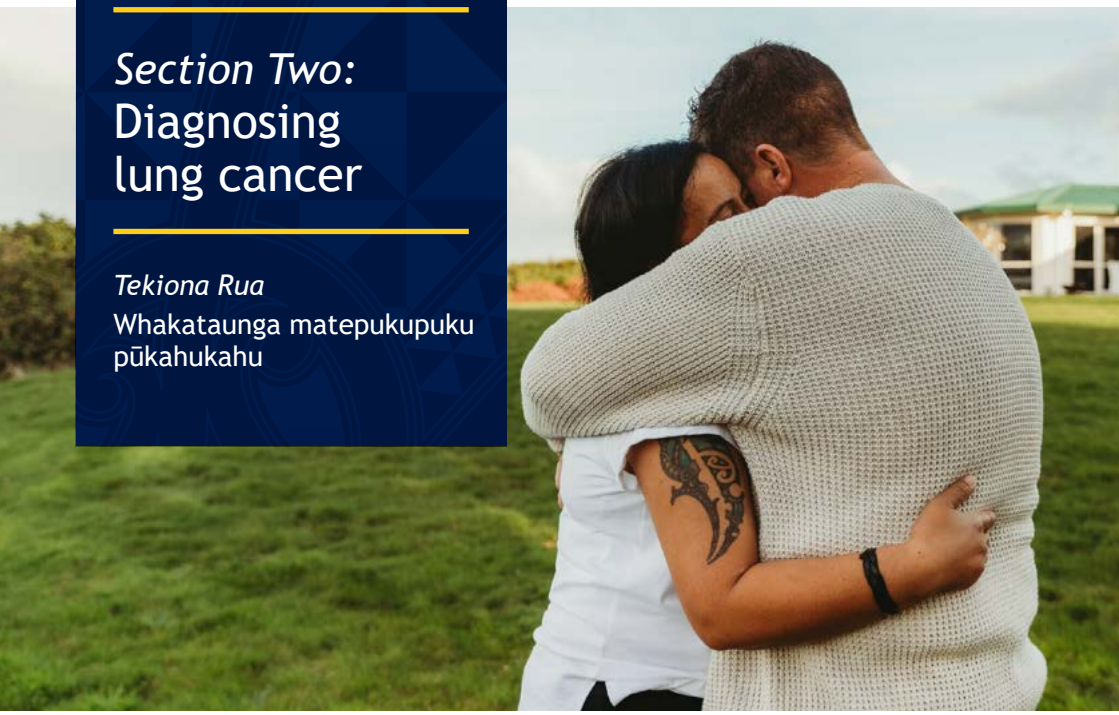
Pollution *(eg smog)* Research shows that air pollution may increase the risk of lung cancer. It is hard to know the risk for each person because it depends on the quality of the air where they live and how much pollution they are exposed to.

Symptoms of lung cancer

The symptoms of lung cancer can be different from person to person. Some people with cancer have no symptoms. They may find out they have lung cancer when it is seen on a chest X-ray done for another reason. Other people may notice some, or all, of the following symptoms:

- A cough that doesn't go away or a change in a cough you have had for a long time
- Loss of voice or a change in voice (hoarseness)
- Feeling breathless or wheezy without exercising, or becoming unable to do your usual activities
- A chest infection that doesn't improve with treatment, or frequent chest infections
- Chest, upper back or shoulder pain that does not go away
- Coughing up blood
- Weight loss for no reason, or loss of appetite
- Feeling very tired

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



Section Two: Diagnosing lung cancer

Tekiona Rua
Whakataunga matepukupuku pūkahukahu

Key points:

- If there is concern that your symptoms may be lung cancer, further tests (investigations) will be done.
- The purpose of these tests is to find out whether you have lung cancer, the type of lung 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 advise what the best treatment options are for you.
- Common tests include:
  - chest X-ray
  - lung function test
  - sputum cytology
  - biopsy
  - testing for gene changes
  - imaging tests (scans).

Ngā kōrero matua:

- Mehemea he āwangawanga ōu tērā pea kua puta he matepukupuku pūkahukahu nā ō tohumate, ka whakahaerehia anō he whakamātautau atu.
- Ko te whāinga o ēnei whakamātautau ko te kimi mehemea kua whai koe i te matepukupuku pūkahukahu, te momo matepukupuku kua puta kia koe, me te tiro mehemea kua rauroha ki wāhi kē o tō tinana.
- Ka āwhina ngā whakamātautau ka whai koe, i tō rōpū maimoa ki te whakatau ko tēhea te kōwhiringa maimoa pai rawa mōu.
- Ka whai ko ēnei whakamātautau:
  - Whakaata roto uma
  - Whakamātautau mahinga pūkahukahu
  - Hūare cytology
  - Unuhanga kikokiko
  - Whakamātautau panoni ki ngā ira
  - Whakamātautau ataata.

Diagnosing lung cancer

If you are concerned that you may have lung cancer or you have noticed any of the symptoms of lung cancer, you may see your GP or whānau doctor first. They will talk to you about your symptoms and examine your chest. They will also ask you about any risk factors for lung cancer you may have.

If your GP or whānau doctor is concerned that your symptoms may be due to lung cancer, they will recommend further tests (investigations).

The purpose of these tests is to find out whether you have lung cancer, the type of lung 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 what the best treatment options are for you.

You may have some, or all, of these tests:

Chest X-ray (CXR)

An X-ray of the chest may show cancers one centimetre wide or larger.

Lung function test

You may have a lung function test, known as spirometry, which checks how well your lungs are working.

Sputum cytology

A sample of your sputum (spit, mucus) may be tested for cancer cells.

Biopsy

A biopsy often takes small samples of tissue from your lung or lymph nodes. 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, this will show the type of cancer you have.

There are different ways to take a biopsy. Your doctor will explain which one is right for you. Types of biopsy include:

- **bronchoscopy:** Uses a thin, flexible tube called a bronchoscope, to look at the inside of the breathing tubes and lungs. Bronchoscopy is used to look for cancer and to take a small sample of tissue for testing
- **endobronchial ultrasound (EBUS):** A special type of bronchoscopy. The bronchoscope has a small ultrasound probe on the end. This can measure the size and position of a cancer or lymph nodes and help direct a biopsy needle to the right place
- **percutaneous (through the skin) Needle Biopsy**: A very thin needle is placed between the ribs, into the lung. Some cells or tissue are taken for testing
- **mediastinoscopy:** Uses a thin, flexible tube called a mediastinoscope to look at, and take samples of, the lymph nodes in the centre of the chest next to the lungs. Mediastinoscopy is a surgical operation carried out under general anaesthetic
- **surgical biopsy:** This may be done to confirm a diagnosis or as a surgical procedure to remove the cancer. Surgical biopsy can be done in two ways: keyhole surgery, known as video-assisted thoracoscopic surgery (VATS), or thoracotomy, where a larger area of the chest is opened to get better access to the lung.

Testing for gene changes (mutations)

Some people may have a lung cancer which contains a change in a specific gene or protein that helps the cancer to grow. Laboratory doctors (pathologists) test for these changes in lung cancer cells from the tissue that was taken during a biopsy.

CT, MRI and PET-CT scans

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

Further tests

Your treatment team may recommend other tests, including:

- general blood tests
- scans of other body organs such as bones, liver, brain and kidneys.

Section Three: Staging lung cancer

Tekiona Toru
Te whakawāhanga matepukupuku pūkahukahu

Key points:

- Staging describes:
  - the size of the cancer
  - if there is cancer in the lymph nodes
  - if the cancer has spread to other parts of the body.
- Lung cancer is given a number from stage 1 to stage 4. The lower the number, the less your cancer has spread.
- Small cell lung cancer can be further divided into two stages:
  - Limited disease
  - Extensive disease

Ngā kōrero matua:

- Ka whakamārama te whakawāhanga:
  - te rahi o te matepukupuku.
  - mehemea he matepukupuku kei ngā tīpona waitinana.
  - mehemea kua rauroha te matepukupuku ki wāhi kē o te tinana.
- Ka hoatuna he nama mō te matepukupuku pūkahukahu mai i te wāhanga 1 ki te wāhanga 4. Mena he iti te nama, he iti ake te rauroha o tō matepukupuku.
- Ka taea te whakawehewehe anō i te matepukupuku pūkahukahu pūtau-iti ki ngā whakawāhanga e rua:
  - Tahumaero here
  - Tahumaero whānui

Staging non-small cell lung cancer

Staging describes:

- the size of your 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 the TNM information collected from the tests you have had to give the cancer a number from stage 1 to stage 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.

Non-small cell lung cancer		
Stage 1	The cancer is no bigger than 4cm and hasn't spread outside the lung or to any lymph nodes.	Early lung cancer
Stage 2	The cancer can be different sizes. It may have spread to: • nearby lymph nodes • other parts of the lung • areas just outside the lung.	Loco-regional lung cancer

Stage 3	The cancer can be any size and has usually spread to lymph nodes. It may also be growing into: • other parts of the lung • the airway • surrounding areas outside the lung.	Locally advanced lung cancer or Regionally advanced lung cancer
Stage 4	The cancer can be any size. It may have spread to lymph nodes and one of the following: • The lung on the other side • The fluid in the pleura around the lungs or the heart • Another part of the body, such as the liver, bones or brain.	Advanced lung cancer

Staging small cell lung cancer

Small cell lung cancer can be divided into two stages, or doctors may use the TNM system:

- Limited disease – the cancer can be seen only in one lung and/or nearby lymph nodes on the same side of the chest
- Extensive disease – the cancer has spread outside the lung, within the chest area, or in fluid around the lungs (known as pleural effusion), or to other parts of the body.

Section Four: Making treatment decisions

Tekiona Whā
Te mahi whakataunga maimoa

Key points:

- The treatment choices you are offered will be based on all the information available about the cancer and your general health.
- The recommended treatment will depend on:
  - the type of lung cancer and its stage
  - your general health
  - how well you can breathe
  - your personal wishes and goals of care.
- 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 respiratory doctor
  - a surgeon
  - a medical oncologist

- a radiation oncologist
- a palliative care team
- other allied health professionals.

- You can ask another doctor for a second opinion about your cancer or treatment options if you want to.

Ngā kōrero matua:

- Ka hāngai ngā kōwhiringa maimoa ka hoaturia ki a koe i runga i ngā pārongo katoa e wātea ana mō tō matepukupuku me tō hauora whānui.
- Ka whakawhirinaki te maimoa ka taunakitia ki ēnei:
  - te momo matepukupuku pūkahukahu me tōna whakawāhanga
  - tō hauora whānui
  - te āhua o te whakahā
  - ōu ake wawata whaiaro me ōu ake whāinga manaakitanga.
- Ka tautāwhina koe e tētahi rōpū ngaio hauora, tae noa ki ēnei pea:
  - tō tākuta whānau
  - Ngā tapuhi mātai matepukupuku me ngā kaitakawaenga manaakitanga
  - he tākuta romahā
  - tētahi mātanga kokoti
  - He mātanga mātai matepukupuku
  - he mātanga mātai matepukupuku iraruke
  - ētahi atu ngaio hauora haumi.
- E āhei ana koe ki te uiui i tētahi atu tākuta mō he whakaaro tuarua e pā ana ki tō matepukupuku, ki ngā kōwhiringa maimoa rānei, mehemea ka pīrangi koe.

How treatment decisions are made

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

Recommendations will depend on:

- the type of lung cancer and its stage
- your general health
- how well you can breathe
- your personal wishes and goals of care.

The treatment team

From the time you are diagnosed with lung cancer, you will be cared for by a team of health professionals, who may include:

- 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 receiving cancer treatment
- a respiratory doctor, who helps to diagnose and stage lung cancer and improve breathing
- a surgeon (cardiothoracic), who specialises in lung 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 palliative care team, who specialises in symptom management and quality of life.

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

Talking to your cancer treatment team

When you first learn you have lung cancer, you may have many questions. Before you visit your cancer treatment team, we suggest you think about the questions you would like them to answer and how much detail you are comfortable with. 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 44 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 of 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 Commission

Your rights as a health and disability service consumer are protected by the Health and Disability Commission's Code of 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 here:
www.hdc.org.nz/your-rights/the-code-and-your-rights

Interpreting services

New Zealand's 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 are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. You can speak to a member of your health care team about arranging interpreters in your local area.

Talking to others

Once you have talked about your treatment options with your treatment team, you may want to discuss this 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, or a hospital social worker or 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 GP or whānau doctor or cancer nurse coordinator.

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

Taking part in a clinical trial

There are many new and emerging treatments for cancer. Clinical trials are a vital part of the search to find better cancer treatments.

Clinical trials test new and modified treatments to see if they are better than existing treatments. In randomised clinical trials, 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.

People all over the world have taken part in clinical trials that have improved cancer treatments, but not all treatments tested in trials turn out to be helpful.

If you are asked to participate 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 the trial or not.

Section Five: Lung cancer treatments

Tekiona Rima
Ngā maimoa matepukupuku pūkahukahu

Key points:

- Research shows that if you are a smoker and you quit smoking, your treatment is more effective.
- Depending on the stage of your cancer, your state of health and your preferences, treatment for lung cancer may include:
  - surgery
  - radiation treatment
  - chemotherapy
  - targeted treatments and immunotherapy
  - palliative care and supportive care
- or combinations of any of these.
- Complementary treatments are healing practices or products that can be used alongside medical care.
- Traditional Māori healing methods can include rongoā Māori, romiromi or mirimiri, massage therapy and spiritual healing.

- Traditional Pacific healing treats the whole person, including your mental, emotional, physical and spiritual wellbeing and recognises the importance of community wellbeing.
- If you are thinking about using complementary, traditional Māori or Pacific treatments, please talk about them with your cancer treatment team.

Ngā kōrero matua:

- E ai ki ngā rangahau, mehemea he tangata kai paipa koe, ā, ka mutu tō kai paipa, ka whai kiko o maimoatanga.
- Kei te āhua o te wāhanga o tō matepukupuku, te āhua o tō hauora, me ōu hiahiatanga, tērā pea ka whai tō maimoa i ētahi o ēnei:
  - hāparapara
  - maimoa iraruke
  - hahau
  - Maimoa whakahāngai me te haumanu-taunga
  - Atawhai taurima me te manaaki tautoko, he kōwhiringa rānei o ēnei rurua.
- He mahi whakaora, he hua rānei ngā maimoatanga kīnaki kīhāi e whai wāhanga i te taha o te manaaki hauora aro whānui.
- Kei roto i ngā mahi whakaoranga Māori taketake ko te rongoā Māori, te romiromi, te mirimiri rānei, te haumanu romiromi me te whakaoranga ā-wairua.
- Ka maimoa te whakaoranga Te moana-nui-ā-Kiwa taketake i te tangata katoa, tae noa ki tō oranga hinengaro, oranga aronganui, oranga tinana, me tō oranga wairua.
- Mehemea e whakaaro ana koe ki te whakamahi i te maimoa whakaoranga Māori taketake, whakaoranga Te-moana-nui-ā-Kiwa, tēnā koa kōrerohia ēnei me tō rōpū maimoa matepukupuku.

Treatment options

Your cancer treatment team will advise you about the possible treatments for your lung cancer. Depending on the stage of your cancer, your state of health and your preferences, treatment may include surgery, radiation treatment, chemotherapy, targeted treatment, immunotherapy and palliative care, or combinations of these.

Sometimes treatment may 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 still recommend treatment options that may reduce the symptoms of the cancer and improve your quality of life.

Type of lung cancer	Main treatment options
Non-small cell lung cancer	• Early-stage cancer may be treated with surgery followed by chemotherapy (adjuvant chemotherapy). • If surgery is not possible, appropriate or acceptable, a combination of radiation treatment and/or chemotherapy may be recommended. • Some types of advanced non-small cell lung cancer may respond to immunotherapy treatment. From 1 April 2023, pembrolizumab (Keytruda), atezolizumab (Tecentriq) and durvalumab (Imfinzi) are funded for patients who meet the Special Authority criteria set by Pharmac. • Targeted therapy can be effective for people with advanced cancer who have a specific gene change. • Palliative treatment and supportive care are available (see page 31).
Small cell lung cancer	• Treatment is usually with chemotherapy and radiation treatment to the primary tumour in the lung. • You may be offered radiation treatment to the brain to reduce the chance of cancer spreading to the brain. • Surgery is not usually an option for treatment. • Palliative treatment and supportive care are available (see page 31).

Research shows that if you are a smoker and you quit smoking, your treatment is more effective. If you smoke, your treatment team will advise you to stop smoking before you have any treatment.

Speak to your treatment team if you need support to stop smoking.

Surgery

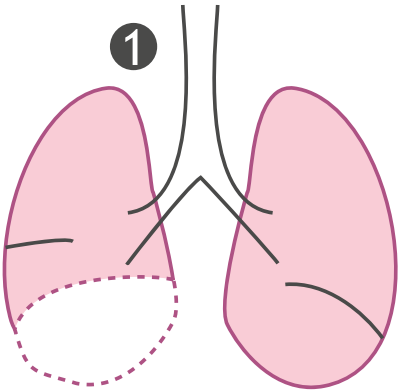
If you have been diagnosed with early-stage, non-small cell lung cancer, you may be offered surgery to remove the cancer.

Sometimes you may have surgery before the diagnosis of lung cancer has been confirmed. While you are under anaesthetic, the surgeon removes a small piece of abnormal tissue (called a 'frozen section') and looks at it under a microscope to confirm if the growth is cancer. If cancer is confirmed, the surgeon will continue with the operation to remove the affected part of your lung.

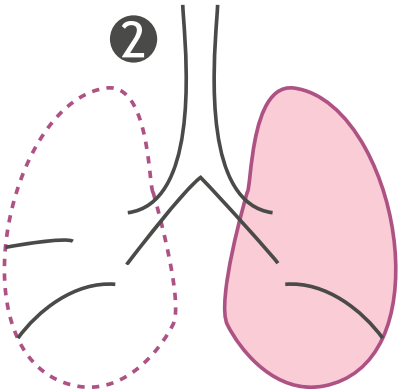
At the time of your lung cancer surgery, the surgeon will also sample lymph nodes from around the lung and mediastinum to stage your cancer and help decide if any further treatment (such as chemotherapy) is needed.

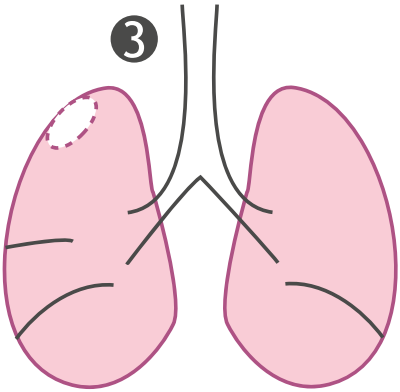
There are three main types of surgery for lung cancer (see below).

Types of lung surgery



1. Lobectomy: a lobe of the lung is removed
2. Pneumonectomy: one whole lung is removed
3. Wedge resection or segmentectomy: only part of the lung (not a lobe) is removed





Recovering from surgery

Your recovery after surgery will depend on many factors. However, there are two things you can do before surgery to help:

- Increase your physical activity (walking short distances) if you can.
- Current smokers should stop smoking as soon as possible. This will reduce the risk of complications immediately after surgery, help with recovery after surgery and also improve general heart and lung health. Stopping smoking will also reduce the risk of developing another cancer in the future.

After lung surgery, you may feel short of breath. Physiotherapy can help to improve your breathing and mobility and will be an important part of your recovery.

Chemotherapy treatment

Chemotherapy is medication used to kill cancer cells or slow their growth. It affects cells throughout your body.

For more information on chemotherapy, see the Cancer Society's *Chemotherapy, Immunotherapy and Targeted Treatment* booklet, available on our website: cancer.org.nz/chemotherapy

When chemotherapy treatment is given

Chemotherapy may be given:

- before surgery, to try to shrink the cancer and make an operation easier (rarely done)
- before radiation treatment (occasionally done)
- during radiation treatment (chemoradiation) to increase the effectiveness of the radiation treatment (often done)
- after surgery to reduce the chances of the cancer coming back (occasionally done)
- as palliative treatment for a large cancer in the lung or for cancer that has spread outside the lung, to reduce symptoms and improve your quality of life or extend your life (often done)
- as the standard first treatment for most people with small cell lung cancer (often done).

How chemotherapy is given

Chemotherapy is given into a vein (IV) or as tablets.

If it is given into a vein, it may be given 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.

Some people may need a central venous access device (CVAD) 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.

For more information on CVADs, see the Cancer Society's *Chemotherapy, Immunotherapy and Targeted Treatment* booklet, available on our website: cancer.org.nz/chemotherapy

IV treatment is usually given to you as an outpatient at your local treatment centre, at regular intervals, over several months. Not all people with lung cancer will receive the same treatment.

Side effects of chemotherapy

Chemotherapy side effects vary depending on the combination of medications you receive. Some of the common side effects that you may experience include:

- increased risk of infection
- increased risk of bleeding or bruising
- reduced immunity
- hair loss
- infertility
- fatigue
- forgetfulness and concentration problems (chemo brain)
- nausea and vomiting
- constipation or diarrhoea
- hearing loss
- numbness and tingling in your hands and feet (peripheral neuropathy)
- sore mouth and ulcers.

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

- 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
- Severe diarrhoea
- Gum or nose bleeds, or bleeding that doesn't stop
- Pain or burning when passing urine, or blood in urine

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

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.

For more information on how radiation treatment works, see the Cancer Society's *Radiation Treatment/Haumanu Iraruke* booklet, available on our website: cancer.org.nz/radiation-treatment

When is radiation treatment offered?

Radiation can be used:

- on its own to treat early-stage lung cancer to try to cure the cancer
- to treat cancer that has spread to the lymph nodes within the chest, usually together with chemotherapy if the treatment aims to try to cure the cancer
- after surgery to reduce the chances of the cancer coming back in selected circumstances
- to the brain as part of the treatment plan for small cell lung cancer (Prophylactic Cranial Irradiation – PCI)
- to treat cancer that has spread to other organs such as the brain or bones (palliative treatment)
- with or without chemotherapy to reduce symptoms of lung cancer, improve your quality of life or extend your life (palliative treatment).

How radiation treatment is given

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 lung cancer.

Treatment is given daily or on alternate working days, and your treatment team will provide you with more information about how long your treatment will last. The machine 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.

Where radiation treatment is provided

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

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

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

Side effects of radiation treatment for lung cancer

People react in different ways to treatment. These are the common side effects of radiation treatment for lung cancer. You may experience none, some, or all of these:

- Fatigue (tiredness) – can occur during and after treatment
- Red and dry skin in the area being treated
- Nausea (feeling sick) or vomiting
- Painful swallowing
- Shortness of breath, and a dry cough
- Loss of chest hair
- Chest tightness or pain

The availability of targeted treatment and immunotherapy for advanced lung cancer

There have been recent advances in lung cancer treatment. Unfortunately, these treatments are expensive and not all options that might be helpful for the management of your lung cancer are funded by Pharmac. You may like to ask your oncologist if there are any unfunded treatments or clinical trials available that may be beneficial for you. Your medical oncologist can give you an estimate of the cost involved if you choose to fund your own treatment.

Targeted treatment

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

For more information about targeted treatments, see the Cancer Society's *Chemotherapy, Immunotherapy and Targeted Treatment* booklet, available on our website: cancer.org.nz/targeted-treatments

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.

If your cancer contains a change (mutation) in a specific gene or protein that is helping your cancer to grow, you may benefit from targeted treatment.

To find out if your cancer contains these changes, your doctor will take a tissue sample from your cancer and send it to a laboratory for molecular testing. It may take anywhere from a few days to a few weeks to receive the results. Genetic mutations, for example EGFR and ALK, are always tested for in people diagnosed with NSCLC adenocarcinoma of the lung.

In New Zealand, gefitinib (Iressa) and erlotinib (Tarceva) have been approved and funded for use for people with advanced NSCLC (adenocarcinoma) with an EGFR mutation.

Alectinib (Alecensa) has been approved and funded for use for people with advanced NSCLC (adenocarcinoma) with an ALK mutation.

Immunotherapy

Immunotherapy is a type of cancer treatment that helps your own immune system to fight cancer.

For more information about immunotherapy, see the Cancer Society's *Chemotherapy, Immunotherapy and Targeted Treatment* booklet, available on our website: cancer.org.nz/immunotherapy

Your immune system protects you by killing bacteria and diseases. It also helps to

fight cancer. A T-cell is one type of immune cell that does this.

Sometimes a part of your immune system is 'turned off', so it no longer recognises the abnormal cell growth that causes cancer. Immunotherapy helps to 'turn on' this part of your immune system so that it can identify and attack cancer cells.

Currently, in lung cancer treatment, immunotherapy is mostly used for people who have advanced cancer. Sometimes it is used following chemotherapy and radiation treatment, where the aim of treatment is to cure the cancer. It is not yet as widely used as chemotherapy and radiation treatment.

Immunotherapy is not suitable for everyone, so talk to your treatment team to find out whether you might benefit from it.

Funding of Immunotherapy

In New Zealand, immunotherapies pembrolizumab (Keytruda), atezolizumab (Tecentriq) and durvalumab (Imfinzi) are funded for people who meet the Special Authority criteria set by Pharmac. Pembrolizumab (Keytruda) is funded as a first-line treatment for advanced non-small cell lung cancer, atezolizumab (Tecentriq) is funded as a second or later-line treatment for advanced non-small cell lung cancer, and durvalumab (Imfinzi) is funded for stage 3 non-small cell lung cancer.

Nivolumab (Opdivo) has been approved for use but is not funded by Pharmac.

Palliative treatment and supportive care

Palliative treatment and care is for people with cancer of any stage that focuses on maintaining or improving quality of life rather than cure. Depending on your cancer, radiation treatment, chemotherapy, targeted treatments and immunotherapy can be used to slow the growth of cancer and relieve symptoms you may be experiencing.

Everyone with 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 too 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, talk about the treatments and care you may want towards the end of your life. This will then

guide your whānau and doctors if you can no longer tell them yourself.

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

More information is available on this website:
https://www.hqsc.govt.nz/our-programmes/advance-care-planning/

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 to name a few customary remedies based on native plants, massage therapy and spiritual healing.

You can find more information on rongoā Māori and providers on our website: 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 huri ētahi Māori ki ngā kaupapa hauora Māori i ētahi wā mēnā he uaua ki te whakatau ko tēhea, ko tēhea ō ngā momo maimoa me whai. Tae noa rā ki 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.
>
> Mehemea he uaua ki te kōrero i ō hiahia ki ngā kaiwhakarato maimoatanga, rapua tētahi tangata hei kaitaunaki mōu, kia āhei ai ngā tohunga hauora me matanga maimoa ō ngā hōhipera ki te mahi ngātahi

Pacific traditional healing

Traditional healing is also important for Pacific peoples to help in their recovery. It also 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 treatment offered to each person can vary, depending on 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 these treatments, please talk about them with your cancer treatment team. Both 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 so that traditional healers and hospital treatment specialists can work together to support you on your cancer journey.

Other treatments

It is important to discuss any additional treatments you are 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 or 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 treatment

When these treatments are used instead of medical treatment, they are considered alternative therapies. 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

For more information on complementary and alternative medicine, see the Cancer Society's *Complementary and Alternative Medicine* booklet, available on our website: cancer.org.nz/complementary-therapy

Section Six: Managing lung cancer symptoms

Tekiona Ono

Te whakahaere i ngā tohumate matepukupuku pūkahukahu

Key points:

- Lung cancer affects the tissue in and around the lung, and causes symptoms like breathlessness, coughing and chest pain.
- Lung cancer can make you less hungry, cause weight loss, and leave you feeling tired. You may have problems sleeping at night even though you feel tired.
- Talk to your doctor or nurse about any symptoms you may be experiencing. As well as cancer treatments, your doctor may be able to refer you to other services to help you manage your cancer symptoms.

Ngā kōrero matua:

- Ka whakaawe te matepukupuku i te kikokiko kei roto i te pūkahukahu, e karapoti ana hoki i te pūkahukahu me tōna whakaputa tohumate pērā ki te hēmanawa ki te hā, te maremare, me te mamae ki te uma.
- Ka iti ake tō hiakai nā te matepukupuku pūkahukahu, ka puta pea he ngaronga taumahatanga, ka hiamoe koe i te nuinga o te wā. Tērā pea ka raruraru koe ki te moe pai i ngā po ahakoa tō kaha hiamoe.
- Kōrero ki tō tākuta, ki tō tapuhi rānei e pā ana ki ngā tohumate tērā pea ka rongo koe. I tua atu i ngā maimoa matepukupuku, e āhei ana pea tō tākuta ki ētahi atu ratonga hei āwhina i a koe ki te whakahaere i ō tohumate matepukupuku.

Ways of managing lung cancer symptoms

Lung cancer affects the tissue around the lung, and causes symptoms like breathlessness, coughing and chest pain.

Lung cancer can also make you less hungry, cause weight loss, and leave you feeling tired. You may have problems sleeping at night even though you feel tired.

Talk to your doctor or nurse about any symptoms you may be experiencing, even if they are not listed below. As well as cancer treatments, your doctor may be able to refer you to a palliative care service to help you manage your cancer symptoms.

Breathlessness (being short of breath)

Managing lung cancer-related breathlessness will depend on the cause of your shortness of breath.

Your doctor may do some tests to investigate the cause of your breathlessness. Tests may include a chest X-ray and blood tests.

Ways of managing breathlessness include:

- medication
- breathing techniques
- relaxation exercises
- chemotherapy or radiation to shrink a cancer
- oxygen therapy (in hospital and/or at home)
- treatment for pleural effusion (see page 36).

If you are feeling breathless, try the Action Plan for Breathlessness on the inside back cover of this booklet. You may like to cut this Action Plan out and stick it on your fridge or somewhere you can find it easily.

Medication

Your doctor may give you medication to help with breathlessness caused by lung cancer. These might help:

- treat a chest infection or pneumonia
- relieve wheezing or coughing
- reduce fluid build-up in the lungs
- manage anxiety related to breathlessness.

Breathing techniques

Although breathlessness can be a difficult symptom to live with, there are things you can do to reduce the way it affects your life.

You can find more information on breathing techniques, including videos on breathlessness, on our website: cancer.org.nz/breathlessness

Relaxation exercises

There are relaxation exercises you can do to help when feeling short of breath.

You can visit the relaxation space on our website for some exercises to practise at home: cancer.org.nz/relaxation

Pleural effusion

When fluid builds up in the area between the lung and the chest wall (pleural cavity), you may experience shortness of breath, tiredness or pain. This is called a pleural effusion.

Symptoms may be relieved by:

- thoracentesis (pleural tap)
- pleurodesis
- indwelling pleural drains.

Thoracentesis (pleural tap)

Fluid from around the lungs is drained out through a plastic tube inserted under local anaesthetic.

Pleurodesis

If the fluid returns after you have had a pleural tap, your doctor may suggest a procedure called pleurodesis. A pleurodesis uses a medical powder to stick the lung to the chest wall to reduce the chance of fluid building up again. This is usually done under general anaesthetic.

Indwelling pleural drain

If the fluid returns after you have had a pleurodesis, your doctor may consider placing a long-term draining tube into the space where the fluid is.

The tube remains in the space around the lung and is fixed to your skin with a dressing. The tube is connected to a small bottle that collects the fluid. You and your whānau will be taught how to care for this at home.

Cough

Coughing is a common symptom of lung cancer which can be upsetting, especially if you find it hard to stop.

The best way to manage coughing is to treat the lung cancer. If it is not possible to remove the cancer with surgery, using chemotherapy or radiation treatment to try to shrink the cancer can help.

Some medications can be used to reduce the effects of your cough. Commonly used medications are codeine, morphine and steroids.

Sometimes breathing in steam or having saline through a nebuliser (a fine spray) is helpful.

If you are coughing up green or dark yellow sputum (phlegm), you may have an infection and need to see your doctor.

Pain

Not everyone with lung 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 lung cancer.

Pain relief works best when 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 or chemotherapy can also be used to treat cancer pain. 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.

Morphine is a medication very commonly prescribed to reduce pain. It has the added advantage of reducing breathlessness and coughing.

Fatigue (no energy)

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

- Let people help you. Family, friends and neighbours may offer to help with tasks such as meals, shopping, childcare, housework and driving.
- Take a few weeks off work during or after having 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 doctor. Don't 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 trying to eat a meal. If you have nausea, have your meals when you feel like eating.
- Fatigue may be caused by specific things found in blood tests and may be improved by treatment.

Trouble sleeping

Some people with lung cancer have trouble sleeping or have a problem 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 things 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, coffee and soft drinks, and alcohol (especially in the afternoons and evenings). These may give you energy but leave you unable to sleep.
- Use your pain medication as prescribed if pain is keeping you awake.
- If pain is not the issue, ask your doctor about sleeping tablets.

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

Nausea (feeling sick)

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

People have found it helpful to:

- eat small meals at frequent intervals
- avoid fatty or fried foods
- rest before and after eating
- 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 different ways, depending on the cause of your nausea. Let your 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: cancer.org.nz/eating-well-with-cancer

Weight loss

Weight loss is a common symptom of lung cancer. If you are underweight or losing weight, try to eat good sources of protein and include high-energy (high-calorie) foods in your diet.

Good sources of protein and energy include:

- meat, fish or poultry
- milk and dairy products
- legumes (for example, baked beans, kidney beans, chickpeas, lentils) and nuts.

If you have tried increasing your energy intake but still struggle to eat enough, you may benefit from a nutritional supplement drink. Talk with a dietitian or your treatment team to get the right supplements for your needs.

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

Section Seven: Living well with lung cancer

Tekiona Whitu

Te noho ora me te matepukupuku pūkahukahu

Key points:

- Because lung cancer is strongly linked to smoking, many people with lung cancer, whether they have smoked or not, experience negative attitudes from others and sometimes themselves.
- It may be helpful know that:
  - as many as 15 percent of people with lung cancer have never smoked
  - other factors may cause lung cancer, including air pollution, asbestos and second-hand smoke
  - smoking was a normal part of life in New Zealand for many years
  - smoking is one of the most difficult addictions to give up.
- Finding ways to focus positively on your body – such as eating well, starting a new exercise programme, and making positive lifestyle changes – can help you live well with lung cancer.
- A counsellor can help you to talk about your feelings around the impact a cancer diagnosis can have.

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

Ngā kōrero matua:

- Nā te mea he kaha te hāngai o te matepukupuku ki te kai paipa, he nui ngā tāngata whai matepukupuku pūkahukahu e rongo ana i ngā waiaro korehanga mai ētahi atu, mehemea i kai paipa, i kore rānei i kai paipa.
- Tērā pea he pai te mōhio ki ēnei:
  - Tae noa ki te 15 ōrau ngā tāngata whai matepukupuku pūkahukahu kīhai rawa i kai paipa
  - Ara ētahi atu take tērā pea puta ai te matepukupuku pūkahukahu, tae noa ki parahanga hau, te papa kiripaka me te kai paipa whai pānga tuarua
  - Ko te kai paipa tētahi o ngā waranga tino uaua rawa ki te whakamutu.
- Mā te rapu huarahi ki te arotahi pai ki tō tinana- pērā ki te kai pai, te tīmata i tētahi hōtaka korikori hou, me te mahi i ētahi panoni toiora pai- tērā ka āwhina i a koe ki te noho ora me te matepukupuku pūkahukahu.
- Ka āhei tētahi kaitautāwhi ki te āwhina i a koe ki te kōrero mō ōu kāre ā-roto mō te papātanga o tētahi whakatau mate matepukupuku.
- Ka whai ngā hōhipera huri noa i Aotearoa, i ngā kaimahi hauora kua whakangungutia ki te tautoko i ōu hiahia wairua, hiahia ahurea, hiahia whaitaua hoki.
- Kōrero ki tō tākuta whānau, ki tō Kahui Matepukupuku i tō rohe mō ngā ratonga tautoko e wātea ana ki a koe me tō whānau.

Negative attitudes to lung cancer

Because lung cancer is strongly linked to smoking, many people with lung cancer, whether they have smoked or not, experience negative attitudes from others and sometimes themselves.

This can be hard to cope with and you may feel less like talking about your diagnosis and asking for support.

If you are feeling this way, finding someone you trust to talk to (like a friend or family member) may be a good first step. Sometimes, talking with a counsellor can help you to see a way forward.

You can phone the Cancer Information Helpline (0800 CANCER 226 237) for information about services in your area.

It may be helpful know that:

- as many as 15 percent of people with lung cancer have never smoked
- other factors may cause lung cancer, including air pollution, asbestos and second-hand smoke
- smoking was a normal part of life in New Zealand for many years
- smoking is one of the most difficult addictions to give up.

Adjusting to changes in body image, keeping active and eating well

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

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

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

Finding support

For some people, meeting others in a similar situation can help decrease feelings of anxiety, isolation or fear. Support groups 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 feelings around the impact a cancer diagnosis can have, and help you work on healthy 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: 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: cancer.org.nz/spirituality-and-cancer

How families/whānau can help

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

- Learn about lung cancer and its treatment. This will help you to 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, take notes or, when appropriate, 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. For more information on how families/whānau can help, see the Cancer Society's *Supporting Someone with Cancer* booklet, available on our website: 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, cleaning. You can also use it as a secure online channel to send updates to whānau members and friends. This is free to use.

For more information: www.supportcrew.co.nz

Questions you may wish to ask

When you hear you have lung cancer, you and your whānau 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 lung cancer do I have?
- How far has my cancer spread? What stage is it?
- What scans and tests 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'm not sure what you mean."
- "Could you draw a diagram or write it down?"

For more information, see the Cancer Society's *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: cancer.org.nz/questions-to-ask

Section Eight: Resources

Tekiona Waru
Rauemi

What is cancer?

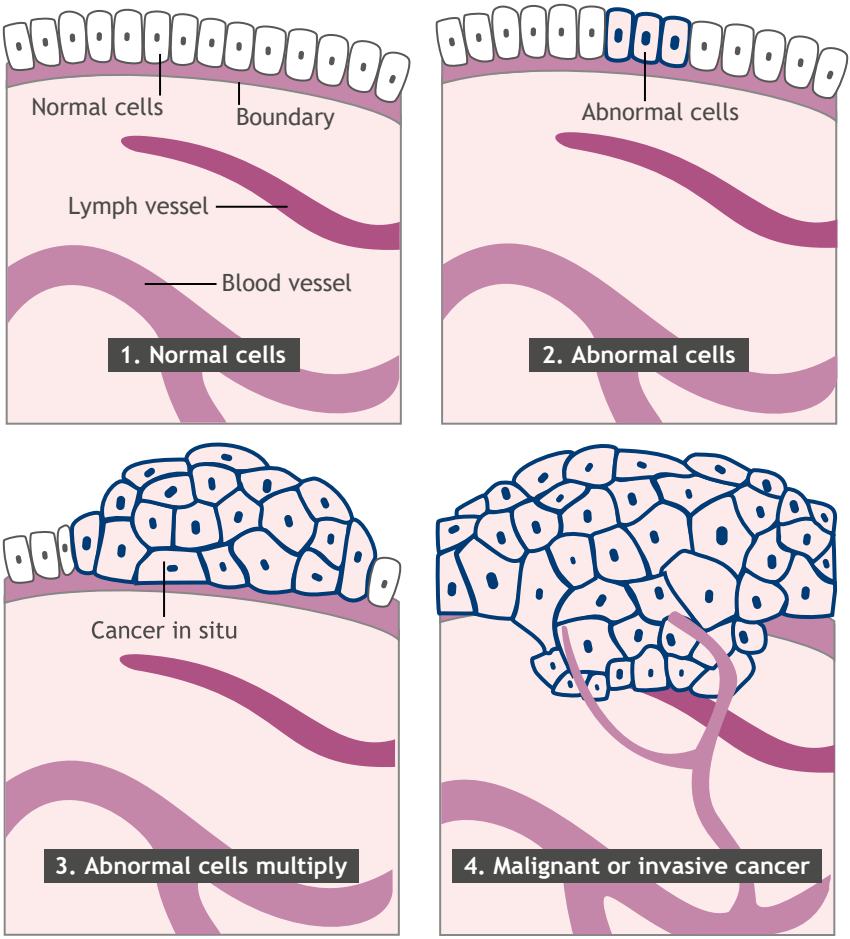
Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells or heal damaged cells after an injury.

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 lifetime.

In a very small number of families, damaged genes may be passed through the 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.



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 organ 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.

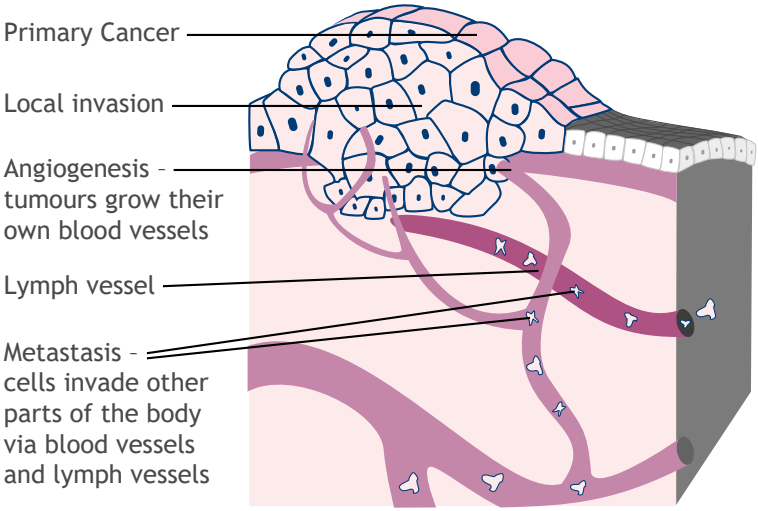
Sometimes cells move away from the original (primary) cancer through the bloodstream or lymphatic systems and start to grow in other body organs. When these cells reach a new site they may form another lump or mass. This is called a secondary cancer or metastasis. For example,if lung cancer spreads to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

If the only place of spread is to nearby lymph nodes, this 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 depends 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 or 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.



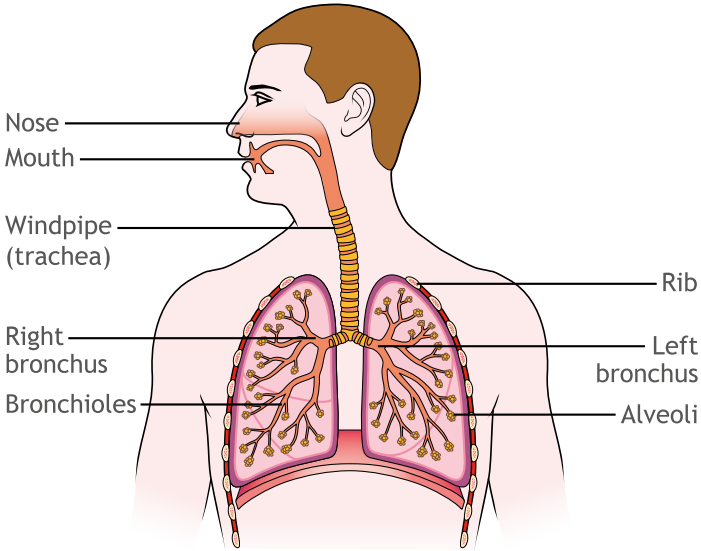
How your lungs work

The lungs are part of the respiratory system that helps you to breathe. The respiratory system also includes the nose, mouth, windpipe (trachea) and airways to each lung — known as the large airways (bronchi) and small airways (bronchioles).

Several parts of the body lie in the space between the lungs, called the mediastinum, including the:

- heart and large blood vessels
- windpipe (trachea)
- lymph glands (also known as lymph nodes).

The respiratory system



This image was produced by Macmillan Cancer Support and is used with permission.

The lungs

There are two lungs, one on each side of the chest, which are protected by the ribcage.

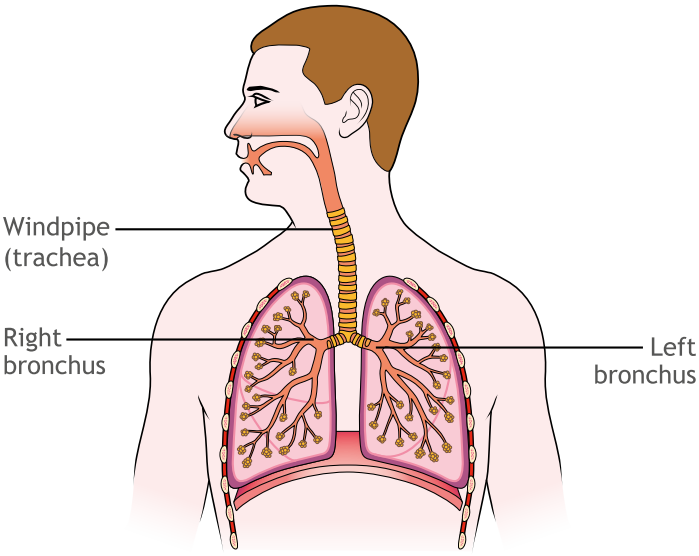
Each lung has different sections, called lobes. The left lung has two lobes (to make space for the heart) and the right lung has three lobes.

The lungs are separated from the stomach and liver by the diaphragm – a wide, thin muscle that helps with breathing. The lungs are surrounded by the pleura. The pleura has an outer layer and an inner layer. Each layer of pleura is about as thin as plastic wrap. Between the two layers is the pleural space (cavity), which normally holds a thin fluid. This fluid allows the two layers of pleura to slide against each other so your lungs can move smoothly against the chest wall as you breathe.

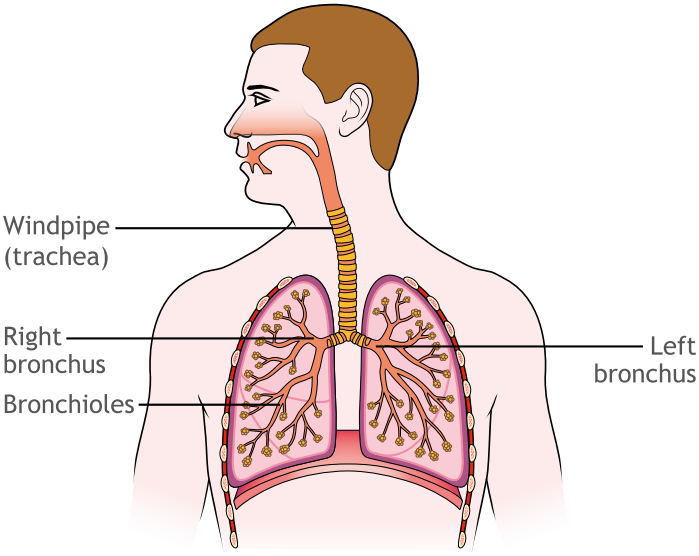
How you breathe

The lungs do not move on their own. The muscles between the ribs and the diaphragm make the chest expand and contract, pulling and pushing air into and out of the lungs.

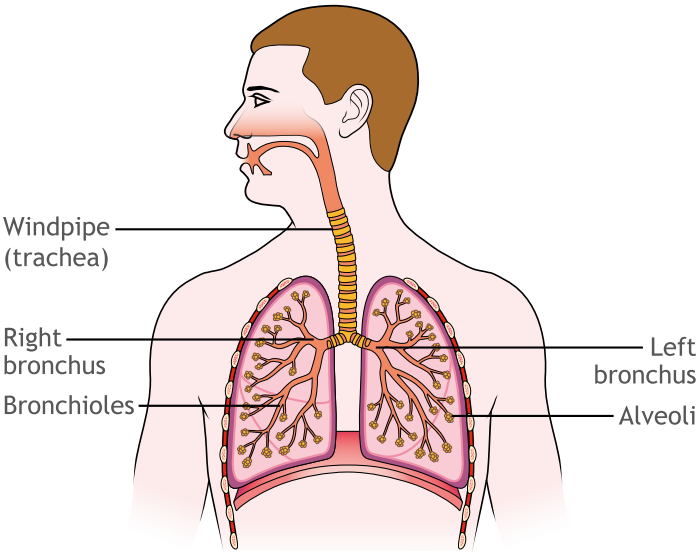
When we breathe in, air goes through the nose or mouth, into the throat, down the windpipe, and through the bronchus and bronchioles until it reaches the alveoli.



The windpipe divides into two airways. These are called the right bronchus and left bronchus.



Each bronchus divides into even smaller tubes called bronchioles.

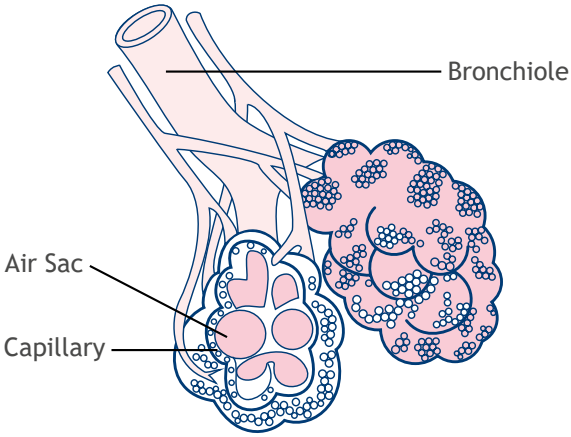


Each bronchiole ends up in tiny, bubble-like air sacs called alveoli.

These images were produced by Macmillan Cancer Support and are used with permission.

Blood flows through very small blood vessels (capillaries) in the thin walls of the alveoli. This allows oxygen to move from the air we breathe into the blood, and carbon dioxide (a waste product) to move from blood to air that is breathed out.

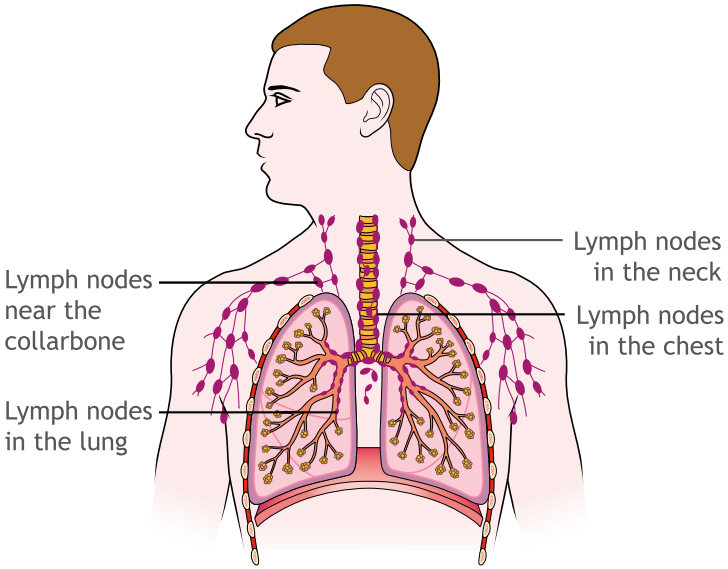
Alveoli



The lymphatic system

Sometimes cancer can spread through the lymphatic system. The lymphatic system is part of the immune system. It is a network of small vessels connected to lymph nodes (glands), which help filter unwanted toxins and waste from the body.

If the cancer cells spread outside the lungs, they are most likely to go to lymph nodes nearby in the chest.



This image was produced by Macmillan Cancer Support and is reused with permission.

Suggested websites

You may be interested in looking for information about lung 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** (cancer.org.nz) and use our links to other good cancer websites, or visit the following websites:

Lung Foundation New Zealand
www.lungfoundation.org.nz/

Lung Foundation Australia
www.lungfoundation.com.au

Cancer Council Australia
www.cancer.org.au

Macmillan Cancer Support (UK)
www.macmillancancersupport.org.uk

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

Benefits and entitlements

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

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

Acknowledgements

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

- **Sean D. Galvin** - Cardiothoracic Surgeon, Capital and Coast District Health Board
- **Brecon Wademan** - Surgeon, Capital and Coast District Health Board
- **Joanna Delahunty** - Clinical Nurse Specialist, Capital and Coast District Health Board
- **Dr David Hamilton** - Consultant Radiation Oncologist, Wellington Blood and Cancer Centre
- **Patricia Wenzlick** - Lung Cancer Nurse Coordinator, Counties Manukau District Health Board
- **Nazma Khan** - Lung Cancer Nurse, Counties Manukau District Health Board
- **Eileen Brown, Julie Holt, Kate Velenski** – Cancer Society Editorial Team
- **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.

Action Plan for Breathlessness

When you are aware of your breathlessness:

1. Tell yourself to stop – pause and breathe out slowly through your mouth.
2. Use positive, reassuring self-talk. (For example, "This will pass, slow down…calm down…I can slow my breathing.")
3. Sigh slowly and gently…letting out a soft sound while you flop and drop your shoulders.
4. Focus on slow and gentle breathing. Make your out-breath twice as long as your in-breath.
5. Put yourself in a position that supports your head and shoulders to relax comfortably (elbows resting on knees or sit/recline well supported).
6. Remind yourself, "Slow down…calm…relax…it will be okay" because you can slow your breathing and get enough air. Allow yourself to feel comfortable and at ease.
7. Breathe out slowly through 'pursed' lips in the shape of an 'O' (as if you were going to blow gently through a straw). This helps you breathe out the old air from your lungs, making room for fresh air.
8. Continue to breathe slowly and gently.
9. Your breathing is slowing. Allow your mind to focus on a feeling or place that helps you feel comfortable and relaxed. Take yourself there while you continue to breathe out slowly in a position that is comfortable for you. Let your body become heavy and loose.

When your breathing has settled:

- Think about breathing in, 'smelling the flowers', through your nose.
- Breathe out slowly and softly through your nose or breathe out slowly and softly through your mouth – enough to lightly flicker a candle flame.
- Feel your breathing deep and low in your body.

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