

Understanding Head & Neck Cancer

Puka matepukupuku upoko me te kaki
A guide for people with head and neck cancer



**Cancer
Society**

Te Kāhui Matepukupuku
o Aotearoa

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About this booklet

This booklet provides you with information about head and neck cancer. It includes the risk factors for head and neck cancer, what head and neck cancer is, and how it is diagnosed.

You can also read about types of treatment and living well during and after treatment. The booklet includes suggested resources to help you manage symptoms of head and neck cancer and the possible side effects of 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 might find most useful, or you can phone the **Cancer Information Helpline 0800 CANCER (226 237)** to talk with our friendly staff.

If you would like a copy of any of the Cancer Society booklets and information sheets you can visit your local Cancer Society office, phone the Cancer Information Helpline, or download these from our website: www.cancer.org.nz

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

Mō tēnei puka

Ka whakarato pārongo tēnei puka ki a koe mō ngā mōhiohio e pā ana ki te matepukupuku upoko me te kaki. Kei roto ko ngā tino take mōrearea mō te matepukupuku upoko me te kaki, he aha hoki te matepukupuku upoko me te kaki, ā, pēhea hoki te whakatau i tēnei mate.

Ka āhei hoki koe ki te pānui i ngā kōrero e pā ana ki ngā momo maimoatanga me te noho ora i te wā e whai ana koe i ngā maimoatanga, me te wā whai muri iho. Kei roto anō hoki ko ētahi rauemi kua whakaarohia hei āwhina ki te whakahaere i ngā tohumate o te matepukupuku upoko me te kaki, me ngā pānga ki te taha o te maimoatanga.

Kua whakarāpopotohia ngā mōhiohio ki roto i ngā 'Meka matua' kei te tīmatatanga o ia tekiona o te puka. Kua whakawhitia hoki ngā kōrero ki te reo Māori.

Tērā pea ka hiahia koe ki te pātai ki tō kapa maimoatanga ko ēhea o ngā tekiona tērā pea ka whai kiko mōu, e āhei ana rānei koe ki te waea atu ki te **Cancer Information Helpline 0800 CANCER (226 237)** ki te kōrero ki tētahi o ā mātou kaimahi hoahoa.

Mehemea e hiahia kape ana koe o tētahi o ngā puka, tētahi o ngā whārangi mōhiohio rānei o te Kāhui Matepukupuku, e āhei ana koe ki te torotoro atu ki te tari Kāhui Matepukupuku o tō rohe, waea atu rānei te Cancer Information Helpline, me tikiake rānei i te mātou paetukutuku: www.cancer.org.nz.

He mea nui ki a mātou ō whakaaro mō tēnei puka. Nō reira, tēnā koa tīmēratia mai ō kōrero, ō whakaaro hoki ki te admin@cancer.org.nz.

My Key Contacts

Date: _____

Diagnosis details: _____

Oncologist Name: _____

Oncologist Contact Details: _____

Nurse Name: _____

Nurse Contact Details: _____

Surgeon Name: _____

Surgeon Contact Details: _____

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Section One: Understanding head and neck cancer

Tekiona Tahi:
Te mōhio ki te
matepukupuku upoko
me te kaki



Key points:

- Head and neck cancer is a general term for a range of cancers that start in the tissue or lymph nodes in the head and neck area.
- The main risk factors for head and neck cancer are drinking alcohol and using tobacco.
- Human papilloma virus (HPV) can increase the risk of cancers in the tongue, tonsil, and throat (oropharynx).
- The symptoms of head and neck cancer can be different from person to person. It is important to have your GP or whānau doctor check any symptoms:
 - A lump (or lumps) in the neck can be the first sign of head and neck cancer. These lumps are generally painless and may slowly get bigger.
 - Some head and neck cancers cause pain, coughing, or changes in swallowing, hearing, vision, or speaking.

Ngā Kōrero Matua:

- He rerenga kōrero whānui te matepukupuku upoko me te kaki mō te whānui o ngā matepukupuku ka tīmata ki te kiko, ki ngā tīpona waitinana rānei kei roto i te upoko, i te kaki rānei.
- Ko ngā āhuatanga mōrearea matua mō te matepukupuku upoko me te kaki, ko te mahi inu waipiro me te momi tupeka.
- He Wheori te Human papilloma virus (HPV) tērā e whakapiki ake i te mōrearea o te puta o ngā matepukupuku ki te ārero, te miramira, me te korokoro (oropharynx).
- Tērā pea he rerekē ngā tohumate o te matepukupuku upoko me te kaki māi ia tangata, ki ia tangata. He mea nui rawa kia tirohia e tō GP, tō tākuta whānau rānei, ki te tiro tiro i ngā tohumate:
 - He tohu tuatahi pea tētahi puku ki te kaki, o te matepukupuku upoko me te kaki rānei. I te nuinga o te wā, noho mamae-kore ai ēnei puku, ā, tērā pea ka piki iti haere nei.
 - Tērā ētahi matepukupuku upoko me te kaki e puta ai he mamae, he maremare, he rerekētanga ki te mahi horomi, te mahi whakarongo, te mahi kite me te mahi kōrero.

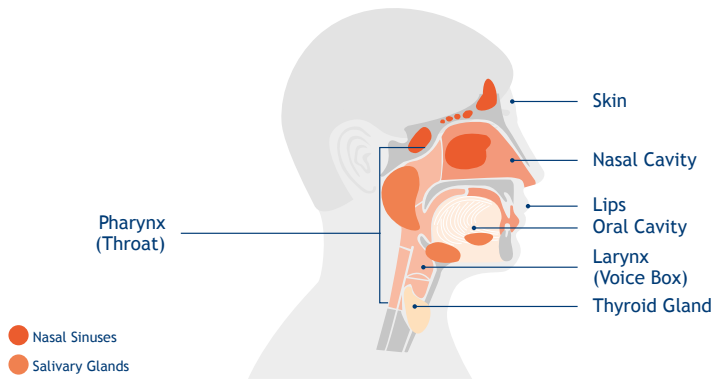
What is head and neck cancer?

Head and neck cancer is a general term for a range of cancers that start in the tissue or lymph nodes in the head and neck area. It includes cancers of the:

- mouth
- tongue
- throat (nasopharynx, oropharynx, and hypopharynx)
- voice box (larynx)
- nose and sinuses
- salivary glands
- skin of the head and neck (including the scalp and ear)
- thyroid.

Cancer that starts in the brain, eye, oesophagus (food pipe), or bones of the head/spine is not usually considered head and neck cancer.

In this booklet, head, neck, and mouth cancer are referred to as head and neck cancer.



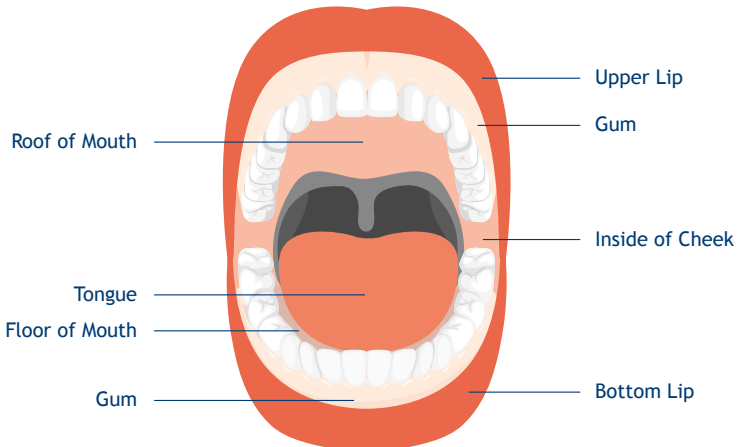
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How head and neck cancers get their names

Head and neck cancers are named after the part of the body where they start.

Mouth cancer (oral cancer)

Cancer that starts in the mouth is called oral cancer. The mouth includes the lips, tongue (the front bit you can see), gums, cheeks, roof of your mouth (hard palate) and floor of your mouth (under your tongue).



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Tongue cancer

The tongue has two parts:

- The part you can see (the oral tongue)
- The part that disappears into the back of your throat and that you cannot see (the base of the tongue)

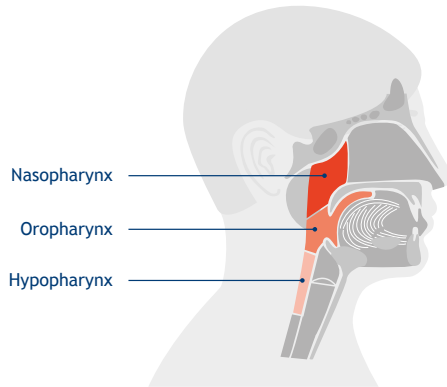
Cancer on the part of the tongue that you can see is called oral cancer.

Cancer on the part of the tongue that you cannot see is called oropharyngeal cancer.

Throat cancer

The throat (pharynx) has three main parts:

- Nasopharynx
- Oropharynx
- Hypopharynx



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Nasopharynx:

The nasopharynx is the top part of the throat that starts behind the nose. Cancer that starts in this space is called nasopharyngeal cancer.

Oropharynx:

The oropharynx is the middle part of the throat that starts behind the mouth. It includes the soft part of the roof of the mouth (soft palate), the part of the tongue you cannot see (tongue base), the tonsils, and the back and side walls of the throat. Cancer that starts in this space is called oropharyngeal cancer. Many oropharyngeal cancers are linked to the Human Papilloma Virus (HPV) (see page 18).

Hypopharynx:

The hypopharynx is the bottom part of the throat that sits behind the voice box (larynx). Cancer that starts in this space is called hypopharyngeal cancer.

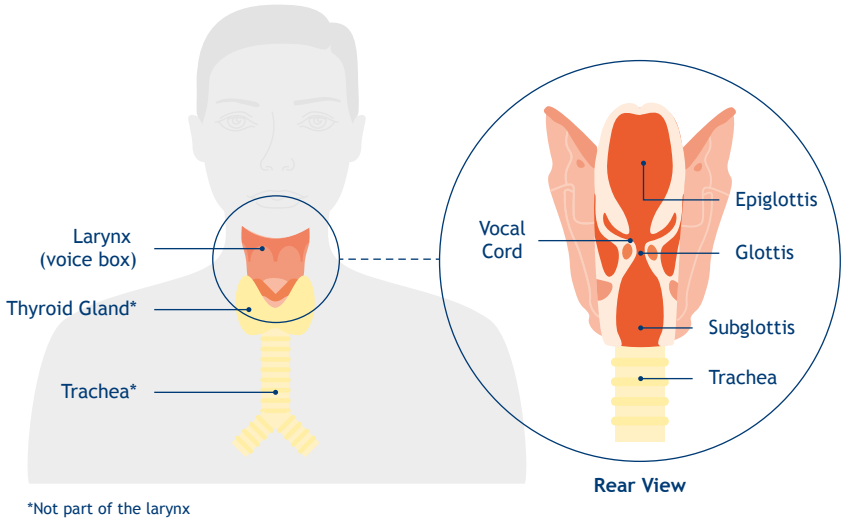
Laryngeal cancer (cancer of the larynx)

Laryngeal cancer affects the larynx. Your larynx is more commonly called your voice box and has two vocal cords inside. When the air you breathe moves past the vocal cords they vibrate—this is how you make different sounds when you speak.

The larynx sits near the entrance to your airway (trachea) in your neck. The epiglottis acts as a flap to cover the trachea when you swallow. This stops the food you eat and drink from entering your lungs.

The larynx has three parts:

- Supraglottis—the space above the vocal cords
- Glottis—the middle of the larynx where the vocal cords are
- Subglottis—the space below the vocal cords that attaches to your airway



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Nose and sinus cancer

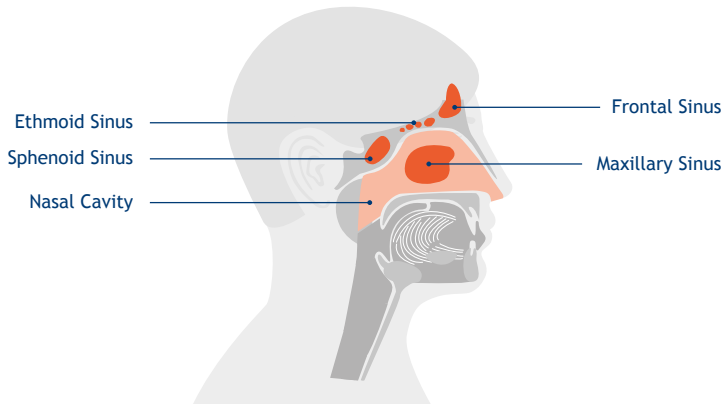
Cancer that starts inside the nose or in the paranasal sinuses is called nasal and sinus cancer.

The space inside the nose is called the nasal cavity. This space warms, moistens, and filters the air that you breathe.

The bones around the nasal cavity have small, hollow spaces in them called paranasal sinuses. The sinuses affect the tone and sound of your voice.

There are usually four pairs of paranasal sinuses (some may be missing or not fully developed):

- Frontal sinuses—behind the forehead
- Ethmoid sinuses—above the nose and between the eyes
- Sphenoid sinuses—behind the nose and between the eyes
- Maxillary sinuses—under the eyes and in the cheek area



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Salivary gland cancer

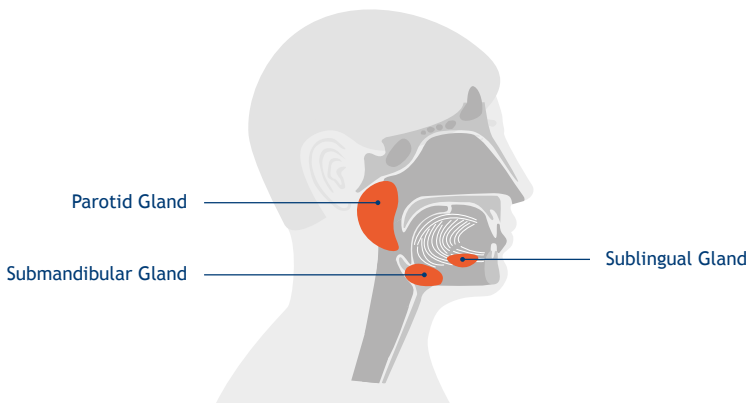
Cancer that starts in any of the salivary glands is called salivary gland cancer.

The salivary glands make saliva (spit), which keeps your mouth moist and makes it easier to swallow food.

There are three main pairs of salivary glands:

- Parotid glands—on each side of the mouth, in front of the ears
- Sublingual glands—under each side of the tongue
- Submandibular glands—under each side of the jawbone

There are many smaller glands in the lining of the mouth and throat. These are known as the minor salivary glands. Most salivary gland cancers start in the parotid glands.



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Non-melanoma skin cancer

New Zealand has a very high rate of both melanoma and non-melanoma skin cancer. The head and neck area is commonly affected due to regular exposure to the sun, often without any skin protection.

Some skin cancers can spread (metastasise) to other parts of the head and neck, such as the lymph nodes and the parotid gland.

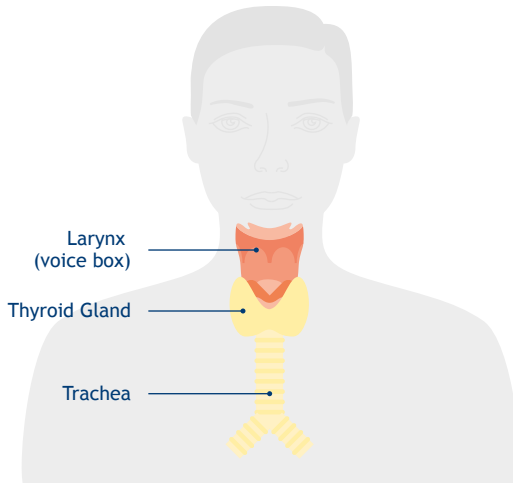


For more information about being SunSmart, visit www.sunsmart.org.nz.

Thyroid cancer

The thyroid gland is located low in the central neck, below the voice box (larynx) and in front of the windpipe. It produces a hormone called thyroxine. Thyroxine helps to regulate your weight, body temperature, growth, and development.

Cancers that start in the thyroid gland are often lower grade and grow more slowly than other head and neck cancers. There are some higher-grade, faster-growing types of thyroid cancer, but these are rare.



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Types of head and neck cancer

Cancers of the head and neck are also named by the type of cell where the cancer first started to grow.







Squamous cell carcinoma (SCC)	Cancer that starts in the cells that line the surfaces of the mouth, nose, throat or skin.	Most common (90%)
Lymphoma	Cancer that grows in the lymphatic system (immune system) and travels to your lymph nodes in your head and neck.	Common For more information on lymphoma, visit www.cancer.org.nz/cancer/types-of-cancer/blood-cancer/
Melanoma	Cancer that grows in the cells that give colour to your skin and eyes. Melanoma can also start in the cells that line the mouth.	Uncommon For more information on melanoma, visit www.cancer.org.nz/cancer/types-of-cancer/skin-cancer/
Adenocarcinoma	Cancer that starts in the glands of the head and neck.	Rare
Sarcoma	Cancer that grows in the blood vessels, cartilage, or muscles in the head and neck.	Very rare For more information on sarcoma, visit www.cancer.org.au/cancer-information/types-of-cancer/rare-cancers/soft-tissue-sarcoma

What are the risk factors for head and neck cancer?

Anything that can increase your chance of developing cancer is called a risk factor. Some risk factors can be changed, such as not smoking. Some risk factors cannot be changed, such as having a strong family history of cancer.

Having one or more risk factor does not mean that you or your whānau will develop cancer. Most people have at least one risk factor but will 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 head and neck cancer include the following:

	Chewing tobacco or betel nut (araca and gutka) increases the risk of developing mouth cancer.
	Contact with certain chemicals and dusts through workplaces can increase the risk of throat cancer (oropharyngeal).
	Head and neck cancers are more common in men than in women.
	Head and neck cancer is more common in people over the age of 50. However, younger people can be affected too.
	HPV can increase the risk of cancers in the tongue, tonsil, and throat (oropharynx).
	If you drink a lot of alcohol (more than 10 standard drinks a week) you increase your risk of developing head and neck cancer. If you smoke and drink alcohol, the risk is even greater.
	Smoking tobacco is the number one risk factor for head and neck cancer. It includes smoking cigarettes, cigars, and pipes. The more you smoke, the greater the risk. People who do not smoke can also get head and neck cancer, but their risk is much lower. The long-term health impacts of vaping are unknown.

The link between throat cancer and Human Papilloma Virus (HPV)

HPV is a group of common viruses that affect the surfaces of different areas of the body, including the throat, cervix, and skin. There are many types of HPV, and most people will be infected at some stage in their lives but will never know that they have had an HPV infection.

Most types of HPV are not linked to cancer. It is important to know that most people infected by HPV do not develop cancer. Usually, the body's immune system gets rid of the virus.

However, some forms of HPV (mainly HPV 16 and HPV 18) increase the risk of developing cancer of the throat (oropharynx). These are called HPV positive head and neck cancers.

HPV immunisation began in New Zealand in 2008. HPV immunisation is free for everyone aged 9 to 26, and for non-residents under the age of 18.



For more information about vaccination against HPV, visit:

www.immunise.health.nz/about-vaccines/nz-immunisations/hpv-human-papillomavirus-vaccine/

Symptoms of head and neck cancer

The symptoms of head, neck, and mouth cancer depend on where the cancer is. In its early stages, head and neck cancer may have no symptoms. Cancer that begins in the head or neck usually spreads to lymph nodes in the neck before it spreads elsewhere.

A lump (or lumps) in the neck can be the first sign of cancer of the mouth, nose, throat, voice box (larynx), or thyroid gland. These lumps are generally painless and may slowly get bigger. Some people feel very tired (fatigue) when cancer is growing.

Common symptoms of head and neck cancer

Mouth (oral) cancer

- Mouth pain or pain swallowing
- A sore or swelling that does not go away
- Unusual bleeding or numbness
- Red or white patches on the gums, tongue, or mouth
- Bad breath
- Changes in speech (difficulty pronouncing words)
- Difficulty chewing or swallowing food
- Losing weight without trying
- A lump in the neck
- Loose teeth, or dentures (false teeth) that no longer fit
- Earache or ringing in the ears

Nasal or paranasal sinus cancer

- Decreased sense of smell
- A blocked nose (especially on one side) that does not go away, or a blocked ear
- Regular nosebleeds
- Increased mucus (snot) in the back of the nose or throat
- Regular headaches
- Difficulty swallowing
- Loose or sore upper teeth
- A lump in the nose or mouth, or on the face
- Pressure or pain in the ears
- A watering or bulging eye
- Double vision
- Loss of sight (vision). Can be complete or partial

Salivary gland cancer	<ul style="list-style-type: none"> • A lump or swelling near the ear, jaw, or lip, or inside the mouth • Sides of the face and neck look different • Difficulty in opening the mouth wide, or finding it hard to swallow • Weakness, drooping, or numbness on one side of the face (palsy)
Pharyngeal cancer	<ul style="list-style-type: none"> • Throat pain or difficulty swallowing • A sore throat or cough that does not go away • Coughing up blood • Bad breath • Losing weight without trying • A change in the sound of the voice that does not go away • Dull pain in the chest • A lump in the neck • Pain in the ear, or regular ear infections • Feeling unable to able to breathe properly • Numbness in the face • Blocked nose • Loss of hearing • Headaches
Laryngeal cancer	<ul style="list-style-type: none"> • A lump or swelling in the neck or throat • A sore throat that does not go away • A change in the sound of the voice that does not go away • Difficulty or pain when swallowing • Constant coughing • Feeling unable to breathe properly • Losing weight without trying • Pain in the ear
Skin	<ul style="list-style-type: none"> • An ulcer or sore that does not heal • Crusting or bleeding of an area of skin

Thyroid

- Swelling of the thyroid gland (goitre)
- Swelling of the lymph nodes in the neck
- Change in voice
- Problems with swallowing or breathing
- Pain in the front of the neck or throat
- A cough that does not go away

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

Section Two: Diagnosing head and neck cancer

*Tekiona Rua: Te whakatau
i te matepukupuku upoko
me te kaki*



Key points:

- If your GP or whānau doctor is concerned that your symptoms may be signs of head and neck cancer, they will recommend further tests.
- The purpose of these tests is to find out whether you have head and neck cancer and, if you do, the type of head and neck cancer you have, and if the cancer has spread to other parts of your body.

Common tests include:

- blood tests
 - imaging tests (scans and X-rays)
 - scopes (endoscopy or nasendoscopy)
 - biopsy
 - HPV testing.
- The results of any tests you have will help your treatment team to decide on the best treatment for you.

Ngā Kōrero Matua:

- Mehemea kai te māharahara tō GP, tō tākuta whānau rānei, tērā pea he tohu ngā whakatao o te matepukupuku upoko me te kaki, ka taunakitia e rātou kia whāia anō he whakamātautau.
- Ko te pūtake o ēnei whakamātautau, ko te rapu mehemea kei te whai koe i te matepukupuku upoko me te kaki, te momo matepukupuku upoko me te kaki kai te whai koe, me te tiro mehemea kua roha ki wāhi kē o tō tinana.

Ko ngā whakamātautau ka whāia, ko ēnei:

- Whakamātautau toto
 - Whakamātautau ata (ngā titiro whakatao me ngā whakaata roto)
 - Ngā Scope (endoscopy, te nasendoscopy)
 - Unuhanga
 - Whakamātautau HPV
- Ka āwhina ngā hua o ngā whakamātautau ka whāia e koe, i tō kapa maimoatanga ki te whakatao i te maimoatanga pai rawa mōu.

Diagnosis

If you have noticed any of the symptoms of head and neck cancer, you will usually see your GP or whānau doctor first. They will talk to you about your symptoms, ask about any risk factors you may have, and give you a physical examination. Sometimes, it might be your dentist who notices a change in your mouth.

If your GP, whānau doctor or dentist is concerned that your symptoms may be signs of head and neck cancer, they will refer you to a specialist doctor for further tests.

The purpose of these tests is to find out if you have cancer and, if you do, the type of head and neck 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.

You may have one or more of the following tests:

Physical examination

The doctor will look carefully at your ears, eyes, mouth, gums, lips, cheeks, throat, tongue, nose, and neck for any changes or lumps. They may also gently feel both sides of your neck to check your lymph nodes.

Ultrasound scan

An ultrasound scan uses soundwaves to build a picture of your neck and lymph nodes.

X-rays

X-rays are used to create digital pictures of your jaw (including your teeth) and chest.

Scopes (endoscopy)

A scope is a thin, flexible tube with a light and camera on the end that is used to look for any changes in your nose, throat, voice box (larynx), and oesophagus (food pipe).

The most common scopes are nasoendoscopies and laryngoscopies.

If needed, a biopsy can be taken while you are having a scope.

Biopsy

A biopsy removes small samples of tissue from your nose, mouth, throat, 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, the information will help your treatment team to learn more about the type of head and neck cancer you have.

There are different ways of getting biopsies from the head and neck area, and your doctor will talk to you about the best options for you.

HPV testing

If cancer cells are seen in your biopsy sample, your doctor may ask for further testing (using the same sample) to see if the cancer cells are positive for high-risk types of HPV.

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 body.

If there is a concern that cancer has spread to other parts of your body, you may have a CT, MRI, or PET-CT scan to find out how much cancer there is in your body and where it is located (staging - see page 27). The results of your tests will help your treatment team to decide on the best treatment for you.

Further tests

Your treatment team may recommend other tests, including:

- general blood tests
- hearing tests
- scans of other body organs such as bones and your liver, brain, and kidneys
- test for other viruses—e.g. Epstein-Barr virus.

Section Three: Staging head and neck cancer

Tekiona Toru:
Te whakawāhanga
matepukupuku upoko
me te kaki



Key points:

- Staging describes the size of your cancer, and if it has spread to lymph nodes or other parts of your body.
- Head and neck cancer is given a number from stage 1 to stage 4. The lower the number, the less the cancer has spread.
- Cancers in the oropharynx (tongue, tonsil, and throat) are staged differently, depending on whether they are linked to HPV.

Ngā kōrero matua:

- Ka whakamārama te mahi wāhanga, i te rahi o tō matepukupuku, mehemea kua roha ki ngā tīpona waitinana, ki wāhi kē rānei o tō tinana.
- Ka hoatuna he tau ki te matepukupuku upoko me te kaki, mai i te 1 ki te 4. Ko te iti ake o te tau, ko te iti ake o te roha o te matepukupuku.
- Ka whakawāhanga rerekētia te oropharynx (te arero, te miramira, te korokoro) e ai ki tōna whai hononga ki te HPV.

Staging head and neck 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).

Cancers in the oropharynx (tongue, tonsil, and throat) are staged differently, depending on whether they are linked to HPV.

Staging is based on the results of tests that you have had, such as scans, biopsies, and surgery. Your treatment team will use the T, N and M information to give the cancer a stage or number from 1 to 4. Stage 1 is the earliest stage and stage 4 is more advanced cancer. Knowing the stage will help the treatment team decide on the best treatment for you.

Your doctor or another member of your treatment team will be able to give you more information about the stage of the cancer. In general:

Simplified staging of head and neck cancers

Stage	Size of cancer and if it has spread	Also called
Stage 1	The cancer is small and found only in one place.	Early or local cancer
Stage 2/3	The cancer has spread to other parts of your head and neck.	Locally advanced cancer
Stage 4	The cancer has spread to other parts of your body.	Advanced, secondary, or metastatic cancer

Section Four: Making treatment decisions

Tekiona whā: Te whakarite
whakataunga maimoatanga



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 head and neck cancer and its stage
 - If the cancer is positive for HPV
 - How treatment will affect your appearance and function (e.g. speech and ability to chew and swallow)
 - Your general health
 - Your personal wishes and goals of care.
- You will be cared for by a team of health professionals.
- Before you visit your treatment team, make a list of any questions that you would like them to answer.
- You can ask another doctor for a second opinion about the cancer or your treatment options if you want to.

Ngā kōrero matua:

- Ka hāngai katoa ngā maimoatanga ka tukuna ki a koe i runga i ngā mōhiohio e wātea ana e pā ana ki te matepukupuku me tō hauora whānui.
- Ka whakawhirinaki te maimoatanga ka taunakitia ki ēnei:
 - Te momo matepukupuku upoko me te kaki, me te wāhanga kua eke
 - Mehemea kua mautika te matepukupuku i te Human Papilloma Virus (HPV)
 - Ka pēhea te whaipānga o te maimoatanga ki tō āhua me tō āheitanga ki te noho ora tonu (arā, te kōrero, te āheitanga ki te ngaungau me te horomi)
 - Tō hauora whānui
 - Ōu ake hiahia whaiaro me ōu ake whāinga manaakitanga
- Ka tiakina koe e tētahi kapa maimoatanga ngaio hauora.
- I mua i tō tūtaki i tō kapa maimoatanga, whakaritea he rārangi o ngā pātai e hiahia ana koe mā rātou hei whakautu.
- E āhei ana koe ki te pātai ki tētahi atu tākuta mō tētahi whakataunga tuarua e pā ana ki te matepukupuku, ki ōu nā kōwhiringa maimoatanga mehemea e hiahia ana koe.

How treatment decisions are made

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

Recommendations will depend on:

- The type of head and neck cancer and its stage
- Whether the cancer is positive for HPV
- How treatment will affect your appearance and function (e.g. speech, ability to chew and swallow)
- Your general health
- Your personal wishes and goals of care.

The treatment team

From the time that you are diagnosed with head and neck 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
- the hospital dentist (and after treatment, your own dentist)
- oncology nurses and cancer care coordinators, who specialise in care for people receiving cancer treatment
- an ear, nose, and throat surgeon or maxillofacial surgeon who specialises in surgery of the mouth, jaw, face, and neck
- a plastic surgeon who specialises in reconstructive surgery of the head and neck
- 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 speech-language therapist who specialises in helping with communication and swallowing problems
- a dietician who helps with nutrition and diet changes during and after treatment.

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

Talking to your cancer treatment team

When you first learn you have head and neck cancer, you may have many questions. Before you visit your treatment team, we suggest that 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 could be helpful to have a support person with you when you visit. See page 72 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 treatment team or your GP or whānau doctor to refer you to another doctor to get a second opinion.

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.



Find more at: 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 appointment. 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 treatment 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 your 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 and decide on what treatment options are best for you.

Contact your treatment team who will be able to give you an indication about the likely waiting time. They can also refer you for additional support if needed e.g. counselling.



To read more about coping with waiting, visit:

www.cancer.org.nz/cancer/living-with-cancer/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 treatments for cancer.

Clinical trials test new and modified treatments to see if they are better than existing treatments. If you are offered a place 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.

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 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: Head and neck cancer treatments

Tekiona rima:
Ngā maimoatanga
matepukupuku upoko
me te kaki



Key points:

- Talk to your treatment team about the things you can do before treatment starts to help with your recovery.
- Before any treatment begins, it is likely that you will need to see a dentist. The dentist will talk to you about how to care for your mouth before, during, and after treatment.
- Depending on the type and stage of cancer, treatment may include:
 - surgery
 - radiation treatment
 - chemotherapy
 - targeted treatment
 - palliative care
 - any combination of these.

- Many people use complementary, traditional Māori, or Pacific therapies alongside their hospital cancer treatment. While many of these therapies are safe to use while you are having hospital treatment, it is always best to discuss what therapies and treatments you are using with both your hospital treatment team and your therapist just to be sure.

Ngā kōrero matua:

- Kōrero ki tō kapa maimoatanga e pā ana ki ngā mea e āhei ana koe ki te mahi i mua i te tīmatatanga o te maimoatanga hei āwhina i tō whakaoranga.
- I mua i te tīmatatanga o ngā maimoatanga, kāore e kore me haere koe ki te kite i tētahi tākuta niho. Māna koe hei kōrero me pēhea te tiaki i tō waha i mua i te maimoatanga, i te wā o te maimoatanga, whai muri hoki i te maimoatanga.
- E ai ki tōna momo me te wāhanga kua eke te matepukupuku, tērā pea ka whāia ko ētahi o ēnei maimoatanga:
 - Hāparapara
 - Maimoatanga iraruke
 - Hahau
 - Maimoatanga whakahāngai
 - Atawhai taurima
 - He kōwhiringa o ēnei
- He maha ngā tāngata whakamahi ai i te haumanu tautoko, te haumanu Māori taketake, ngā haumanu Moana-nui-a-Kiwa rānei, i te taha o ngā maimoa matepukupuku o tō rātou hōhipera. Ahakoa he haumarū te nuinga o ēnei haumanu ki te whakamahi i te wā e whai maimoa ā-hōhipera koe, he pai ake ki te matapaki ko ēhea ngā haumanu, ngā maimoatanga e whakamahi ana koe i te taha o tō kapa maimoa hōhipera me tō kaiwhakatika, kia mōhio tūturu ai koe.

Before treatment starts

Before you are diagnosed with head and neck cancer, you may have already had problems with speech, swallowing, or the health of your teeth and gums.

Your recovery after treatment will depend on many factors. However, there are some things you can do before treatment starts to help in your recovery.

See a dentist

Before any treatment begins, it is likely that you will need to see a dentist. The dentist will talk to you about how to care for your mouth before, during and after treatment.

If you have tooth decay (holes in your teeth) or gum disease, this will need to be sorted before treatment (especially radiation treatment) can begin to reduce the risk of getting an infection.

Improve your diet and nutrition

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, and poultry
- milk and dairy products
- legumes e.g. 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 supplement for your needs.

If you are unable to eat and drink, your treatment team may talk to you about having a PEG feeding tube placed into your stomach to help meet your nutritional needs (see page 63).



Find more at: www.cancer.org.nz/assets/Downloads/Booklet-eating-well-with-cancer.pdf

Avoid or reduce alcohol

If you drink alcohol, stopping drinking or reducing the amount of alcohol you drink can help make your treatment more effective, and reduce the risk of side effects.

If you would like support to reduce the amount of alcohol you drink, your treatment team, GP or whānau doctor can arrange this for you.

Increase your physical activity

Light exercise, such as walking, or keeping up your normal exercise routine will help build strength for your recovery. Do not start a new exercise programme without talking it through with your GP or whānau doctor first.



Find more at: www.cancer.org.nz/assets/Downloads/Booklet-keeping-active-with-cancer.pdf

Stop smoking

Current smokers should stop smoking as soon as possible. This will reduce the risk of complications immediately after surgery, help with your recovery after cancer treatment, and improve your heart and lung health. Stopping smoking will also reduce the risk of developing another cancer in the future.



To find out more visit Quitline: www.quit.org.nz

Treatment options

Your cancer treatment team will advise you on the possible treatments for head and neck cancer. Depending on the stage of the cancer, your state of health, and your choices, treatment may include surgery, radiation treatment, chemotherapy, palliative care, or combinations of these.

Treatment options by cancer type

Mouth (oral) cancer

Lips
Tongue (oral)
Gums
Cheek
Roof of mouth
Floor of mouth

- Surgery (common)
- Radiation treatment (sometimes)
 - Radiation treatment alone
 - Radiation treatment after surgery (adjuvant)
- OR-
- Radiation treatment with chemotherapy (chemoradiation)
- Targeted treatment (cetuximab) alongside radiation treatment may be an option for locally advanced squamous cell carcinoma (SCC) for people unable to have chemoradiation

Nasal or paranasal sinus cancer	Nose Paranasal sinuses	<ul style="list-style-type: none"> • Surgery (common) • Radiation treatment (sometimes) <ul style="list-style-type: none"> • Radiation treatment alone • Radiation treatment after surgery • (adjuvant) <p>-OR-</p> <ul style="list-style-type: none"> • Radiation treatment with chemotherapy (chemoradiation)
Salivary gland cancer	Parotid Sublingual submandibular	<ul style="list-style-type: none"> • Surgery (main treatment) • Radiation treatment (occasionally after surgery)
Pharyngeal (throat) cancer	Nasopharynx Oropharynx Hypopharynx	<ul style="list-style-type: none"> • Radiation treatment (most common) <ul style="list-style-type: none"> • Radiation treatment alone • (adjuvant) <p>-OR-</p> <ul style="list-style-type: none"> • Radiation treatment with chemotherapy (chemoradiation) • Occasionally after surgery • Surgery (sometimes) • Targeted treatment (cetuximab) alongside radiation treatment may be an option for locally advanced squamous cell carcinoma (SCC) for people unable to have chemoradiation
Laryngeal cancer	Larynx	<ul style="list-style-type: none"> • Early laryngeal cancer <ul style="list-style-type: none"> • Surgery • (adjuvant) <p>-OR-</p> <ul style="list-style-type: none"> • Radiation treatment • Advanced laryngeal cancer <ul style="list-style-type: none"> • Surgery followed by radiation treatment (with or without chemotherapy) • Radiation treatment (sometimes followed by surgery)

Skin	Pinna (outer ear) Scalp Face Neck	<ul style="list-style-type: none"> • Early skin cancer <ul style="list-style-type: none"> • Surgery -OR- • Radiation treatment • Advanced skin cancer <ul style="list-style-type: none"> • Surgery followed by radiation treatment (with or without chemotherapy) • Radiation treatment (sometimes followed by surgery)
Thyroid	Thyroid	<ul style="list-style-type: none"> • Early thyroid cancer <ul style="list-style-type: none"> • Surgery to remove half of the thyroid • Advanced thyroid cancer <ul style="list-style-type: none"> • Surgery to remove the thyroid • Surgery followed by radio-iodine in some types of thyroid cancer

Surgery

Many people with head and neck cancer have surgery. Your treatment team will discuss the best surgical options for you.

Surgery may be done for different reasons. You may have surgery to:

- completely remove the cancer
- remove lymph nodes if the cancer has spread to them, or if there is a chance the cancer might spread to them
- reduce pain or ease symptoms (palliative surgery)
- improve your appearance and ability to swallow and/or speak after treatment (reconstructive surgery). See page 42.

Surgery for mouth (oral) cancer

The type of surgery you have will depend on the size of the cancer and where it is in your mouth.

Types of surgery include:

- glossectomy—removes all or part of the tongue
- mandibulectomy—removes all or part of the lower jaw (mandible)
- maxillectomy—removes all or part of the upper jaw (maxilla).

Surgery for nose or sinus cancer

The type of surgery you have will depend on how close the cancer is to any major blood vessels and your brain.

Types of surgery for nose and sinus cancer include:

- craniofacial resection—removes any sinuses and/or bones of the face and head affected by cancer
- maxillectomy—removes part (or all) of the upper jaw (maxilla) and may also remove the top teeth, part of the eye socket, and/or the nasal cavity
- orbital exenteration—removes the eye and surrounding tissue
- rhinectomy—removes all or part of the nose
- endoscopic sinus surgery—removes tissues of the nasal cavity and sinuses using an endoscope that is inserted through a nostril.

Surgery for salivary gland cancer

The type of surgery you have will depend on which salivary glands are affected by the cancer.

Surgery to remove salivary glands can be difficult because many of the nerves of the face and neck are very close to these glands.

Any surgery used to treat salivary gland cancer will remove either all or part of the affected gland and some of the surrounding tissue. Sometimes the surgeon will also remove any nearby lymph nodes.

Surgery for pharyngeal (throat) cancer

The type of surgery will depend on the size of the cancer and where in the throat it is.

Types of pharyngeal surgery include:

- pharyngectomy—removes part (or all) of the pharynx (throat)
- oropharyngectomy—removes some of the oropharynx (the middle part of the throat that starts behind the mouth)
- hypopharyngectomy—removes part of the hypopharynx (the bottom part of the throat that sits behind the voice box (larynx))
- laryngopharyngectomy—removes the voice box (larynx) and most of the pharynx.

Surgery for laryngeal (larynx) cancer

Laryngeal cancer affects the larynx. Your larynx is more commonly called your voice box.

Three types of surgery may be used depending on the size and location of laryngeal cancer.

- Endoscopic resection—used in early-stage laryngeal cancer. Surgery is done using an endoscope.
- Partial laryngectomy—removes part of the voice box. You may need a temporary tracheostomy (breathing tube) during your recovery.
- Total laryngectomy—removes the larynx and sometimes nearby lymph nodes. You will have a hole (stoma) left in your neck to help you breathe. See page 60 for information on tracheostomy.

Ways to talk after a laryngectomy

After a partial laryngectomy you will still have part of your voice box, but you may have some problems with your voice and swallowing.

After surgery to remove your voice box, you will no longer have vocal cords to create a voice, and you may need to learn to speak again in a different way.

Mechanical speech

A battery-powered device called an electrolarynx is used to create a mechanical voice. The device is held against your neck or cheek or placed inside your mouth. You press a button on the device to make a vibrating sound.

Tracheoesophageal puncture speech

The surgeon creates a small hole between your trachea (windpipe) and oesophagus (food tube). A small voice prosthesis or valve is inserted to direct air from your trachea to the oesophagus. This creates a low-pitch, throaty voice.

Oesophageal speech

You swallow air and force it up through your oesophagus to produce a low-pitched sound. This technique can be difficult and needs training with a speech-language therapist.

Surgery for skin cancer

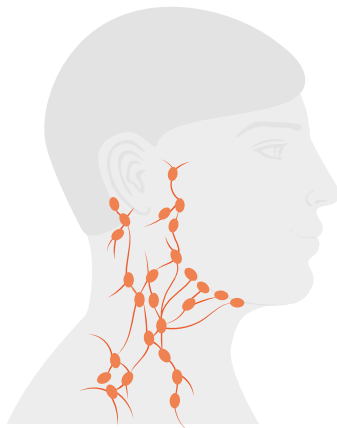
Surgery is the main treatment for cancer that starts in the skin. The type of surgery will depend on the type and stage of cancer.

Surgery for thyroid cancer

Surgery is the most common treatment option for thyroid cancer. It can include:

- hemithyroidectomy—removes half of the thyroid
- total thyroidectomy—removes all of the thyroid
- neck dissection—see page below.

Surgery to remove lymph nodes from the neck (neck dissection)



Lymph nodes in the head and neck area

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

Lymph nodes are small, bean-shaped glands that are found throughout the body. They contain immune cells to help the body fight infection. Lymph nodes also filter lymph fluid. There are more than 300 lymph nodes in the head and neck.

Your cancer treatment team may recommend removing some (or all) of the lymph nodes from one side, or sometimes both sides, of your neck. This surgery is called a neck dissection.

This may be done if:

- tests show that cancer has already spread to the lymph nodes
- there is an increased risk of the cancer spreading to the lymph nodes.

Reconstructive surgery

If a large area of tissue is removed during surgery, you may need additional surgery to rebuild (reconstruct) the area. This is called reconstructive surgery. It is also done if surgery is likely to affect how you swallow or how you look.

You can have reconstructive surgery using:

- a skin graft—a thin piece of skin is taken from another part of your body to cover the place where the cancer has been removed
- a flap repair—skin, and the tissue that is under it, is taken from another part of your body, e.g. your thigh, arm, back, or tummy (abdomen), and attached to the area where the cancer has been removed
- a bone graft—bone from another part of the body (usually the lower leg) is used to replace the area of bone that has been removed. This may be needed if the cancer is in the jawbone
- an artificial replacement—this is known as a prosthesis and uses material such as titanium or silicone to re-create areas such as bones in the face or palate that have been removed. E.g. a dental plate called an obturator can be used to cover gaps in the roof of the mouth.

Recovery after surgery

Recovery from surgery to treat head and neck cancer may take a long time. Your treatment team will talk to you about the benefits and side effects of surgery.

Depending on the type of head and neck cancer, some people recover fully and can gradually return to their usual activities. For others there may be longer-term changes to their appearance and to how they speak, eat, and drink.

Your treatment team may refer you to a rehabilitation service, where you will receive support such as speech-language therapy or physiotherapy. This can help in your recovery and teach you ways to manage any changes you have. Counselling services can also help you to adjust to these changes.

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.



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

When is radiation treatment offered?

Radiation can be used:

- on its own as the main treatment for pharyngeal and laryngeal cancer
- after surgery (adjuvant) to treat any cancer cells not removed with surgery and to reduce the chance of the cancer coming back
- with chemotherapy (chemoradiation) to increase the effects of the radiation
- to improve your quality of life or extend your life (palliative treatment)
- to treat cancer that has spread to other organs such as the brain or bones (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 head and neck 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 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.

Sometimes radiation treatment and chemotherapy are used together. This is called chemoradiation.

Combining the treatments can make the side effects of radiation treatment worse.

Wearing a mask

If you are having radiation treatment to your head and neck, you will have a mask made to keep your head completely still



Image taken from Cancer Society of New Zealand radiation treatment booklet

and in the right position for treatment. It will be made of plastic mesh, so you will be able to see and breathe through it.

Some people find that the thought of wearing a mask throughout treatment makes them feel anxious or claustrophobic. If you have any concerns, talk to your treatment team, as they are experienced in helping people to manage this.

Where radiation treatment is provided

Radiation treatment is available at specialist treatment centres in Auckland, Hamilton, Tauranga, Palmerston North, Wellington, Christchurch, and Dunedin (2023).

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 hospital, or your local Cancer Society can advise you on what help may be available.



You can find more information about the National Travel Assistance Scheme on our website: www.tewhatauora.govt.nz/our-health-system/hospitals-and-specialist-services/national-travel-assistance/

Side effects of radiation treatment for head and neck cancer

People react to treatment in different ways. Side effects are usually temporary, but some may last for several weeks to a few months. They may also be permanent.

These are the common side effects.

- Fatigue (tiredness)—can occur during and after treatment
- Mouth sores
- Dry mouth
- Thick saliva
- Painful swallowing
- Difficulty breathing
- Red and dry skin in the area being treated
- Loss of appetite
- Hair loss in the area being treated

Chemotherapy treatment

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



You may want to read the booklet *Chemotherapy/Hahau*, available on our website www.cancer.org.nz/chemotherapy or phone the Cancer Society Information Helpline at 0800 CANCER (226 237) to ask for a copy to be sent to you.

When chemotherapy is given

Chemotherapy may be given:

- before surgery or radiation treatment to try to shrink the cancer (neoadjuvant)
- alongside radiation treatment (chemoradiation) to increase the effectiveness of the radiation treatment
- after surgery to reduce the chances of the cancer coming back (adjuvant)
- as palliative treatment to reduce symptoms and improve your quality of life or extend your life.

How chemotherapy is given

Chemotherapy is given through a vein (IV) or as tablets. If it is given through 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 need a central venous access device (CVAD) such as a portacath or a peripherally inserted central catheter, which stays in place for the whole of their treatment. It is a fine tube placed in the arm or chest that ends in the large veins inside the chest.



For more information on CVADs, see the Cancer Society's *Chemotherapy, Immunotherapy and Targeted Treatment* booklet, available on our website: www.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 head and neck cancer will receive the same treatment.

Side effects of chemotherapy

The chemotherapy side effects depend on the combination of medications you receive. 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 the hands and feet (peripheral neuropathy)
- sore mouth and ulcers.

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.

The availability of targeted treatment and immunotherapy for head and neck cancer

There have been recent advances in head and neck cancer treatment. Unfortunately, these treatments are expensive and Pharmac has decided not to provide funding for all the treatments that might be helpful for the management of your cancer. 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 targets 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: www.cancer.org.nz/targeted-treatments

Targeted treatment medication travels through the bloodstream. Each medication blocks a specific target, e.g. 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.

In New Zealand, Cetuximab is available and funded to treat locally advanced squamous cell carcinoma (SCC) of the head and neck when people cannot receive the standard chemotherapy medication. It attaches to the surface of the cancer cells to prevent them growing and dividing and is used alongside radiation therapy (2023).

Side effects of targeted treatment

Although targeted treatment reduces harm to healthy cells, it can still have side effects. These depend on the medication used and how your body responds. Some people do not experience any side effects and others have more than one. The more common side effects include:

- skin problems—redness, dryness, flaky skin, rash and swelling
- sore mouth and mouth ulcers
- fatigue
- diarrhoea
- an increase in blood pressure
- problems with bleeding and bruising.

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: www.cancer.org.nz/immunotherapy

Your immune system protects you from infections by killing bacteria and diseases. It also helps to fight cancer. A T-cell is one type of immune cell that does this.

Sometimes 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 head and neck 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 the treatment is to cure the cancer. It is not yet as widely used as chemotherapy and radiation treatment.

In New Zealand, checkpoint inhibitor immunotherapies pembrolizumab (Keytruda) and Nivolumab (OPDIVO), have been approved for use for some people with squamous cell carcinoma (SCC) of the head and neck. These treatments are not currently funded in New Zealand (2023).

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

Side effects of immunotherapy

The side effects of immunotherapy depend on the type of treatment you receive and how your body responds. They will be different from those of other cancer treatments. Immunotherapy can cause flu-like symptoms and your immune system to be over-active, resulting in a range of side effects. This is your body's expected response to the treatment. The more common side effects include:

- Fatigue
- Dry eyes
- Skin rash
- Diarrhoea
- Joint pain.

Supportive care and palliative treatment

Supportive care

Anyone with head and neck cancer may need supportive care. That includes the management of physical symptoms, emotional and spiritual support, and guidance to help them plan ahead.

Supportive care is mostly provided by primary health care teams, Cancer Society support workers, and palliative care services.

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 treatment and care you may 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.



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

Specialist palliative care

You may need extra support if the symptoms you are experiencing are complex or difficult to manage. Your primary care team may refer you to a specialist palliative care service.

Palliative care is often provided by primary health care teams as part of supportive care. It is a good idea to ask for palliative care early rather than wait until things become difficult to manage. This can help to reduce stress for you and your whānau.

Specialist palliative care can be offered at home or in a hospital, rest home, or hospice. Coordinated care is provided by specialist doctors, nurses, social workers, spiritual care workers, and cultural health services. Their services include, for example, helping you with physical and emotional symptoms and helping you to get practical support.

You may also be faced with decisions that are hard to make during your illness. The specialist palliative care team may be able to explain things to you and help you to find answers. In general, specialist palliative care services are free. There may be a charge for hiring some equipment if you are being cared for at home.

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 and mirimiri—therapies that 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

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 treatment 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 either Māori or Pacific traditional healing, please discuss it with your cancer 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. Then the 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 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 treatments

Complementary treatments (sometimes called integrative therapy) are healing practices and products that are not usually part of standard medical care. A few 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.



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

Section Six: Living well with head and neck cancer

*Tekiona ono: Te noho ora
me te matepukupuku
upoko me te kaki*



Key points:

- A diagnosis of head and neck cancer, and side effects of treatment, can cause changes in your everyday life. These may include changes in body image, energy levels, nutrition, work, your financial situation, and your emotional health.
- 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 head and neck cancer.
- A counsellor can help you to discuss your feelings about the impacts 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:

- Ka puta pea he rerekētanga ki ōu mahi ia rā, ia rā, ngā runga i te whakatao o te matepukupuku upoko me te kaki me ngā whai pānga o te maimoatanga. Tērā pea ka puta he rerekētanga ki tō ata tinana, ki ō taumata pūngao, tō kai tōtika, tō mahi, tō tūnga pūtea, me tō hauora hinengaro.
- Mā te rapu huarahi ki te arotau pai ki tō tinana - pērā ki te kai tōtika, te tīmata hōtaka korikori, me te whakamahi whakarerekētanga oranga pai - tērā ka āwhina i a koe noho ora me te matepukupuku upoko me te kaki.
- Ka āhei tētahi kaiwhakarato tohutohu ki te āwhina i a koe ki te kōrero mō ōu kāre-ā-roto e pā ana ki te papānga tērā ka puta nā runga i te whakatao.
- Whai ai ngā hōhipera, huri noa i te motu, i ētahi kaimahi hauora kua whakangungutia, e wātea ana ki te tautoko i ō hiahia ā-wairua, ā-ahurea, ā-whakatūtū hoki.
- Kōrero ki tō tākuta whānau, ki tō Kahui Matepukupuku ā-Rohe rānei, mō ngā ratonga tautoko e wātea ana ki a koe me tō whānau.

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 head and neck cancer.



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

Keeping active

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

It is important to start any new activity slowly and build up gradually. It can be hard to exercise after treatment for head and neck cancer, especially if the treatment has affected your movement.

However, exercise can give you many benefits. The most important thing is to find what works best for you. Maybe you could try exercising in a few short sessions throughout the day rather than in a long single session.

Walking is usually easy to build into your daily routine, or you may choose other activities like yoga or tai chi, which can help to rebuild balance, muscle, and bone strength.



For more information on keeping active, see the Cancer Society's Keeping Active with Cancer booklet, available on our website: www.cancer.org.nz/cancer/living-with-cancer/being-active

Returning to work

Depending on any ongoing effects you are experiencing, you may find it hard to return to work after treatment. If possible, postpone going back to work or, if you need to go back earlier than you would like, consider speaking to your employer about the possibility of making some changes to your work schedule. You might be able to work reduced hours, take regular short breaks, or have lighter duties.



You can find more information on returning to work on our website: www.cancer.org.nz/cancer/living-with-cancer/life-after-cancer-treatment/working-after-your-treatment-is-over

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 head and neck cancer or its treatment, 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 with financial support on our website: www.cancer.org.nz/how-we-can-help/financial-impacts-of-cancer/



The Cancer Society has partnered with Sorted to produce a guide to help people navigate finances during a difficult time. The guide is available here: www.sorted.org.nz/guides/protecting-wealth/managing-your-money-after-being-diagnosed-with-a-serious-or-terminal-illness

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 visit these pages for more information:



- Applying for KiwiSaver hardship withdrawal: sorted.org.nz/guides/kiwisaver/applying-for-a-kiwisaver-hardship-withdrawal/
- Our information sheet, Benefits and Entitlements, available here: 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

It is a good idea to have your advance care planning (see page 49) 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. <ul style="list-style-type: none"> • 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 on your behalf.	Personal care and welfare - the person you nominate can only act on your behalf when you are no longer able to make decisions for yourself. You can only nominate one person for personal care and welfare.



For more information, visit these websites.

- Community Law (www.communitylaw.org.nz)
- Citizens Advice Bureau (www.cab.org.nz)

Finding support

For some people, meeting others who are in similar situations can help decrease feelings of anxiety, isolation, or fear. Support groups and online forums offer you the opportunity to share your experiences and learn different ways to deal 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 head and neck cancer. Counselling can be very useful in helping you and your whānau to 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 whānau, or a friend, of someone diagnosed with head and neck cancer, you are learning to cope with your own feelings and emotions. You may want to help but do not know what to do. Here are some suggestions that may be useful.

- Learn about head and neck 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 your 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 the person with cancer may want their own space, or to talk with their treatment team alone.



The Cancer Society offers a range of resources to support you. For more information on how whānau can help, see the Cancer Society's 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 and friends. This is free to use.



For more information, visit www.supportcrew.co.nz

Caring for someone with head and neck cancer

Supporting or caring for someone with head and neck cancer can be challenging and tiring, and you may have to take on roles within your whānau that are new to you. There are community organisations and services that can support you and your whānau. You could:

- Try to get a good understanding of support services you can access for help. Local hospitals and hospices across New Zealand offer different services. Your GP or whānau doctor, practice nurse, or local Cancer Society can help guide you
- Check what extra services are available in your area, such as help with driving to treatment and medical appointments, online shopping (delivered or click and collect), gardening, and childcare
- Keep a ‘to do’ list, such as for lawn mowing, shopping, and cleaning. That way, when others offer help, you will already have a list of things they could do. Check out the Support Crew service or ask a friend to do this for you. For more information: www.supportcrew.co.nz
- Suggest things that friends can do to give you a break, such as a coffee date, seeing a movie, going for a walk, or simply spending time together
- Find out how others manage in this situation—talk to other supporters or contact Carers New Zealand (www.carers.net.nz) or Cancer Connect and Cancer Chat (<https://www.cancer.org.nz/how-we-can-help/support-we-offer/connecting-with-people-with-similar-cancer-experiences/>)
- Get some support for yourself. Counselling can be very useful in helping you to understand your feelings and develop coping strategies
- Talk to your GP or whānau doctor if you are feeling overwhelmed—it is important not to forget about your own health needs. Keep up your usual health checks, screening programmes, and vaccinations
- Read A Guide for Carers (www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers-spreads.pdf) It has some good information on the help available for people who care for and support whānau with health conditions.

Section Seven: An A-to-Z guide to managing symptoms and side effects of head and neck cancer



A

Appearance changes

Changes to your appearance may leave you feeling less confident, especially if you have had surgery to remove part of your face or jaw.

Sometimes reconstructive surgery can be done. This aims to give you the best possible function and appearance after treatment. Surgical scars will fade in time and are often planned to fit into the natural lines of your face and neck.

Your treatment team will talk to you about the changes you may experience after treatment. They can also suggest ways to help you cope with any changes and refer you to support services as needed.

You may like to get in touch with the Look Good Feel Better programme. This free programme for men and women explains how to use skin care, hats, and wigs to help restore appearance and self-esteem during and after treatment. www.lgfb.co.nz.

Appetite changes

Some treatments to the head, neck, nose, and mouth may affect your appetite.

After some treatments you may lose your sense of taste. Other people find that food can taste salty or metallic. This can affect your appetite, and you may lose weight.

Your sense of appetite may improve slowly over several months. Sometimes it is a permanent change.

Making food look appealing, or using different textures, may help to improve your enjoyment of food. A dietician or speech-language therapist may be able to help.

Tip: Try a nutritional supplement drink if you have lost your appetite for food or you are finding it difficult to eat.

Arm weakness/shoulder stiffness

Sometimes surgery that removes the lymph nodes in your neck can affect the nerves in your shoulder. This can make your arm feel weak and your shoulder stiff. It usually resolves over time. A physiotherapist will be able to give you exercises to help improve your strength.

B

Breathing changes

Depending on the location of the cancer, you may have difficulty breathing. People with nasal cancer may find it hard to breathe through the nose. People with cancers of the throat and larynx may feel it is hard to get enough air in.

To help you breathe you may need a tracheostomy (breathing tube) at the front of your neck. This may be:

- temporary—to help bypass the cancer or after radiation treatment if your throat swells
- permanent—if your voice box (larynx) has been removed (laryngectomy).

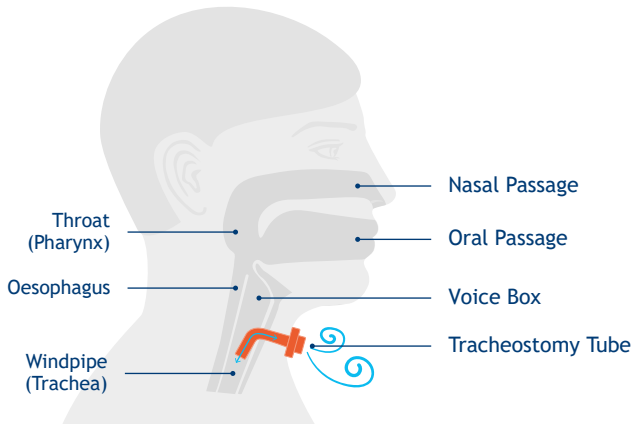
What is a tracheostomy?

A tracheostomy is a small hole in the lower part of your neck that goes directly into your trachea (windpipe). It is held open by a small plastic tube.

While you have a tracheostomy, you cannot usually talk with the tube in place. You will need a pen and paper, a mobile phone, or a laptop to communicate.

If you need a permanent tracheostomy, a speech-language therapist will teach you how to talk and swallow.

A physiotherapist will show you exercises and ways to clear your airway to help when you have a cold or cough.



D

Dental problems

If you need any teeth removed, this will need to be done before starting radiation treatment to allow time for the gums to heal.

It is not unusual to have ongoing problems with your teeth after head and neck treatments due to a lack of saliva. Saliva cleans and protects teeth from decay. Using a daily fluoride toothpaste or mouthwash will help. You should see your dentist for a checkup every 4-6 months.

Drinking water, chewing sugar-free gum, and avoiding sucking sugary sweets or drinks will help prevent decay. It is also important to brush your teeth several times a day with a soft toothbrush.

Depression

Low mood or depression can be common when you have head and neck cancer, especially if you have experienced physical changes such as a change in your facial appearance or the permanent loss of sight, taste, or smell, or you are unable to communicate like you did before.

If you or the people around you are concerned about how you may be feeling, talk to your treatment team or GP or whānau doctor for support. Counselling may be

useful to help you adjust to some of the changes or feelings that you are experiencing.

Dry mouth (xerostomia)

A dry mouth can be caused by radiation treatment to the head and neck and may be permanent. A dry mouth makes it harder to keep your mouth and teeth clean. Saliva protects teeth and gums, so a lack of saliva may increase tooth decay. Using a fluoride toothpaste and simple salt and bicarbonate of soda mouthwash regularly may help.

Tips:

- Ask your treatment team about products such as artificial saliva, enzyme gels, mouthwashes, lozenges, and lubricants to help keep your mouth and lips moist.
- Try sipping cool drinks during the day. Carry a bottle of water with you. Avoid sugary, alcoholic, or acidic drinks.
- Avoid very dry food like crackers.
- Use sauces or gravy to make food moist and easier to swallow.
- Avoid sucking sugary lollies; instead, try sugar-free gum to reduce tooth decay.
- Smoking can make a dry mouth worse, so try to give up or cut down.

F

Facial palsy

If the nerves in the face are damaged during treatment, it can affect how the muscles in your face move. You may be unable to smile, frown, or close an eye, or your face may droop.

Depending on the area that is affected, the way your face moves and how it looks might be able to be improved with procedures such as nerve transfers and Botox injections. This will only be considered once you have recovered from treatment.

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. Family, 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 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 trying to eat a meal. If you have nausea, have your meals when you feel like eating.
- Fatigue may be caused by some specific things that can be found in blood tests and may be improved by treatment.

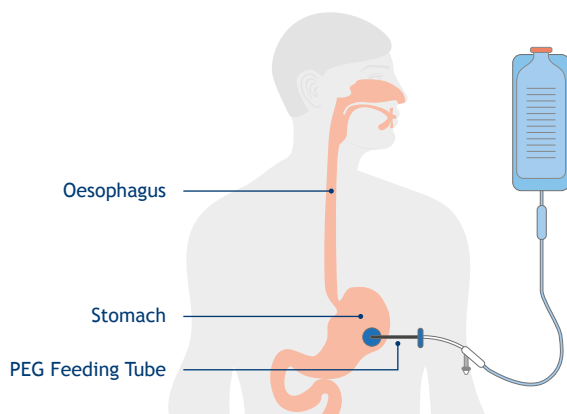
Feeding Tubes

If you are unable to eat and drink, your treatment team may suggest you have a feeding tube put into your stomach to make sure you get enough nutrition. This is usually temporary but, in some cases, it may be permanent.

Feeding tubes can be managed at home with support and guidance from your treatment team.

The most common type of feeding tube used in head and neck cancer is called a PEG (Percutaneous Endoscopic Gastrostomy) tube. The PEG tube goes into your stomach through an opening made on the outside of your tummy (abdomen).

Your dietician will prescribe special liquid nutrition that will go straight into your stomach through the PEG tube. You will be told what other fluids and medications can be put through the PEG tube.



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Fertility

Some cancer treatments can affect your fertility, so you may not be able to have children in the future. Depending on your age and wishes before treatment, there may be some fertility-preservation options available. Ask your treatment team about fertility as early as possible, as it may mean you have more options for protecting or preserving yours.



www.cancer.org.nz/cancer/cancer-treatment/side-effects-of-cancer-and-treatment/fertility-effects

H

Hearing changes

Your hearing may be affected by surgery or chemotherapy. You may experience hearing loss or difficulty hearing high-pitched sounds, or hear a ringing or buzzing sound (tinnitus). If you notice any changes in your hearing, let your treatment team know straight away.

If your hearing loss is likely to be permanent, your treatment team can refer you to an audiologist (a person trained in hearing loss). They will test how much hearing loss you have and recommend ways to help.

Getting used to changes in your hearing can take time, but there are some things you can try that may make it a little easier.

Tips:

- Let people know that your hearing is not as good as it used to be and ask them to look at you when you are talking with them.
- Try to reduce background noise (TV, radio) when you are talking with people.
- If you are in a group situation, sometimes asking one person to relay the conversation to you may be helpful.

If you are experiencing tinnitus, Tinnitus Australia has a lot of useful self-help tools and information available on its website www.tinnitusaustralia.org.au.

I

Intimacy and sex

Head and neck cancer can affect your sexuality in emotional and physical ways.

Treatment for head and neck cancer can affect your self-esteem and ability to express your desires, and make kissing or oral sex difficult or less enjoyable.



See our booklet www.cancer.org.nz/assets/Booklet-sex-and-cancer-2.PDF

If the cancer was HPV related (see page 18) you and your partner may be worried about them getting HPV from sex. Research shows it is not usual for long-term partners of people with oral HPV to get HPV related cancer themselves. New partners may be at risk and may want to use condoms, but for most people the virus is cleared by the immune system. www.hpv.org.nz

J

Jaw changes

Jaw stiffness (trismus)

Sometimes radiation treatment and/or surgery cause some face muscles to become stiff. This is called trismus.

The stiffness can mean that you are not able to open your mouth wide. This can affect eating, speech, and oral hygiene.

A speech-language therapist can show you some simple mouth-opening exercises to help keep your mouth and jaw as flexible as possible.

Changes to the jawbone (osteoradionecrosis)

Radiation treatment to the head and neck can sometimes affect the blood supply to the jawbone. If the bone is further damaged by surgery or the removal of teeth, or if dentures are irritating the jawbone, a very rare condition called osteoradionecrosis can develop.

If you notice any problems with your teeth or gums, or swelling, pain, heaviness, or numbness in your jaw after radiation treatment, it is important to get it checked immediately by your GP or whānau doctor or your dentist.

L

Lymphoedema

Lymphoedema is swelling in an area of the body caused by the lymph vessels being removed or blocked. It is a long-term side effect of some treatments for head and neck cancer.

If you have had radiation treatment or surgery to remove lymph nodes, there is a risk of developing lymphoedema in your face and/or neck. The risk increases if both sides of your neck have been treated. Sometimes the symptoms of

lymphoedema can take months or years to develop, although some people who are at risk never develop it.

The main symptoms of lymphoedema may come and go. They include swelling and redness, and your skin may feel warmer to touch.

Sometimes the swelling develops internally and is hard to see. If this happens, the area may feel different—some people describe it as a mild tingling sensation.

Lymphoedema is easier to manage if it is treated early, so it is important to see your GP or whānau doctor if you notice any of these symptoms.

The best treatment for lymphoedema is a programme of exercise, massage, skin care and medical taping, and sometimes a properly fitted compression garment. Damage to the lymph nodes means it is not usually possible to reverse the swelling, so the aim of treatment is to manage the swelling on a long-term basis.



To find a lymphoedema therapist near you, follow the link to the Lymphoedema New Zealand website: www.lymphoedemanz.org.nz



See our information sheet www.cancer.org.nz/assets/Downloads/Info-sheet-living-with-lymphoedema.pdf

M

Mouth pain (mucositis)

Soreness in the mouth is commonly called oral mucositis. It is often caused by chemotherapy and radiation treatment.

Mucositis can make any part of your mouth red, sore, and ulcerated. It is painful and can make eating, swallowing, and talking difficult.

Your treatment team can prescribe medications to help reduce the pain. If the pain is not well managed and you are having difficulty eating or drinking, let your treatment team know. They may recommend a feeding tube for a short period of time until treatment ends.

If you have a sore mouth, the following suggestions may be useful:

- Try eating soft or pureed foods, such as soup, smoothies, and yoghurt.
- Avoid eating hot, spicy, or very cold food and drink.
- If eating and drinking is painful, you may benefit from a nutritional supplement drink. Talk with your dietician to get the right supplement for your needs.
- Use a salt and bicarbonate mouthwash regularly throughout the day.

- Keep your teeth, gums, and mouth clean using a soft toothbrush and fluoride toothpaste to reduce the risk of a mouth or throat infection.
- Take pain relief before meals as prescribed.
- Avoid alcohol and tobacco as they can irritate the lining of your mouth and throat.

MOUTHWASH RECIPE

1. Add 1 tsp of salt and 1 tsp of baking soda to 1 litre of water.
2. Mix well until dissolved.
3. Store in the fridge and discard after 24 hours.
4. Use as a mouthwash and rinse mouth as required. Spit it out—do not swallow.

The mix is a good cleanser. It helps healing, helps to break down thick saliva, and reduces tooth decay.

Use often during the day, after food, and before going to sleep at night.



For more information, see www.cancer.org.nz/assets/Downloads/Info-sheet-eating-and-mouth-problems.pdf

N

Nutrition

People with head and neck cancer may find eating difficult and experience weight loss. Eating well can increase your energy and helps you to cope with the side effects of treatment.

If you are unable to eat and/or drink enough to meet your nutritional needs, you will be referred to a dietician for individual support.

If you have tried increasing your food and fluid intake but are still finding it difficult, your dietitian may suggest you try using nutritional supplement drinks. Some supplement drinks are available from supermarkets, and others from pharmacies. You may be able to get prescriptions for some of these after an assessment by your dietician.

If your nutritional needs are still unable to be met, your treatment team may suggest a feeding tube (see page 63).

P

Pain and discomfort

Not everyone will have pain or discomfort that continues after treatment. If you do, it can usually be well managed by taking pain-relieving medications regularly. Tell your treatment team if the pain continues so they can help.

If lymph nodes are removed or treated with radiation therapy, you may have pain, stiffness, and numbness in your neck and shoulder. This may make neck movements like lifting an arm difficult.

Ask your treatment team or physiotherapist for exercises to help manage and reduce the pain. They may suggest ways of positioning your body to reduce pain and stiffness. Sometimes the numbness will be permanent.

S

Smell changes

Some treatments to the head, neck, nose, and mouth may affect your sense of smell.

If you have had surgery to remove cancer from the bones of your face, or your sinuses, you may lose your sense of smell.

Your sense of smell may improve slowly over several months. Sometimes it is a permanent change.

Making food look appealing, or using different textures, may help to improve your enjoyment of food. A dietician or speech-language therapist may be able to help.

Tips:

- Use ready-made meals or ask someone else to cook for you if cooking smells bother you.
- If losing your sense of smell has decreased your appetite, you may want to try a nutritional supplement drink.
- If your sense of smell has changed:
 - check food expiry dates
 - check regularly that the smoke detectors in your home are working.

Speech or talking

Your ability to talk may be affected by the cancer and/or cancer treatment. After treatment, you may lose the ability to speak clearly or experience changes in your voice. These changes will depend on where the cancer is located and the type of treatment you have.

Tips:

- Work with a speech-language therapist to improve your speech and learn strategies for communicating with your family and friends.
- Do speech therapy exercises to improve the strength and range of motion of your lips, tongue, jaw, and larynx.
- Use technology (e.g. a computer, tablet, or mobile phone) to write and send notes. NZ Relay helps people who have difficulty speaking to connect with friends and whānau over the phone. Visit www.nzrelay.co.nz for more information.

Sticky mucus

Your mouth may now have mucus that is thick and sticky. Keeping your mouth clean and moist and using a salt and baking soda mouthwash regularly may help. Have tissues ready in case you wish to spit out the mucus. Should the mucus change colour to green/yellow/brown tell your GP/whānau doctor or treatment team. See page 67 for a mouthwash recipe.

Stiff neck

After a neck dissection you may have stiffness or weakness in your shoulders. This is because the nerve that helps shoulder movement may have been affected by surgery. A physiotherapist will give you exercises you can do to help improve this.

Swallowing

Many people with head and neck cancer have problems swallowing (dysphagia). Signs of difficulty in swallowing may be:

- you are taking longer to chew and swallow food
- you are coughing or choking while drinking or eating
- food is sticking in your mouth.

You may have trouble swallowing before, during, and after treatment and it may be caused by the cancer itself or the treatment. Ask to see your speech-language therapist early in your treatment so they can support you with exercises and techniques to help keep your swallowing safe.

Swallowing and chewing involves the lips, teeth, tongue, and muscles of the mouth, face, jaw, and throat. Swallowing is an important function to help maintain weight.

If you are finding it difficult to swallow, you may like to:

- speak to a speech-language therapist
- talk with a dietitian or a speech-language therapist about the best foods to eat and different textures to try

- ask if there are any medications you could try to help reduce any pain you have when swallowing
- do face and mouth exercises regularly to improve the muscles in your head and neck
- if it is safe, continue to eat and/or drink during treatment to keep the muscles that help you to swallow working.

T

Taste changes

Some treatments to the head, neck, nose, and mouth may affect your sense of taste. Your sense of taste may improve slowly over several months, but sometimes it will change permanently.

Making food look appealing, or using different textures, may help to improve your enjoyment of food. A dietician or speech-language therapist may be able to help.

Tips:

- Try adding fresh herbs or flavourings to food.
- Clean your mouth and teeth before and after eating.
- If you are a smoker, stopping smoking will help to improve your sense of taste.

Trismus

See page 65.

V

Vision changes

If an eye has been removed, the empty eye socket will be replaced with a sphere of tissue from another part of your body. This is temporary and is used to keep the shape of the eye socket so you can be fitted with an artificial eye when you have recovered from surgery.

You will still be able to see with your remaining eye, but your peripheral (side) vision and depth perception will change, and your balance may be affected. These changes should not prevent you from continuing activities such as driving and

playing sports, but they may take time to get used to.

Before you start driving again you may need a medical certificate from your doctor or optician for Waka Kotahi NZ Transport Agency.

W

Weight loss and malnutrition

The side effects of cancer and its treatments can make it hard to maintain your weight.

Even a small amount of weight loss over a short period of time can cause malnutrition.

Malnutrition is when you are not able to get enough vitamins and nutrients from the food you eat to keep your body healthy and to maintain your weight. Making changes to your diet and adding a supplement drink may be all you need. Some people need additional support to help maintain their nutrition, such as feeding tubes.

Tips:

- Let the treatment team know if you are losing weight or in pain or have problems swallowing.
- Try eating several small meals throughout the day rather than three large ones.
- Try to eat high-energy, high-protein foods at each meal or snack, e.g. drink milk or add cheese to meals.
- Talk to your treatment team or a dietician if you are having difficulty maintaining your weight. They will be able to talk to you about the different nutritional supplements that are available.

There is more information on our website: www.cancer.org.nz/cancer/living-with-cancer/managing-your-weight.

Questions you may wish to ask

When you find out that you have head and neck 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 them know if there are things you do not want to be told.

- What type of head and neck cancer do I have?
- What grade is it?
- What scans do I need?
- What treatment do you advise for my head and neck 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?
- Are there any clinical trials that I could be eligible for?
- What are the risks and possible side effects of each treatment?
- Will I have to stay in the 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 cancer 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” or
- “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?

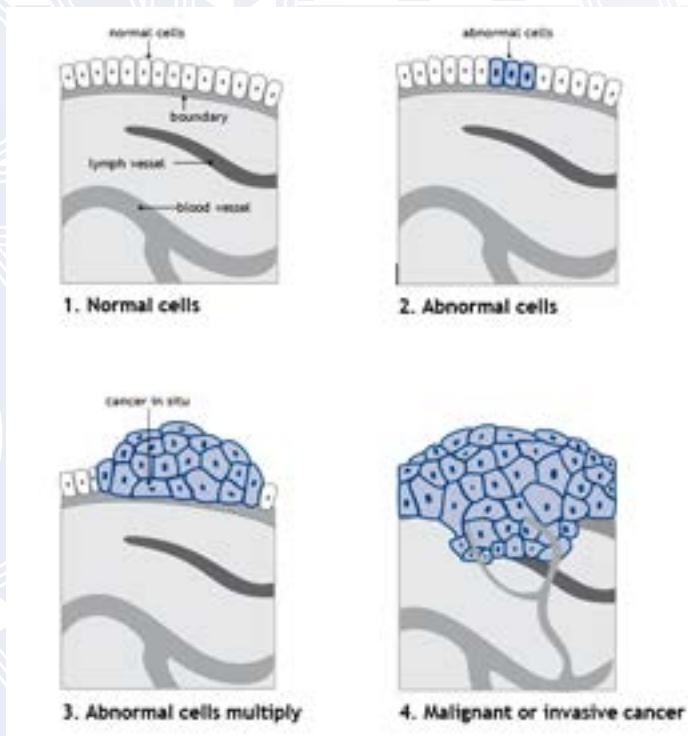
Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells, or heal damaged cells after injury.

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.



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 advanced cancer, secondary cancer, metastatic cancer or stage 4 (IV) cancer. For example, if lung cancer spreads to the bone, it is called lung cancer with bone metastasis.

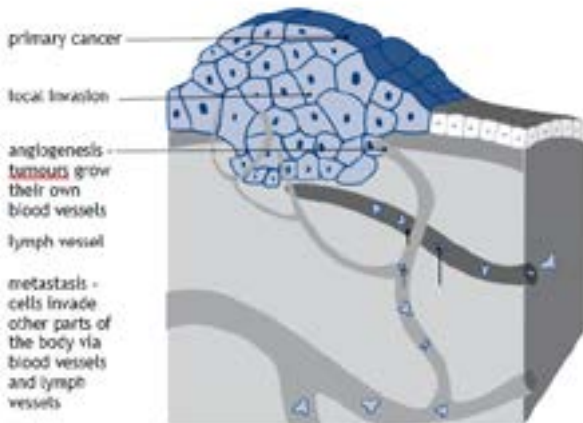
If the only place of spread is nearby lymph nodes, it is called regional nodal spread. Your cancer doctor will still refer to it as lung cancer even though it has spread to another part of your body.

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, chemotherapy, immunotherapy, targeted treatments, hormone treatments and palliative care.

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 head and neck 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:

Changing Faces

changingfaces.org.uk

Head and Neck Cancer Alliance

headandneck.org

Head and Neck Cancer Australia

headandneckcancer.org.au

Head and Neck Cancer Support Aotearoa

hnca.org.nz

Head and Neck Cancer Support Network

headandneck.org.nz

NZ Relay

nzrelay.co.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](#)

[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](#)

[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
74 Langdons Road

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

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 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

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 @cancersocietynz



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