

Understanding Brain Tumours

Te whai māramatanga mō ngā puku roro
A guide for people with a brain tumour



**Cancer
Society**

Te Kāhui Matepukupuku
o Aotearoa

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About this booklet

This booklet provides you with information on what a brain tumour is, how brain tumours are diagnosed, the different types of brain tumours, and how they are treated. There is also a section on living well during and after treatment.

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

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

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

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

Ngā kōrero mō te pukapuka nei

Whakarato ai tēnei puka i ngā mōhiohio e pā ana ki te āhua o te puku roro, pēhea whakatau ai te puku roro, ngā momo puku roro rerekē, me te āhua whakamaimoatia ai. Kei roto anō hoki ko tētahi tekiona mō te noho ora i te wā o te maimoatanga, me te wā whai muri hoki.

Kua whakarāpopototia ngā mōhiohio ki roto i ngā 'Kōrero matua' kei te tīmatatanga o ia tekiona o te puka. Kua whakamāoritia anō hoki aua kōrero matua.

Tērā pea ka hiahia koe ki te uiui i tō rōpū maimoatanga e pā ana ki ngā tekiona whaihua ake mōu. Ka āhei koe ki te waea atu ki te **Cancer Information Helpline 0800 CANCER (226 237)** ki te kōrero ki tētahi o ā mātou kaimahi hoahoa.

Ka taea e koe te tono kape o ngā puka me ngā whārangi mōhiohio a te Kāhui Matepukupuku mai i tō Kāhui Matepukupuku ā-rohe, mā te waea atu ki te Cancer Information Helpline, mā te tikiake i tō mātou paetukutuku: cancer.org.nz.

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

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Section One: Understanding brain tumours

Tekiona Tahi

Te whai māramatanga mō
ngā puku roro



Key points:

- The brain is the control centre of the body. It helps us to think, feel, learn, and move. It also controls our memory, personality, and behaviour, and helps regulate important body functions such as breathing and heart rate.
- A brain tumour is the growth of abnormal cells in a part of the brain.
- Primary brain tumours may spread to other parts of the nervous system but do not usually spread to other parts of the body.
- Symptoms depend on how slowly or quickly the tumour grows and where it is in the brain.

Ngā kōrero matua:

- Ko te pū whakahaere o te tinana te roro. Ka āwhina i a tātou ki te whakaaro, ki te rongō, ki te ako me te nekeneke haere. He whakahaere anō hoki i ō tātou pūmahara, ō tātou tuakiri, o tātou whanonga me tōna āwhina ki te whakarite i ētahi mahinga nui o te tinana pērā ki te mahi whakahā, me te tere o te manawa.
- Ko te tipu o ngā pūtau tino rerekē ki tētahi wāhi o te roro, te puku roro.
- Tērā pea ka hōrapa haere ētahi puku roro ki ētahi atu wāhi o te pūnaha io tōpū engari, i te nuinga o te wā, kīhai e hōrapa ki wāhi kē o te tinana.
- Ka hāngai ngā tohumate ki te pōturi, ki te tere rānei o te tipu o te puku, me te wāhi e tau ana ki roto i te roro.

What is a brain tumour?

A brain tumour is a growth of abnormal cells in a part of the brain. The growth is known as a tumour. Brain tumours can be primary or secondary (metastatic), depending on where they start.

Primary brain tumour

A brain tumour that starts in the brain is called a primary brain tumour. Primary brain tumours may spread to other parts of the nervous system, but do not usually spread to other parts of the body.

Secondary (metastatic) brain tumour

Secondary brain tumours are made up of cancer cells that start in another part of the body. For example, lung cancer that spreads to the brain is called lung cancer with brain metastases.



This booklet is about primary brain tumours.

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

What is the brain?

The brain is the control centre of the body. It helps us to think, feel, learn, and move. It also controls our memory, personality, and behaviour, and helps regulate important body functions, such as breathing and heart rate.

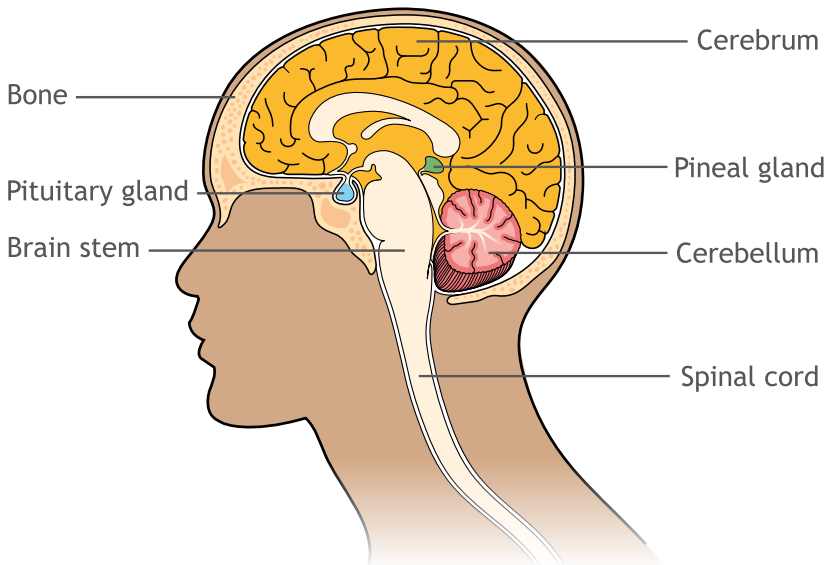
It is made of billions of nerve cells called neurons. Neurons are held in place by supporting cells called glial cells. There are different types of glial cells, including astrocytes, oligodendrocytes, and ependymal cells.

How is the brain connected to the rest of the body?

The brain is connected to the rest of the body by the spinal cord. The brain and spinal cord are known as the central nervous system (CNS).

The spinal cord is a long column of nerves down the middle of the spine (backbone). It starts at the base of the brain and goes down to the small of the back. The nerves from the spinal cord send messages back and forth between the brain and the rest of the body. The bones of the spine (vertebrae) protect the spinal cord.

The brain and spinal cord are covered by three thin membranes called meninges. The spaces between the meninges are filled with a watery fluid called cerebrospinal fluid (CSF), which cushions the brain and spinal cord. The brain is also protected by a covering of bone called the skull.



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

Parts of the brain

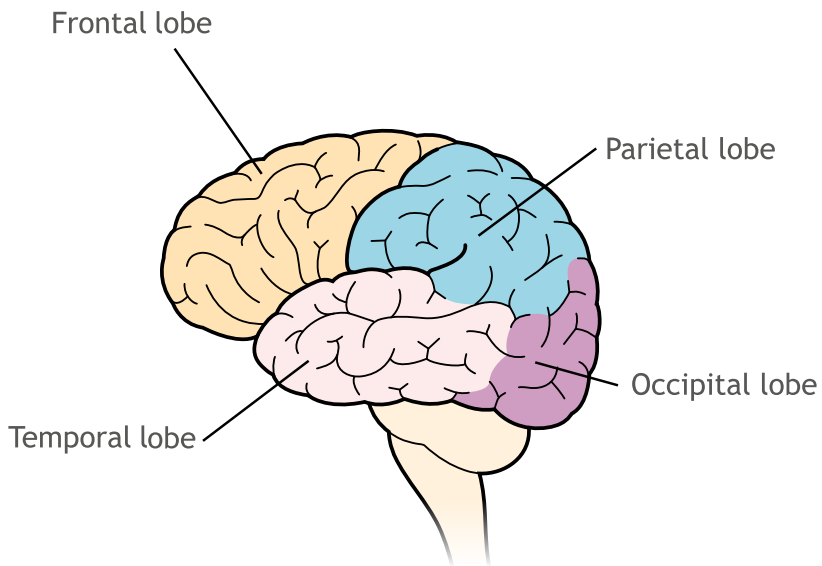
The main parts of the brain are the cerebrum, cerebellum, brain stem, cranial nerves, and pituitary and pineal glands.

Cerebrum

The cerebrum is the largest part of the brain and is made up of two halves, called hemispheres. The right half of the cerebrum controls the left side of the body, and the left half of the cerebrum controls the right side of the body.

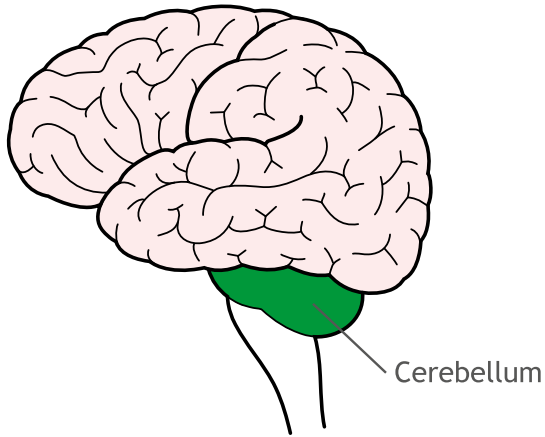
Each half of the cerebrum is divided into four areas, called lobes, which control different body activities.

- Frontal lobe: emotions, personality, thinking, and planning
- Temporal lobe: understanding sounds and memory
- Parietal lobe: awareness and understanding of the things around you
- Occipital lobe: vision



Cerebellum

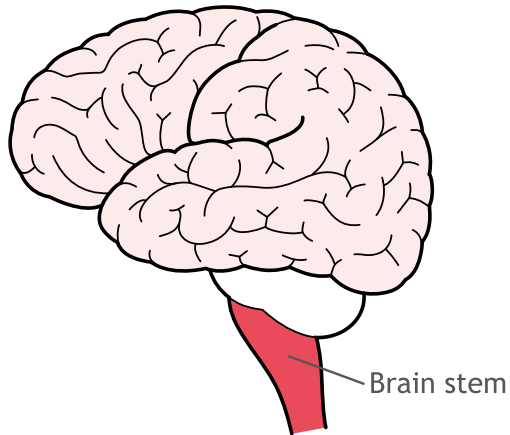
The cerebellum is below the cerebrum, at the back of the brain. It controls balance and coordination.



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

Brain stem

The brain stem connects the brain to the spinal cord. It controls basic body functions that keep us alive, including breathing, blood pressure, and temperature.



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

Cranial nerves

Cranial nerves run from the brain and the brain stem to the eyes, nose, ears, tongue, face, and shoulders. The nerves carry messages about sensations such as taste, smell, sight, and hearing to the brain.

The pituitary gland

The pituitary gland is a small gland the size of a pea, found behind the nose and just below the base of the brain. It makes hormones, which are chemical messengers that control how your body works. The pituitary gland also controls hormones made by many other glands of the body.

The pineal gland

The pineal gland is a small gland found deep in the brain. It makes melatonin, the hormone that helps control sleep.

What are the risk factors for a brain tumour?

Anything that can increase your chances of cancer is called a risk factor. Having one or more risk factors does not mean that you or members of your whānau will develop cancer. Most of us have at least one risk factor but may never develop cancer. Others with cancer may have no known risk factors.

Risk factors that we know make some people more at risk of a brain tumour than others include:

- age – most types of primary brain tumour are more common in older people
- gender – men are more likely than women to develop most types of primary brain tumour
- inherited or genetic conditions – some brain tumours are more common in people with certain rare inherited or genetic conditions, such as neurofibromatosis and Lynch syndrome
- previous radiation treatment to the head.

Symptoms of a brain tumour

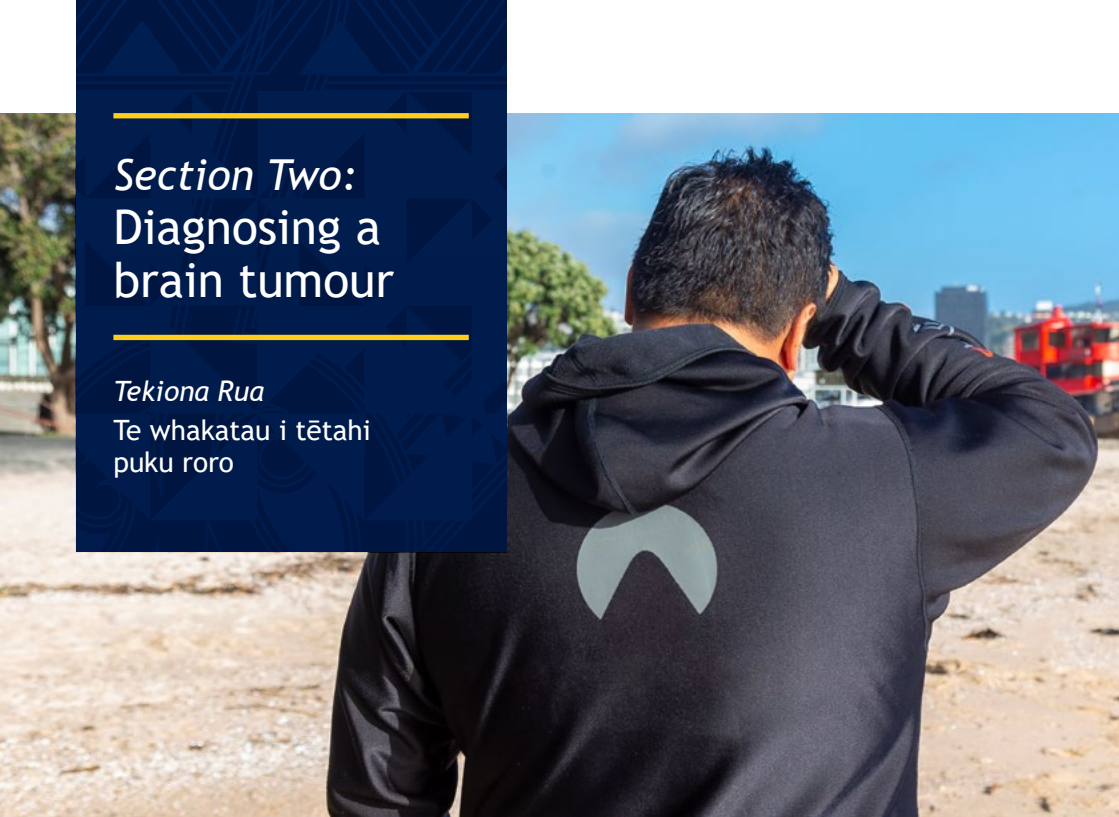
Symptoms depend on how slowly or quickly the tumour grows, and where it is in the brain. They may include:

- weakness in part of the body
- loss of balance or coordination
- feeling sleepy (drowsy)
- changes in memory
- personality or behaviour changes
- changes in thinking, including difficulty in recognising words
- changes in speech or vision
- blackouts, or a fit known as a seizure, which can be severe (body convulsion) or mild (a brief disturbance of awareness or sensation, or jerking muscles).

As a tumour grows it takes up more space in the skull and pushes on the brain. This results in swelling (oedema), which can affect the supply of blood and oxygen to healthy brain cells. It is known as raised intracranial pressure and can lead to symptoms such as:

- headaches – often worse when you wake up in the morning
- feeling sick (nausea) or being sick (vomiting).

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



Section Two: Diagnosing a brain tumour

Tekiona Rua

Te whakatau i tētahi
puku roro

Key points:

- If there is concern that your symptoms may be a brain tumour, further tests (investigations) will be done to check how the different parts of your brain and body are working.
- The purpose of these tests is to find out whether you have a brain tumour and the type of brain tumour you have.
- The results of any tests you have will help your treatment team to decide on the best treatment options for you.
- Common tests include:
 - neurological examination (see page 14)
 - blood tests
 - imaging tests (scans)
 - lumbar puncture
 - biopsy
 - testing for gene changes.

Ngā kōrero matua:

- Mehemea ka puta he māharahara tērā pea he puku roro kē ngā tohumate, ka whāia anō he whakamātautau ake (ngā tirotirohanga) ki te arowhai e pēhea ana te mahi o tēnā wāhi, o tēnā wāhi o tō roro, o te tinana hoki.
- Ko te whāinga o ēnei whakamātautau, ko te tiro mēnā kua whai puku roro koe, me te tiro ki tōna momo.
- Ka āwhina ngā whakamātautau ka whāia e koe, i tō rōpū maimoa ki te whakatau ko tēhea te kōwhiringa maimoatanga pai rawa mōu.
- Ko te nuinga o ngā whakamātautau ka whakamahia ko ēnei:
 - arowhai ā-pūnaha iotōpū
 - whakamātautau toto
 - whakamātautau ata
 - wero tuaiwi
 - unuhanga
 - whakamātautau rerekētanga ira

Diagnosing a brain tumour

If you have noticed any symptoms of a brain tumour, you will often see your GP or whānau doctor first. It can be helpful to take a list of your symptoms, and how long you have had them, with you to your appointment. You may also be asked about your family history of cancer and any risk factors you may have.

If the doctor is concerned that your symptoms may be signs of a brain tumour, they will examine you to check how the different parts of your brain and body are working. This is called a neurological (body's nervous system) examination.

The doctor may check for any signs of raised pressure around your brain by looking into your eyes using an instrument called an ophthalmoscope. This allows the doctor to see if there is any swelling in the optic nerve, which sends information from the eyes to the brain.

The doctor will also test the following.

- Your reflexes – usually by tapping your knee with a small rubber hammer
- The strength of your arms and legs
- Your balance and coordination, by watching how well you can walk
- Sensation – such as your ability to feel light touch or pinpricks

They may also ask you some simple memory questions.

You may be referred to a neurologist (a specialist brain doctor) or neurosurgeon (a specialist brain and spinal-cord surgeon) for further tests (investigations).

The purpose of these tests is to find out whether you have a brain tumour and the type of brain tumour you have. The results of any tests you have will help your treatment team to decide on the best treatment options for you.

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

Blood tests

Your doctor or neurologist may suggest blood tests to check your general health and how well your body is working.

CT, MRI and PET-CT scans

CT, MRI and PET-CT scans are imaging tests that may be used to build a detailed picture of your brain.

Lumbar puncture

A doctor uses a needle to collect a sample of fluid from your spinal column, known as cerebrospinal fluid or CSF. The fluid is checked for cancer cells. This is sometimes called a spinal tap.

Surgical biopsy

If a scan shows an abnormal area that looks like a tumour, you may need a biopsy to remove some or all of the tissue. This is done by a neurosurgeon in one of two ways.

- During surgery (called a craniotomy) to remove the brain tumour
- Using a needle inserted through a small opening in the skull

Genetic testing

If you have had a biopsy or removal of part, or all, of the tumour, your doctor will send your tumour tissue for genetic testing to identify molecular markers. Molecular markers are genetic features found in the tumours' DNA.

Genetic testing of the tumour can give your doctor more specific information about the type of tumour you have. This information can be used to help guide the best course of treatment for you.



For more information on genetic testing, you may want to visit:
www.braintumoursupport.org.nz

Section Three: Classifying brain tumours

Tekiona Toru

Te whakarōpū i ngā puku
roro



Key points:

- Unlike other cancers, there is no staging system for primary brain tumours. Instead, they are grouped by:
 - grade
 - type
 - results of genetic testing.
- A brain tumour is given a grade (a number from 1 to 4) depending on how the cells look under a microscope.
 - Low-grade brain tumours (grade 1 and 2)
 - High-grade brain tumours (grade 3 and 4)
- Brain tumours are named after the type of brain cell that the tumour starts to grow in.

- There are many different brain tumours. They are divided into two main types.
 - Gliomas
 - Non-glial tumours
- Anyone diagnosed with a brain tumour is not allowed to drive. Your doctor will assess if and when it is safe for you to drive again.

Ngā kōrero matua:

- Atu i ētahi atu matepukupuku, kīhai he pūnaha whakawāhanga mō ngā puku roro tuatahi. Oti rā, ka whakarōpūhia mā:
 - te māhiti
 - te momo
 - te whakatau o ngā whakamātautau iranga.
- Hoaturia ai he māhiti ki te puku roro (he nama mai i te 1 ki te 4) e ai ki te āhua o ngā pūtau ka tirohia ana i raro i te karu whakarahi
 - Ngā puku roro māhiti-iti (māhiti 1 me te 2)
 - Puku roro māhiti nui (māhiti 3 me te 4)
- Whakaingoatia ai ngā puku roro e ai ki te momo pūtau roro i tīmata ai te tipu o te puku ki roto.
- He maha tonu ngā puku roro rerekē. Kua ritua ki raro i ngā momo matua e rua.
 - Puku pūtau roro
 - Kore puku pūtau roro
- Kīhai ngā tāngata kua whakatauria kua puta he puku roro ki a rātou, e āhei ana ki te taraiwa. Mā tō rata e aromatawai mehemea he pai noa iho mōu ki te taraiwa anō

Classifying brain tumours

Unlike most other types of cancer, there is no staging system for primary brain tumours. Instead, they are grouped by grade, type, and genetic testing.

The way brain tumours are classified is complicated, and many of the medical words used to describe them can be difficult to understand. Ask your treatment team to explain anything that you are unsure of.

Grades of brain tumour

Brain tumours are given grades (numbered from 1 to 4) depending on how the cells look under a microscope.

- **Low-grade brain tumours (grade 1 and 2)**

Usually, low-grade brain tumours grow slowly and are unlikely to spread to other parts of the brain.

Often they are not cancer but can be difficult to cure. Because low-grade tumours can cause symptoms if they grow, they may need treatment.

Some low-grade brain tumours can change over time and become high-grade tumours (cancer).

- **High-grade brain tumours (grade 3 and 4)**

High-grade brain tumours are cancer. They grow more quickly than low-grade brain tumours, and cause problems by spreading into nearby parts of the brain or the spinal cord. They do not usually spread to other parts of the body.

Types of brain tumour

Brain tumours are named after the type of brain cell that the tumour starts to grow in. For example, a brain tumour that starts in the brain's glial cells is called a glioma.

There are many brain tumour types. They are divided into two main types:

- **Gliomas** – these are the most common types of primary high-grade brain tumours. Astrocytomas are the most common glioma.

Less common types include oligodendroglioma, mixed gliomas (made of more than one type of cell) and ependymoma

- **Non-glial tumours** – these include meningioma, central nervous system (CNS) lymphomas, pituitary gland tumour and pineal gland tumour

Gliomas

Gliomas start in the glial cells of the brain. Glial cells are glue-like cells that hold the brain together.

Gliomas are described as grade 1 to 4 according to how quickly they are likely to grow.

Astrocytoma

Astrocytoma is the most common type of glioma. It starts in the astrocyte cells and is graded from 1 to 4.

Grade 1	Pilocytic astrocytoma	Slow growing and unlikely to spread.
Grade 2	Diffuse astrocytoma	Slow growing and may spread to nearby brain tissue. Can change to a higher-grade tumour over time.
Grade 3	Anaplastic astrocytoma	Can grow quickly and spread to nearby brain tissue.
Grade 4	Glioblastoma (GBM)	Grows very quickly and can spread to other parts of brain. GBM is the most common type of glioma in adults.

Oligodendroglioma

Oligodendroglioma is a glioma that starts in a glial cell called an oligodendrocyte. Oligodendrocyte cells make myelin, which covers the nerves and helps signals from the brain travel quickly along the nerves.

Oligodendrogliomas can be low grade or high grade. High-grade tumours are also called anaplastic oligodendroglioma.

Mixed glioma

A mixed glioma is made of different types of glial cells. They include, for example, oligoastrocytomas – a type of mixed glioma that affects the oligodendrocytes and astrocytes.

With genetic testing now available, a more specific diagnosis can often be given. A diagnosis of a truly mixed glioma is becoming less common.

Ependymoma

In adults, most ependymomas start in the ependymal cells that line the spinal cord and the ventricles of the brain. They can spread into the fluid that surrounds the brain (the cerebrospinal fluid).

Ependymoma is very rare and can be low-grade or high-grade.

Non-glial tumours

Meningioma

Meningiomas start in the layers of tissue (meninges) that cover the brain and spinal cord. Most meningiomas are slow-growing, low-grade tumours.

Primary central nervous system (CNS) lymphoma

A primary central nervous system lymphoma is a rare cancer that starts in the lymphatic system (part of the body's immune system). Lymphoma most often occurs in the cerebrum, but can also be found in the cerebrospinal fluid, the eyes, or the spinal cord.



For more information, you may want to visit the website of Leukaemia & Blood Cancer New Zealand: www.leukaemia.org.nz

Pituitary gland tumour

Pituitary gland tumours start in the pituitary gland. Most pituitary tumours are low-grade. They usually grow slowly and tend not to spread. They can cause problems with vision and the production of hormones.

Pineal region tumours

Pineal region tumours start either in the pineal gland or in the tissues around it. The most common type of pineal tumour is a germinoma.



For more information on different types of brain tumours, you may want to read: www.braintumoursupport.org.nz/brain-tumour-types

Driving after diagnosis of a brain tumour

Anyone diagnosed with a brain tumour is not allowed to drive.

Your doctor will assess if, and when, it is safe for you to drive again.

You can contact your local Cancer Society office for driving services available in your area.



Section Four: Making treatment decisions

Tekiona Whā
Te whakamahi whakataunga
maimoatanga

Key points:

- The treatment choices you are offered will be based on all the information available about the tumour in your brain and your general health.
- The recommended treatment will depend on:
 - the type and grade of the brain tumour
 - where the tumour is in the brain
 - your general health
 - your personal wishes.
- You will be cared for by a team of health professionals that may include:
 - your GP or whānau doctor
 - oncology nurses and cancer care coordinators
 - a neurologist
 - a neurosurgeon
 - a medical oncologist
 - a radiation oncologist

- Before you visit your treatment team, think about any questions you would like to have answered.
- You can ask another doctor for a second opinion about the tumour in your brain or the treatment.

Ngā kōrero matua:

- Ka hāngai ngā kōwhiringa ka hoatu ki a koe, i runga anō i ngā mōhiohio katoa e wātea ana mō tōu ake puku roro, me tō hauora whānui
- Ka whakawhirinaki te maimoatanga kua taunakitia ki ēnei:
 - te momo puku roro, me te māhiti o te puku roro
 - te wāhi e noho ana te puku i roto i te roro
 - tō oranga whānui
 - ōu ake hiahia.
- Ka tiakina koe e tētahi rōpū ngaio ā-hauora, tērā pea kai roto ko ēnei tāngata:
 - tō GP, tō rata ā-whānau rānei
 - ngā tapuhi mātai matepukupuku me ngā kairuruku atawhai matepukupuku
 - tētahi mātai matepukupuku
 - tētahi mātanga io tōpū)
 - tētahi mātanga mātai matepukupuku ā-hauora
 - tētahi mātanga mātai matepukupuku ā-iraruke
- I mua i tō haere ki te tiroiro i tō rōpū maimoatanga, ata whakaarohia ētai pātai tērā pea ka hiahia koe kia whakautua.
- E āhei ana koe ki te tono i tētahi atu rata mō tētahi whakaaro tuarua e pā ana ki tō puku roro, te maimoatanga rānei.

How treatment decisions are made

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

Recommendations will depend on:

- the type and grade of the brain tumour
- where the tumour is in the brain
- your general health
- your personal wishes and goals of care.

The treatment team

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

- your GP or whānau doctor, who will often be the first person you see
- oncology nurses and cancer care coordinators, who specialise in the care of people receiving cancer treatment
- a neurologist, who specialises in diseases of the brain and nervous system
- a neurosurgeon, who specialises in surgery to the brain
- 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.

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

Talking to your treatment team

When you first learn you have a brain tumour, you may have many questions. Before you visit your treatment team, we suggest you think about the questions you would like them to answer and how much detail you are comfortable with. There is a lot of information to take in, so it can be helpful to have a support person with you when you visit. See page 51 for some questions you may wish to ask your treatment team.

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

Asking for a second opinion

You may want to ask another doctor about the tumour in your brain or treatment to help you feel more confident about your treatment decision. You can ask your treatment team or 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.



You can find more information here:

www.hdc.org.nz/your-rights/the-code-and-your-rights

Interpreting services

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

Talking to others

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

Coping with waiting

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

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



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

Taking part in a clinical trial

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

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

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: Brain tumour treatments

Tekiona Rima
Ngā maimoatanga puku roro



Key points:

- Your treatment team will advise you on the best treatment for the tumour in your brain.
- Depending on the type and grade of brain tumour, treatment may include:
 - steroids
 - surgery
 - radiation treatment
 - chemotherapy
 - palliative careor a combination of these.
- Complementary treatments are healing practices or products that are not usually part of standard medical care.

- Traditional Māori healing methods can include rongoā Māori, romiromi or mirimiri, massage therapy, and spiritual healing.
- Traditional Pacific healing treats the whole person, including your mental, emotional, physical, and spiritual wellbeing.
- If you are thinking about using complementary, traditional Māori, or Pacific treatments, please talk about them with your cancer treatment team.

Ngā kōrero matua:

- Mā tō rōpū maimoa koe e tohutohu e pā ana ki te maimoatanga pai rawa mō tō puku roro.
- Tērā pea ka uru ko ēnei maimoatanga, e ai ki te momo puku roro me te māhiti puku roro:
 - ngā pūtaiaki
 - mahi hāparapara
 - maimoatanga iraruke
 - mahi hahau
 - Atawhai whakangāwarihe whiriwhiringa rānei o ēnei.
- He whakawaiwai whakaora, he hua whakaora rānei ngā maimoatanga whakahāngai kāore e whai wāhanga ana i te taha o ngā mahi atawhai ā-hauora.
- Ka taea te whakauru te rongoā Māori, te mahi romiromi, te mirimiri rānei, me te mahi whakaora ā-wairua, ki raro i ngā huarahi whakaora Māori taketake.
- Maimoa ai te whakaora taketake o Te Moana-nui-ā-Kiwa i te katoa o te tangata, tae noa ki te oranga hinengaro, oranga tinana.
- Mehemea e whakaaro ana koe ki te whakamahi i te maimoatanga whakahāngai, te maimoatanga Māori taketake, tēnā koa kōrero ki tō rōpū maimoatanga matepukupuku mō aua maimoatanga.

Treatment options

Your treatment team will advise you on the best treatment for the tumour in your brain. Depending on the type and grade of the tumour, treatment may include steroids, surgery, radiation treatment, chemotherapy, or palliative care, or a combination of these.

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

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

Steroids

Medications called steroids are commonly used as part of treatment for a brain tumour. Steroids are made naturally in the body, but they can also be produced artificially and used as medication.

The main purpose of taking steroids when you have a brain tumour is to reduce the swelling in the brain caused by the tumour or treatment. Steroids can be given before, during, and after both surgery and radiation treatment.

The most commonly used steroid for people with brain tumours is dexamethasone.

It is important to always take the prescribed dose of steroids. Do not stop taking them without talking to your doctor first. If you continue to experience symptoms, ask your treatment team for advice.

Side effects of steroids

The side effects of steroids depend on the dose and the length of treatment.

Taking steroids for a short time may cause the following side effects.

- Increased appetite
- Weight gain
- Trouble sleeping
- Restlessness
- Mood swings, feeling angry or agitated for no reason
- Anxiety
- High or unstable blood sugar levels in people with diabetes

Taking steroids for several months can have additional side effects, including:

- puffiness or swelling in the feet, hands, or face due to your body retaining fluid
- high blood pressure
- unstable blood sugar levels
- diabetes
- muscle weakness
- loss of bone density (osteoporosis)
- increased risk of getting infections.

Talk to your treatment team about the best ways to manage side effects. Your doctor may adjust your steroid dose to help ease them. Most side effects from steroids go away after you have finished taking them.

Surgery

Surgery in the brain is called neurosurgery.

You may have surgery to:

- help diagnose a brain tumour (take a biopsy)
- remove part of the tumour (partial resection or debulking)
- remove the whole tumour (total resection).

Types of surgery

Craniotomy

A craniotomy is an operation where a piece of the skull (bone) is removed to make an opening so that your surgeon can operate on your brain. The surgery is usually done under general anaesthetic.

Once the surgeon has made an opening in the skull, they will remove the entire tumour (total resection) or as much of it as they can safely (partial resection or debulking).

Awake craniotomy

Some people have a craniotomy while they are awake. This operation may be recommended if the tumour is near parts of the brain that control speech or movement. The operation is done while you are awake, but you will be given medication to help you relax.

Although you are awake, the surgery will not be painful as the brain does not feel pain.

The surgeon will use an electrode to stimulate the brain during the operation. They will also ask you to speak or move parts of your body. Using the electrode and asking you to perform simple tasks helps the surgeon to identify important parts of the brain that they do not want to damage.

Recovery after surgery

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

Some people recover fully and can gradually return to their usual activities. For others, there are longer-term changes in how they speak, move, and think. Your doctor may refer you to a rehabilitation service to receive treatments such as physiotherapy and occupational therapy. These can help your recovery and teach you ways to manage any changes you experience.

Genetic profiling

Samples of your tumour taken when you have a biopsy may be sent to a special laboratory to get information on the DNA (deoxyribonucleic acid) of your tumour. This is called genetic or DNA profiling.

Genetic profiling can give your doctor detailed information about your tumour to help guide the best course of treatment for you. It may also help to identify clinical trials that you might be able to join.

Radiation treatment

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



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

When is radiation treatment offered?

Radiation can be used:

- after surgery to destroy any remaining brain tumour cells
- to treat tumours that cannot be removed by surgery
- to reduce symptoms caused by a brain tumour.



How radiation treatment is given

External beam radiation treatment

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

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

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

Stereotactic radiation treatment

A specialised radiation treatment machine is used to give very precise, targeted radiation treatment to some brain tumours. Only a few treatment centres in New Zealand offer this treatment.

Sometimes it is called stereotactic radiosurgery – but it does not need an operation.

Wearing a mask (a shell, or head mould)

If you are having radiation treatment to your brain, you will have a mask made. It is hard to keep your head completely still, so the mask is used to keep you in the right position for treatment. It is 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. Talk to your treatment team about your concerns, as they are experienced in helping you 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 (2022).

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

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



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

Side effects of radiation treatment for a brain tumour

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

These are the common side effects that you may experience.

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

Chemotherapy treatment

Chemotherapy uses medication to kill tumour cells or slow their growth. It affects cells throughout your body. It is used to reduce the risk of a brain tumour returning or to control the growth of a brain tumour that cannot be removed by surgery.



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

When chemotherapy treatment is given

Chemotherapy may be given:

- after surgery to reduce the chances of the brain tumour coming back
- to improve symptoms if you are unable to have surgery
- before, after, or with radiation treatment
- as palliative treatment for a high-grade brain tumour to reduce symptoms and

improve your quality of life or extend your life.

How chemotherapy is given

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

Oral chemotherapy is often used to treat high-grade brain tumours. Your treatment team will give you information on how to take and store this medication safely while you are at home.

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

Not all people with a brain tumour will receive the same treatment.

Side effects of chemotherapy

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

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

The common side effects that you may experience include:

- increased risk of infection
- hair loss
- fatigue – feeling tired
- forgetfulness and concentration problems (chemo brain)
- nausea and vomiting
- constipation or diarrhoea
- 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 for brain tumours

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



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

Targeted treatments are expensive, and Pharmac has decided not to provide funding for some treatments that might be helpful for the management of a brain tumour. You may like to ask your oncologist if there are any unfunded treatments available that may be beneficial for you. Your medical oncologist will be able to give you an estimate of the cost involved if you are thinking of funding your own treatment.

In New Zealand, bevacizumab (Avastin) has been approved for use in people with high-grade, relapsed glioma. This treatment is not currently funded by Pharmac (2022).

Supportive care and palliative treatment

Supportive care

Anyone with a brain tumour may need supportive care. It includes the management of physical symptoms, emotional and spiritual support, and guidance to help you plan ahead.

Supportive care will mostly be provided by your primary health care team, 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. This 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 or mirimiri. These therapies are based on the use of native plants, massage therapy and spiritual healing.



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

Hauora Māori

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

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

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

Traditional Pacific healing

Traditional healing is also important to Pasifika, 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 them 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 treatment

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

Alternative treatments

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



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

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



Section Six: Managing symptoms of a brain tumour

Tekiona Ono

Te whakahaere tohumate
puku roro



Key points:

- Brain tumours affect the tissue in and around the brain and causes symptoms like nausea, headaches, and seizures.
- Brain tumours can change the way you think and your memory, mood, and personality.
- Talk to your doctor or nurse about any symptoms you may be experiencing. As well as providing cancer treatments, your doctor may be able to refer you to other services to help you manage your cancer symptoms.

Ngā kōrero matua:

- Papā ai te puku roro ki te kiko kei roto i te roro, e karapoti ana hoki i te roro me tana whakaputa tohumate pērā ki te hiaruaki, ānini māhunga, me ngā rehu ohotata.
- Ka rerekē katoa ō whakaaro, tō pūmahara, tō kaingākau, tō tuakiri nā te puku roro.
- Kōrero ki tō rata, ki tō tapuhi rānei mō ngā tohumate tērā pea kei te rongo koe. I tua atu i tana kaha ki te hoatu maimoatanga matepukupuku, tērā pea ka āhei tō rata ki te tuku i a koe ki ētahi atu ratonga ki te āwhina i a koe ki te whakahaere i ō tohumate matepukupuku.

Ways of managing symptoms of a brain tumour

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

Fatigue (no energy)

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

- Let people help you. Whānau, friends and neighbours may offer to help with tasks such as meals, 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 (see page 44 for more information on exercise)
- Try to eat a healthy, well-balanced diet. Some people find small, frequent snacks more appealing than meals.
- Fatigue may be caused by specific things that can be found in blood tests and may be improved by treatment.

Nausea (feeling sick)

If you have a brain tumour you may feel sick at some point. This can be caused by many things, including the cancer itself and cancer treatments.

People have found the following suggestions helpful.

- Try to eat small amounts (snacks) often.
- Have your meals when you feel like eating.
- Avoid fatty or fried foods.
- Rest before and after eating.
- Do not lie flat during or after eating.
- Drink plenty of fluids.
- See a dietitian or nurse for dietary advice.
- Try relaxation or mindfulness exercises.
- Do something enjoyable as a distraction from feeling sick.

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



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

Headaches

Not everyone with a brain tumour has headaches. If you do have headaches, you may not be in pain all the time and they can usually be well managed.

There is a range of prescription medications and complementary therapies, such as relaxation techniques, that can help with headaches due to a brain tumour.

You may have a headache due to raised pressure in your brain caused by the tumour or treatment. This is often treated with steroids. For more information on steroids, see page 28.

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

Seizures

Seizures, also called fits or convulsions, are caused by abnormal electrical activity in the brain.

If a person with a brain tumour has not had seizures at the time of diagnosis, there is only a small chance that they will develop seizures later on.

There are two main types of seizure - focal seizures and generalised seizures.

Focal seizures

These are also called partial seizures and affect one part of the body, such as an arm or a leg. The symptoms depend on which part of the brain is affected. They include twitching, jerking, tingling, and/or numbness. You may go 'blank' and stop responding to people around you for seconds or minutes. You might notice odd smells or sensations or experience a feeling of déjà vu.

Partial seizures may cause mood changes and memory loss just before, during, or after the seizures. People often feel extremely tired after a focal seizure.

Generalised seizures

These seizures usually affect the whole body and are known as tonic-clonic seizures.

You might lose consciousness or stop responding to people around you for a few minutes. Your muscles may become tighter, and your arms and legs can make jerky or twitching movements. Your breathing may be shallow, and you may lose bladder and/or bowel control.

If you have a seizure, talk to your treatment team about ways to manage it. Many seizures can be managed with anti-seizure medications, which are also called anti-epileptic medication or anticonvulsants. If you continue to have seizures while you are on prescribed medication, speak to your treatment team for advice.

Ways to help someone who is having a seizure

If you are with someone who is having a seizure, the following tips may be helpful.

- Stay calm and reassure the person.
- Move any hazards away and lower the person to the floor if you can.
- Put something soft under their head.
- Do not try to restrain them or put anything in their mouth.
- Stay with them until the seizure is over.

Call 111 for an ambulance if:

- this is the person's first seizure
- they are injured
- they had food or fluid in their mouth during the seizure
- the seizure lasts longer than a few minutes or they have one seizure after another
- you are unsure what to do.

Trouble sleeping

Some people with brain tumours have trouble sleeping or have difficulties falling asleep, which can affect how well they feel during the day. If you are taking steroid medication or have headaches or nausea, this may also affect your sleep.

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

- Try to wake up at the same time each day and go to bed at the same time each night.
- Create a quiet, dark, and restful place for sleeping.
- Reduce caffeinated drinks like tea, coffee, and soft drinks, and alcohol. These may give you energy but leave you unable to sleep.
- Use your pain medication as prescribed if a headache is keeping you awake.
- Take any steroid medication at the time prescribed (usually early in the day).



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

Changes in your thinking, memory, mood, or personality

You, or those close to you, may notice changes in your memory or your personality. Some people describe feeling very emotional or upset, while others find it hard to think clearly, concentrate, or remember things. Sometimes people behave in ways that seem out of character. These changes do not happen for everyone. You may find having a daily routine with plenty of rest helps you feel better.

With support, you can learn ways to manage the changes. Many people feel better with time.

If you have memory problems, these things may help.

- Try using a diary or online calendar to record appointments.
- Ask your chemist about a medication organiser to help you remember when to take your medication.

Sometimes changes in how you think and in your memory, mood, or personality can create ongoing problems. Your specialist may recommend an assessment by a health professional, such as a neuropsychologist, who can help with ways to manage these changes.



You can find more information on managing change on Brain Injury New Zealand's website: www.brain-injury.nz

Weight gain

Some people with brain tumours put on weight due to steroid medication, which can cause increased appetite and fluid retention.


During treatment you may be less active than usual and gain some weight as a result.

A small increase in weight is not usually a problem, but a large weight gain can affect your general health. Weight gain can also affect how you feel about yourself and your confidence and energy levels.

Talk to your treatment team about safe ways to lose weight. Avoid diets or medications promising rapid weight loss. You are more likely to keep weight off if you lose it slowly and steadily.



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



Section Seven: Living well with a brain tumour

Tekiona Whitu

Te noho ora me te puku roro

Key points:

- 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 a brain tumour.
- If possible, try to avoid going back to work too soon after treatment.
- A counsellor can help you to talk about your feelings on the impacts a cancer diagnosis can have.
- Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural, and advocacy needs.
- Talk to your GP or whānau doctor, or your local Cancer Society, about the support services available for you and your family.
- If you are caring for someone with a brain tumour, it is important to get some support for yourself. Talk to your GP or whānau doctor or phone 0800 CANCER to talk to our information nurses about coping strategies.

Ngā kōrero matua:

- Rapua ngā huarahi ki te arotau pai i tō tinana - pērā ki te kai pai, te tīmata i tētahi hōtaka korikori hou, me te whakamahi panoni pai ki tō toioranga - tērā ka āwhina i a koe ki te noho ora me te puku roro.
- Mēnā ka taea, kua noa iho e tere hoki ki te mahi whai muri i ō maimoatanga.
- Tērā pea mā tētahi kaitautāwhi koe e āwhina ki te kōrero mō ōu kāre ā-roto e pā ana ki ngā papātanga ka puta nā runga i tētahi whakataua kua pā te matepukupuku.
- Kua whai kaimahi ngā hōhipera huri noa i te motu, i ngā kaimahi hauora kua whakangungutia ki te tautoko ōu hiahiatanga wairua, hiahiatanga ahurea, hiahiatanga whaitaua.
- Kōrero ki tō GP, tō rata ā-whānau, tō Kāhui Matepukupuku ā-rohe rānei mō ngā ratonga tautoko e wātea ana mōu me tō whānau.
- Mehemea kei te tiaki koe i tētahi tangata kua pāngia ki te puku roro, he mea nui kia whai tautoko koe mōu ake. Kōrero ki tō GP, ki tō rata ā-whānau, me waea rānei ki: 0800 CANCER ki te kōrero ki ā mātou tapuhi mōhiohio e pā ana ki ngā rautaki whakapakari.

Adjusting to change

You may have many adjustments to make, such as not driving, changing the work you do, or giving up work. You may have to hand over tasks you used to do easily to others at work or within your whānau.

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 a brain tumour.



You can find more information on living well with cancer on our website: 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 a brain tumour, especially if the tumour has affected your movement, balance, or eyesight. 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 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 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: cancer.org.nz/cancer/living-with-cancer/being-active

Returning to work

Depending on the type of tumour you have, and any ongoing effects you are experiencing, you may find it hard to return to work after treatment. If possible, postpone going back to work too soon. 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

If your job involves using machinery, you may not be able to return to this type of work. We recommend that you discuss this with your treatment team if you think it might apply to you.

Talk to your doctor about services that can assist you with returning to work, such as a referral to a social worker or occupational therapist.



There are employment services that specialise in helping people with health needs or disabilities to find work. Examples are Workbridge (www.workbridge.co.nz) and ChoicesNZ (www.choicesnz.org.nz).

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 a brain tumour, you and/or your carer may be entitled to receive income support from the Ministry of Social Development – Work and Income.

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



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



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

Talking to your bank

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



You can visit these pages for more information:

- Applying for KiwiSaver hardship withdrawal: <https://sorted.org.nz/must-reads/applying-for-kiwisaver-hardship/>
- Cancer Society/Sorted NZ financial and legal guide: <https://sorted.org.nz/seriousdiagnosis>

Personal insurance benefits

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

Power of attorney

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

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

It is a good idea to have your advance care planning (see page 34) 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 (<https://www.cab.org.nz/article/BK00001276>)

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 of dealing with problems.



The Cancer Society offers support groups that you may find helpful.

You can phone the Cancer Information Helpline (0800 CANCER 226 237) for further information.

Brain Tumour Support New Zealand has a service called Support Friends: www.braintumoursupport.org.nz/support-friends

Check out the online booklet Behaviour and Personality Change for information and coping tips: <https://brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf>

Counselling

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



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

Cultural and spiritual support

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

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



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

How whānau can help

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

- Learn about brain tumours and their 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 your whānau member or friend may want to talk to their treatment team alone.



The Cancer Society offers a range of resources to support you. For more information on how whānau can help, see the Cancer Society's Supporting Someone with Cancer booklet, available on our website: cancer.org.nz/supporting-someone-with-cancer

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



For more information: www.supportcrew.co.nz

Caring for someone with a brain tumour

Supporting or caring for someone with a brain tumour can be challenging and tiring, and you may have to take on different 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 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, contact Carers New Zealand (www.carers.net.nz), Cancer Connect and Cancer Chat (<https://www.cancer.org.nz/supporting-you/how-we-can-help/connecting-with-people-with-similar-cancer-experiences>), and Brain Tumour Support NZ Support Friends (www.braintumoursupport.org.nz/support-friends)



Check out the online booklet *Behaviour and Personality Change* for information and coping tips: www.brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf

- get some support for yourself. Counselling can be very useful to help you 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.

Taking a break

If you need to take a break from caring, talk to your GP or whānau doctor about respite care.

If you are eligible, they can refer you to a Needs Assessment and Service Coordination (NASC) service. The NASC service will help you apply for funding for respite care and find the respite options that will work best for you.



You can find more information on respite care on the Ministry of Health website: www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respice/respice-supports-and-services

Questions you may wish to ask

When you hear you have a brain tumour, you and your whānau may have many questions. Here is a list of questions you may want to ask to help you make the most of your time with your doctor.

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

- What type of brain tumour do I have?
- What grade is it?
- What scans do I need?
- What treatment do you advise for my brain tumour 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 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 brain tumour 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?”



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

Section Eight: Resources

Tekiona Waru
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Suggested websites

You may be interested in looking for information about brain tumours 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:

Cancer Council, Australia

www.cancer.org.au/cancer-information/types-of-cancer/brain-cancer

Brain Tumour Support NZ

www.braintumoursupport.org.nz

Behaviour and personality change resource

www.brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf

Macmillan Cancer Support (UK)

www.macmillan.org.uk/cancer-information-and-support/brain-tumour

American Brain Tumor Association

www.abta.org

White Matter Brain Cancer Charity Trust

www.whitematterbraincancertrust.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.

Books for talking with children

Jones, F., and Foster-Michell, K. (2015) *Nurse Ted: A children's guide to brain tumours*, UK, **Belrose Books**.

Chilman-Blair, K. (2011) *What's Up with Jo?: Medikidz Explain brain tumours*, **American Cancer Society, Incorporated**.

Suggested resources

Information sheets

[Applying to work and income](#)

[Cancer Society/Sorted NZ financial and legal guide](#)

[Cancer and insurance, employment and legal issues](#)

[Coping with waiting](#)

[Healthy eating and cancer treatment](#)

[Making decisions about treatment](#)

[Searching the internet](#)

[Sex and cancer](#)

[Spirituality, wairuatanga and cancer](#)

[Supporting young adult children when you have cancer](#)

[Telling others about your diagnosis](#)

[Your cancer treatment team](#)

Booklets

[Cancer in the Family](#)

[Eating Well with Cancer](#)

[Emotions and Cancer](#)

[Living Well with Cancer](#)

[Sex and Cancer](#)

[Supporting Someone with Cancer](#)

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](tel:0800226237)).

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

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

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

Auckland/Northland

Auckland

09 308 0160
Domain Lodge
1 Boyle Crescent
Grafton

Whangarei

09 437 5593
Daffodil House
73 Kamo Road
Kensington

information@akcansoc.org.nz

Northland@akcansoc.org.nz

Central Districts

Palmerston North

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

Whanganui

06 348 7402
3 Koromiko Road

New Plymouth

06 757 3006
TSB Cancer Support Centre
71 Lorna Street
Westown

Gisborne

06 867 1795
Morris Adair Building
Gisborne Hospital

Hastings

06 876 7638
310 Orchard Road

Palmerston North

06 356 355
Addis House
135 Ruahine Street

Waikato/Bay of Plenty

Hamilton

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

Rotorua

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

Tauranga

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

Wellington

Wellington

04 389 8421

52-62 Riddiford Street

Paraparaumu

04 298 8514

27 Kāpiti Road

Masterton

06 378 8039

37 Te Ore Ore Road

Nelson

03 539 1137

102 Hardy Street

Blenheim

03 579 4379

The Forum Building

Market Street

info@cancersoc.org.nz

Canterbury-West Coast

Christchurch

03 379 5835

97 Fitzgerald Avenue

Greymouth

03 768 9557

98 High Street

Timaru

03 688 0124

32 Memorial Avenue

Rolleston

03 925 9708

6B Kidman Street

Ashburton

03 307 7691

122 Kermode Street

contact@cancercwc.org.nz

info@cancercwc.org.nz

Otago and Southland

Dunedin

03 477 7447

283 Great King Street

SupportiveCare@cansoc.org.nz

Oamaru

03 434 3284 or 027 674 4200

Waitaki District Community House

100 Thames Street

Balclutha

03 418 3916 or 027 277 7632

Arcade 84

5/37 Clyde Street

Alexandra

03 440 0754 or 027 580 0640

Alexandra Community House Office

14-20 Centennial Avenue

Wanaka

Wanaka Community House

40 McDougall Street

Queenstown

03 442 4281 or 027 536 0066

112B Aurum House

1092 Frankton Road

Southland

149 Spey Street

Invercargill

03 218 4108

National Office

04 494 7270

39 The Terrace

Wellington

admin@cancer.org.nz

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Cancer Society

Te Kāhui Matepukupuku
o Aotearoa

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

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



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