

Living well with advanced cancer

– Te noho hauora me te matepukupuku maukaha



**Cancer
Society**

Te Kāhui Matepukupuku
o Aotearoa



ANY CANCER, ANY QUESTION 0800 CANCER (226 237) Cancer Information Helpline

Your general practitioner: phone _____

Your cancer team: phone _____

Your local Cancer Society: _____

24-hour emergency phone 111

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- Te Kāhui Matepukupuku o Aotearoa

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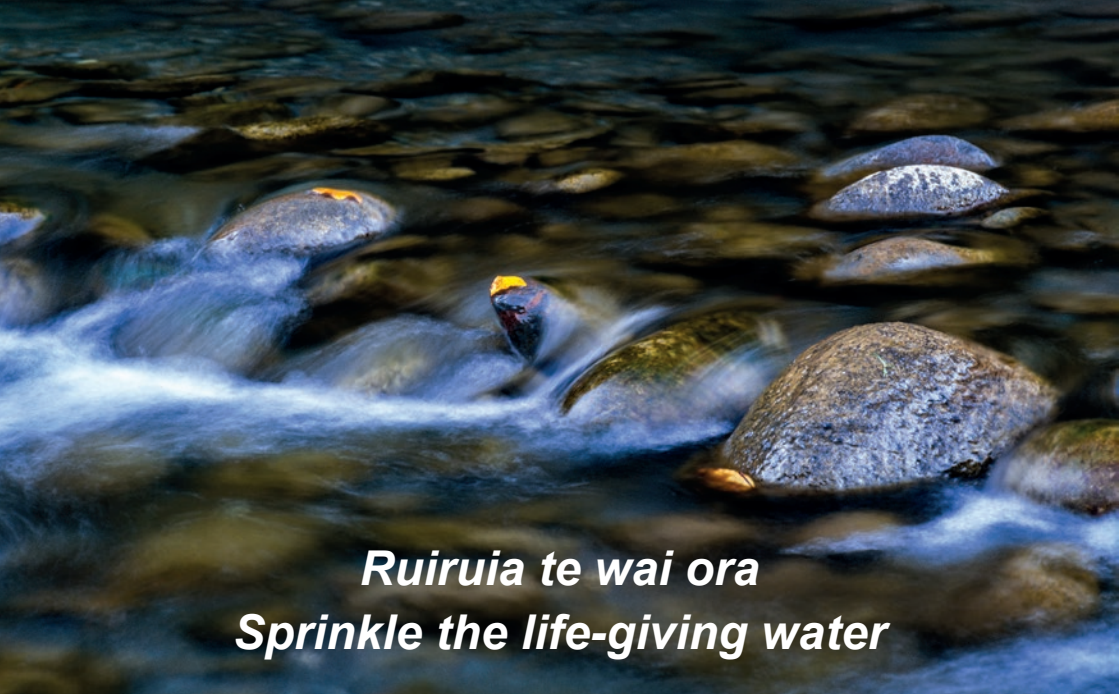
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Ka āhei koe ki te tono kape o ngā puka me ngā whārangi pārongo a te Kāhui Matepukupuku mai i tō Kāhui Matepukupuku ā-rohe, mā te waea atu ki te Waea-āwhina Pārongo Matepukupuku 0800 CANCER (226 237) mō tētahi kape, me tikiake rānei i tō mātou paetukutuku www.cancernz.org.nz.

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Ruiruia te wai ora *Sprinkle the life-giving water*

Introduction

This booklet may be useful if you have advanced cancer and are looking for information and support. Cancer that has advanced beyond early stages is called many things, including advanced, secondary, stage 4 (stage IV), and metastatic cancer. Whatever it is called, it can be overwhelming to hear your cancer has advanced.

This booklet offers general information about advanced cancer and its treatments. It looks at some of the emotional impacts you may experience and provides some suggestions that may help you to live well.

Finally, it includes a section on supporting someone with advanced cancer and a guide to practical things you may want to think about.

You may want to read the booklet with someone who you can talk things over with as you go. Sharing this booklet with others in your family/whānau may be helpful.

There is a list of questions that you might like to ask your cancer care team on page 17.

Kupu whakataki

Tērā pea ka whai kiko tēnei puka mehemea kua pā te matepukupuku maukaha kia koe, ā, kei te rapu pārongo, tautoko hoki koe. He nui ngā ingoa karanga mō te matepukupuku kua aua atu i ngā wāhanga tīmatatanga, tae noa ki te matepukupuku maukaha, te matepukupuku tuarua, te matepukupuku wāhanga 4 (wāhanga 1V), me te matepukupuku metastatic. Ahakoa tōna ingoa, tērā pea he mea āpuru te rongona kua pā te matepukupuku maukaha ki a koe.

Ka hoatu tēnei puka i ngā pārongo whānui e pā ana ki te matepukupuku maukaha me ōna maimoatanga. Ka titiro hoki ki ētahi o ngā pānga ā-ngākau tērā pea ka rongu koe, me tōna whakarato i ētahi whakaaro tērā pea, ka āwhina i a koe ki te noho ora.

Hei whakamutunga, kua whakaurua he tekiona e pā ana ki te mahi tautoko i tētahi kua pāngia ki te matepukupuku maukaha, me tētahi tohutohu ki mō ngā āhuatanga whaitake tērā pea, ka hiahia koe ki te whakaaro.

Tērā pea, ka hiahia koe ki te pānui i te puka i te taha o tētahi e āhei ana koe ki te kōrerorero me koe, i te wā o tō haerenga. Tera pea, he mea āwhina koe te pānui i tēnei puka i te taha o ētahi atu o te whānau.

A close-up photograph of a purple flower, likely a lily, with several yellow stamens protruding from the center. The background is a dark, blurred green. The text "UNDERSTANDING ADVANCED CANCER" is overlaid in white, bold, sans-serif font on the left side of the image.

UNDERSTANDING ADVANCED CANCER

Key points

- Advanced cancer happens when cancer cells move from where the cancer first started (the primary site) through the lymphatic system or the bloodstream to grow in different parts of your body.
- Hearing that you have advanced cancer can be a huge shock and it is common to experience a wide range of thoughts and feelings.
- It may be hard to imagine how you will cope, but in time it is likely your emotional strength will return.
- There are things you can do, such as asking questions (see page 17), focusing on the things that make you feel better, and working through a 'bucket list'.
- There is no right or wrong way. Do what works for you.

Te mōhio mārama ki te matepukupuku maukaha

Ngā pūwahi matua

- Ka puta te matepukupuku maukaha ka neke ana ngā pūtau matepukupuku i te wāhi i tīmata tuatahi ai rātou (te wāhi matua) mā te pūnaha lymphatic, mā te ia toto rānei, ka tipu ki ngā wāhi kē o te tinana.
- He mea tino ohorere te rongo kua pāngia koe ki te matepukupuku maukaha, ā, i te nuinga o te wā, ka puta te maha o ngā whakaaro me ngā rongo o te ngākau.
- Tērā pea, he uaua rawa te pohewa, ka pēhea tō tū pakari ai, heoi anō, tāria te wā, kāre e kore ka kaha anō tō ngākau.
- Ara ētahi mahi me whāia e koe, pērā ki te tuku pātai (tirohia a whārangi 17), te arotahi ki ngā mea whakapiki i tō wairua, me te whakatutuki i tō 'rārangi pākete.'
- Kīhai he huarahi tika, huarahi hē rānei. Kei i a koe te tikanga.

What is advanced cancer?

Advanced cancer happens when cancer cells move from where the cancer first started (the primary site) through the lymphatic system or the bloodstream to grow in different parts of your body.

Many people diagnosed with advanced cancer have had cancer before. For some people, a diagnosis of advanced cancer may be their first experience of cancer.

Sometimes cancer is found to have spread without anyone being able to find where it started from (the primary site). This is known as cancer of unknown primary.

The most common areas that cancer may spread to are the bones, liver, lungs, and brain.

Your treatment team may use different words to describe cancer that has spread. You may hear it called metastatic cancer (mets), secondary cancer, or stage 4 (IV) cancer.

Treatment offered to people with advanced cancer is used to control the growth and spread of the cancer, relieve any symptoms you may have, and improve or maintain your quality of life. While advanced cancer is unlikely to be curable, new treatments are being developed and many people live well with advanced cancer for a longer time.

“Working to maintain quality of life during advanced cancer has enabled me to continue to be active in areas that are important to me. Achieving things I always wanted to achieve.”
Phil

Is there a difference between advanced and terminal cancer?

There is a difference between advanced cancer and terminal cancer. Advanced cancer is a term used to describe cancer that is unlikely to

be curable but can be managed with treatment. This is why many people with some types of advanced cancer live well and for a long time.

Terminal cancer is when the cancer is no longer responding to any treatment. Having more treatment, or a different treatment, is not likely to help. Any medication you are given is to keep you comfortable as you near the end of your life.

This booklet focuses on supporting people to live well with advanced cancer.

Dealing with the emotional impacts of advanced cancer

Hearing that you have advanced cancer can be a huge shock. It is very common to experience a wide range of thoughts and feelings and you might be wondering how long you have left to live.



While we all know on some level that we are going to die, most of us do not think about this much. When you hear you have advanced cancer, it is normal to fear that your death may be sooner than you had expected. It is still possible to live with your cancer and get the most out of life, while at the same time planning ahead for future changes in your health.

“I have been living well with no recurrence for eight years.”
Andrew

What can help when you learn that you have advanced cancer

Take time and let the news sink in. Hearing you have advanced cancer touches every part of your life. You may be unsure what to tell family/whānau and friends, and what to do at home and work. It may be hard to imagine how you will cope, but in time it is likely your emotional strength will return.

Make yourself the priority. Think about other stressful situations or times in your life and remember the things that helped you during those times. You may be able to use similar strategies to help now.

Many people find that the more information they have, the more in control they feel. Do not be afraid to ask questions. If you do not understand or remember the first time, it is fine to ask again. It is also fine to not ask at all if you would rather not know. If you do not want to know details of your prognosis (your likely survival time) let your family/whānau and care team know this.

Many people find it useful to know how advanced cancer will affect their lives. It will be hard for your doctor to give you accurate information, as every person's cancer is different. Many people ask how long they have left to live. Some people live much longer than expected and others live a shorter time. Timeframes will be your doctor's best guesses based on their experience. Sometimes they may not feel able to give you an answer.

There are many differences in how each person will experience advanced cancer. This includes what cancer you have, where it is, your age, previous treatments, and whether you have other illnesses that will affect how long you may live.

“ Through my many recurrences and new diagnoses, I learned that focused determination and stubbornness went a long way towards keeping me on my life path. I have always taken the most optimistic view of outcomes and that has served me well. ”
Phil

For some people, getting on with life as usual works for them. For others, focusing on what they want to get done is important. This may be spending time with family/whānau and friends, working through a ‘bucket list’, or sorting through photos. There is no right or wrong; do what works for you.

We talk more about living with advanced cancer later on page (43).

A close-up photograph of a purple flower, likely a lily, with several yellow stamens protruding from the center. The background is a dark, muted green. The text "TALKING TO YOUR CANCER CARE TEAM" is overlaid in white, bold, sans-serif font on the left side of the image.

TALKING TO YOUR CANCER CARE TEAM

Key points

- Your GP and primary care team will work with you to make sure you are well supported as your cancer changes. They will act as the central point of coordination for your care.
- You may be cared for by a team of health professionals that includes oncologists, GPs, and nurse coordinators. Each has a different role to play in your care.
- It is a good idea to think about any questions you may have (some ideas are shown on page 17) before seeing your cancer treatment team.
- When you hear you have advanced cancer, you may wonder how long you have left to live. This can be a difficult question to ask, and hard for your doctor to answer with any certainty.
- Many people in New Zealand have taken part in clinical trials that have improved cancer treatments. The decision to take part in a clinical trial is yours.



Te kōrero ki tō rōpū matepukupuku manaaki i a koe

Ngā pūwahi matua

- Ka mahi tō Rata (GP) me tō rōpū manaaki matua ki tō taha ki te whakarite kei te kaha tautokotia koe i te wā panoni haere tō matepukupuku. Ka tū rātou hei wāhi matua mō te rurukutanga o tō atawhai.
- Tērā pea ka tiakina koe e tētahi rōpū ngaio hauora e mau ana i ētahi kaimātai matepukupuku, i ētahi rata (GP) me ētahi kairuruku tapuhi. He kawenga anō tā tēnā me tēnā, i te taha o tō atawhaitanga.
- He mea pai ki te ata whakaaro i ngā pātai tērā pea ka puta ki a koe (ara ētahi whakaaro kei te whārangi 17) i mua i tō kite i tō rōpū atawhai matepukupuku.
- Ka rongoa ana koe kua pāngia koe ki te matepukupuku maukaha, tērā pea ka whakaaro koe mō te roa o tō oranga. He pātai uaua tēnei ki te pātai, ā, he uaua hoki mō tō rata ki te whakautu i runga me te whai tūturutanga.
- He nui tonu ngā tāngata ki Aotearoa nei kua whakauru ki ngā whakamātautau haumanu kua whakapai ake i ngā maimoatanga matepukupuku. Kei a koe te tikanga ki te whakauru ki tētahi whakamātautau ā-haumanu.

Talking to the team

Your cancer care team will advise you on the best treatment for your advanced cancer.

Your GP and their primary care team will work with you to make sure you are well supported as your cancer changes. They will act as the central point of coordination for your care. They are an essential part of providing you with good symptom management and referrals to other health services. These services can often be provided in your home.

Treatments may include surgery, radiation treatment, targeted therapies, immunotherapy, chemotherapy, and palliative care. Or you may have no treatment at this time.

The treatment suggested for you will depend on the type of cancer you have, the parts of your body that are affected, and your wishes. It is OK to ask for the supporting research and reasoning behind the recommendations you are given.

Your care team

From the time that you are diagnosed with advanced cancer, you may be cared for by one or more of a team of health professionals.

- **Primary care team** — this includes your GP and GP practice nurse, your community pharmacist and sometimes district nursing services.
- **Medical oncologists** — doctors who prescribe cancer-related medicines, including targeted therapy, hormone therapy, chemotherapy, and immunotherapy.
- **Doctors** who are responsible for prescribing targeted therapies, immunotherapy, chemotherapy, and other aspects of cancer care.
- **Radiation oncologists** — doctors who specialise in the use of radiation treatment (radiotherapy).
- **Radiation therapists** — people who plan and give you your radiation treatment.

- **Surgeons** — doctors who may perform surgery to relieve symptoms and help with diagnosis.
- A **cancer nurse coordinator** and/or a **clinical nurse specialist** — a person who acts as a point of contact for you in different parts of the health service. They support and guide you and your family/whānau to keep you fully informed about your care.
- **Outpatient nurses** — nurses who work alongside doctors during their clinics.
- **Palliative care specialist** — a doctor or nurse whose focus is on managing symptoms to make sure you live well with your cancer.

Your care team may also include other health care professionals such as a speech language therapist, research nurse, social worker, psychologist, dietitian, physiotherapist, practice nurse, community health nurse, pharmacist, and occupational therapist, depending on your needs.

Taking part in a clinical trial

There are many new and emerging treatments for cancer and there may be clinical trials available that you could join. Sometimes these trials give you access to new medications that would not be available outside a trial. At other times, trials test drugs that have not been used in many people before and it may be unclear how effective the treatments are and what side effects they might have. You should discuss this with your specialist. Clinical trials are a vital part of the search for better treatments for cancer, to test new and modified treatments and to see if they are better than existing treatments.

Many people in New Zealand and all over the world have taken part in clinical trials that have improved cancer treatments. The decision to take part in a clinical trial is yours. 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 your treatment.



Asking questions

Before your appointment it may help to write down any questions you may have. Let your cancer treatment team know how much information you want to know at that appointment. We suggest you have a support person with you at any hospital appointments. We have included some suggestions of things to talk to your team about on the next page.

“It was really helpful taking a friend with me. She was able to take notes and we could talk about it later. She picked up some things that I totally missed.”

Juliette

How long will I live?

When you hear you have advanced cancer, you may wonder how long you have left to live. This can be a difficult question to ask, and hard for your doctor to answer with any certainty. You could ask your doctor to describe the best-case scenario, worst-case scenario and typical outcomes for your cancer.

It is also OK not to ask this question or to say that you don't want to know. It is always your choice, and your feelings about this may change.

How long you live for will depend on things such as:

- the type of cancer you have
- how well you respond to treatment
- the way your cancer grows
- your general health.

Travelling to treatment

Talk to your treatment team about the National Travel Assistance Scheme if you need to travel long distances for treatment. Information on the scheme is available through the Ministry of Health website. There may also be accommodation options available for you through the Cancer Society (see page 77).



National Travel Assistance Scheme:

www.health.govt.nz/new-zealand-health-system/claims-provider-payments-and-entitlements/national-travel-assistance





Questions you might like to ask your cancer care team

You might like to know more from your cancer treatment team about:

- what your best or worst outcomes might be and what is most likely in this scenario
- what your treatment choices are
- what side effects you might experience
- how to manage those side effects and who you should talk to about these
- how cancer treatment will change your daily life
- whether you will have to stay in hospital, or if you will be treated as an outpatient
- whether you will be able to drive after treatment
- whether you can get help with transport to your treatment
- how long the treatment might take
- whether there will be any costs for you
- whether treatment will affect your fertility or sex life
- whether the cancer will affect your ability to work and your insurance
- whether treatment might affect your ability to look after your children or grandchildren, or older people in your care
- what further treatment you might need and when it would begin
- what other treatments might be available that are not currently funded
- where you can go for a second opinion if you want one
- what will happen if you choose not to be treated
- whether your cancer is likely to be hereditary and whether you should be referred to a genetics service
- how you can prepare yourself for treatment and what you need to take to your appointments
- which health professionals can support you through treatments or provide special help such as advance care planning or Hospice.



COMMON SITES OF ADVANCED CANCER

Key points

- The most common areas cancer spreads to are the bone, liver, lung, and brain.
- Symptoms of cancer that has spread can often be treated to help you feel more comfortable.

Ngā wāhi kitea nuitia ai te matepukupuku maukaha

Ngā pūwahi matua

- Ko ngā wāhi nui rawa te rauroha o te matepukupuku, ko te kōiwi, ko te ate, ko ngā pūkahukahu, me te roro.
- I te nuinga o te wā, taea ai te whakamaimoa i ngā tohumate o te matepukupuku kua rauroha, hei āwhina i a koe kia hāneanea.

Cancer spread to the bone

Some people experience few or no symptoms, but advanced cancer in the bone can cause a constant aching pain. This pain may increase with activity and may also make sleep difficult. Bone pain is caused by:

- cancer pressing on the bone
- cancer in the bone pressing on nerves
- a fracture (breaking) of the bone.

Advanced cancer in the bone may gradually damage some of the bone tissue, causing the bone to become weak. Early treatment by radiation treatment, medication, or surgery may relieve symptoms.

Cancer spread to the liver

The liver is a large organ that can work efficiently, even when part of it is 'out of action'. Many of the symptoms of advanced cancer affecting the liver may be relieved with appropriate treatment/therapy. Diagnosis is made by CT scan, ultrasound, or MRI.

Symptoms may include:

- weight loss
- lack of appetite
- tiredness
- feeling sick
- jaundice (yellowing of the skin)
- discomfort or pain around the liver (the right side of the abdomen)
- ascites (the collection of fluid in the abdomen, causing swelling).

Cancer spread to the lungs

Cancer cells lodging on the outside of the lungs can irritate the lining that covers the lungs (the pleura). This may cause fluid to build up, which presses on the lungs. This is called pleural effusion. Some people notice a definite change in their breathing. Cancer within the lungs or on the lining of the lungs may cause:

- shortness of breath
- dry cough
- tiredness
- chest pain
- shoulder pain
- coughing up blood (haemoptysis).

Talk to your cancer treatment team if you experience breathing problems pain, or cough up blood.

Cancer spread to the brain

The brain is a large organ that, like the liver, often works very well even when part of it is affected by advanced cancer. The symptoms described below can be managed with medication or radiation treatment. Diagnosis is made by CT scan or MRI.

Any diagnosis of cancer in the brain automatically means you must not drive until you have medical clearance.

Symptoms may include:

- headaches that do not go away and may gradually get worse
- feeling sick and vomiting
- weakness in an arm or leg
- unsteadiness while walking
- changes in vision
- seizures
- confusion, disorientation, or personality changes.

A close-up photograph of a purple flower, likely a lily, with several yellow stamens protruding from the center. The petals are a deep purple color, and the background is a dark, blurred green. The text "TREATMENTS FOR ADVANCED CANCER" is overlaid in white, bold, sans-serif font on the left side of the image.

TREATMENTS FOR ADVANCED CANCER

Key points

- Advanced cancer is often managed with more than one type of treatment.
- Treatments may include supportive care, chemotherapy, radiation treatment, hormone therapy, targeted therapies, immunotherapy, and surgery, or other specialist treatments.
- Preparing an Advance Care Plan is a chance for you to express your thoughts and wishes for the future.
- Speak to your cancer care team if you use traditional treatments (such as rongoā Māori) and complementary treatments alongside medical treatments.

Ngā maimoa mō te matepukupuku maukaha

Ngā pūwahi matua

- I te nuinga o te wā, whakahaeretia ai te matepukupuku maukaha mā te maha o ngā momo huarahi maimoa.
- Tērā pea ko te atawhai tautoko, ko te mahi hahau, ko te maimoa iraruke, ko te haumanu taiaki, ko ngā haumanu whakahāngai, ko te immunotherapy, ko te mahi hāparapara, ko ētahi atu maimoatanga mātanga rānei.
- Mā te whakarite Mahere Atawhai Whakamua ka whai wāhi koe ki te whakaputa i ō whakaaro me o hiahia mō ngā rā e tū mai ana.
- Kōrero ki tō rōpū atawhai matepukupuku mehemea whakamahi ai koe i ngā maimoa taketake (pērā ki ngā rongoā Māori) me ngā maimoa whakamihi i te taha o ngā maimoa hauora.

Treatments you may receive

Advanced cancer is often managed with more than one type of treatment. Your treatment may include supportive care, chemotherapy, radiation treatment, hormone therapy, or targeted therapies. Immunotherapy, and in some cases surgery, may be used. You may be offered a combination of treatments.

Treatment for advanced cancer will depend on the type of cancer you have, where it is in your body and how it will affect you. The aim is to control the cancer for as long as possible, improve any symptoms, and improve your quality of life. Sometimes treatment can shrink the size of the cancer or even stop it growing for a while.

Sometimes there will be no benefit in having cancer treatments (such as radiation or chemotherapy), but you will always be offered supportive care. The earlier you access supportive care the better.

Supportive care

Everyone with advanced cancer needs supportive care. Supportive care will mostly be provided by your primary health care team and palliative



care team. It includes the management of physical symptoms, emotional and spiritual support, and guidance to help you plan ahead.

An important part of planning ahead is preparing an Advance Care Plan. This helps you think about what matters to you for your future health care and end-of-life care.

For more information on advanced care planning, visit www.hqsc.govt.nz/our-programmes/advance-care-planning

Specialist palliative care

Palliative care is often provided by your primary health care team 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 family/whānau.

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.

Specialist palliative care can be offered in a hospital, a rest home, at home, or in a 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.

Chemotherapy

Chemotherapy is often used for cancer that has spread. There are a lot of chemotherapy medications that are used in different combinations and have different strengths.

Most chemotherapy is given into a vein (intravenously), but some might be taken as tablets or capsules. Different types of chemotherapy have different side effects. Many side effects do not last long or can be reduced. Common side effects of chemotherapy include tiredness, hair loss, lack of appetite, sore or dry mouth, and increased risk of infection due to a reduction in blood cells.

Some side effects of chemotherapy can be very serious. Contact your treatment team or go to your nearest hospital emergency department **immediately and tell them you are receiving chemotherapy treatment** if you develop any of the following symptoms:

- Fever — a temperature over 38°C.
- Chills — shivers or shakes, feeling hot or cold.
- Vomiting that continues after taking anti-sickness medication.
- Diarrhoea — four or more loose bowel movements than usual.
- Gum or nose bleeds, or unusual bleeding (if bleeding does not stop after 10 minutes of ice and pressure).
- Pain — burning or blood in urine.
- Chest pain.
- Difficulty breathing.



Radiation treatment

Radiation treatment can shrink cancer in the area of the body where it is given, or slow its growth. It is effective for relieving symptoms such as pain from cancer in your bones, pressure, or bleeding from cancer in other areas. Treatment is carefully planned to have the greatest effect on the cancer cells and to limit damage to the normal tissue around the cancer.

Any side effects from radiation are dependent on where it is given and how much is given. Ask your radiation oncologist about which side effects you might experience.

Hormone treatments

Some cancers grow in response to hormones. These cancers are known as hormone-dependent cancers. The aim of hormone treatment is to lower the amount of hormones the cancer gets. This can help slow the growth of the cancer.

There are several different types of hormone therapy. It is usually given as either tablets or injections. The side effects will vary and depend on the individual medication.

Immunotherapy

Immunotherapy is a type of cancer treatment that helps your **immune system** to fight cancer. While this type of treatment works well for some people, it does not help everyone. It is becoming an important treatment option for a number of advanced cancers.

The side effects of immunotherapy vary depending on the type of treatment you receive and how your body responds. The side effects will be different from other treatments. Immunotherapy can cause flu-like symptoms and your immune system to be over-active, resulting in a range of side effects. Immunotherapy is only publicly funded in New Zealand for a limited number of circumstances.



Targeted treatments

Targeted treatments affect the way cancer cells work, and aim to slow or stop the growth of cancer. These treatments are often taken for a long time. You will need to have regular tests to check how well your treatment is working for you.

Although targeted treatments reduce harm to healthy cells, they can still have side effects. These vary depending on the medication used and how the body responds. Talk to your treatment team about any side effects you may have.

Surgery

Surgery is not used as often as other therapies in advanced cancer treatment. It may be used if the cancer is causing symptoms and surgery can help relieve them. Surgery might not remove all the cancer but it can make you feel better if you have been experiencing pain or discomfort. Surgery may be used to remove secondary cancers in the liver, brain, and lung to prevent complications, improve symptoms, or allow other therapies to work better.

Surgery will only be offered if the surgeon believes you are well enough.

When cancer treatment ends

After some time, the treatment you are having may no longer have any effect on the cancer. You might start to get the side effects of the treatment without any of the benefits, and you may wonder if it is worth continuing with treatment. Making a decision like this is always difficult. Talk with your care team and family/whānau and friends before deciding what you want to do.



More information on these treatments

More information about receiving treatments for advanced cancer can be found in the following information, available at www.cancernz.org.nz.

- Secondary Breast Cancer/Matepukupuku ā-Ū Tuarua
- Advanced Melanoma of the Skin/Tonapuku Maukaha o te Kiri
- Chemotherapy, Immunotherapy and Targeted Treatment
- Radiation Treatment/Haumanu Iraruke
- Palliative Care: www.healthnavigator.org.nz/health-a-z/palliative-care.

Other treatments

Complementary or alternative therapies

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

Many people use complementary treatments. Your treatment team is best placed to discuss the safety of combining these with your cancer treatments.

Alternative therapies are treatments used instead of medical treatment. Some alternative therapists may claim they are cancer cures, even if there is no scientific evidence for this.

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

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



For more information on complementary and alternative medicine, go to www.healthnavigator.org.nz/medicines/c/complementary-and-alternative-medicine.

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 that 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 family/whānau or social domain).



Traditional healing methods can include rongoā Māori, romiromi, or mirimiri, to name a few customary remedies based on native plants, massage therapy, and spiritual healing. More information on rongoā Māori and providers can be found here:



www.health.govt.nz/our-work/populations/maori-health/rongoa-maori-traditional-maori-healing.

Hauora Māori

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

Ka huri ētahi Māori ki ngā kaupapa hauora Māori i ētahi wā mēnā he uaua ki te whakatau ko tēhea, ko tēhea ō ngā momo maimoa me whai. Tae noa rā ki te rongoā Māori, te romiromi, te mirimiri rānei, hei tauria atu. Ka hāngai katoa ki tarutaru otaota whenua me ngā rākau, te haumanu romiromi me te whakaoranga ā-wairua.

Mehemea he uaua ki te korere i ō hiahia ki ngā kaiwhakarato maimoatanga, rapua tētahi tangata hei kaitaunaki mōu, kia āhei ai ngā tohunga hauora me matanga maimoa ō ngā hōhipera ki te mahi ngātahi.

Pacific traditional healing

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

If you are thinking about using these treatments, talk about them with your cancer treatment team. The aim is to provide you with the best possible care that has minimal side effects. If you have difficulty expressing your needs to your treatment providers, find someone to advocate on your behalf so that both traditional healers and hospital treatment specialists are able to work together to support you on your cancer journey.



MANAGING SYMPTOMS OF ADVANCED CANCER

Key points

- Some symptoms are side effects of treatment, while others are caused by the cancer itself.
- The main side effects people experience are fatigue, loss of appetite, nausea (feeling sick), pain, breathing problems, and difficulty sleeping.
- There are ways that side effects can be managed, and more information is available on our website at www.cancernz.org.nz.

Te whakahaere i ngā tohumate o te matepukupuku maukaha

Ngā pūwahi matua

- He pānga ki te taha o ngā maimoatanga ētahi tohumate, engari ētahi atu, nā te matepukupuku tonu i puta ai.
- Ko ngā pānga ki te taha rongō ai te tangata, ko te māuiui, ko te kore hiakai, ko te whakapairuaki (te puta o te māuiui), ko te mamae, ko te uaua o te whakahā, me te uaua ki te moe.
- Ara ētahi huarahi anō e taea ai te whakahaere i ngā pānga ki te taha, ā, he nui ngā pārongo ake kei runga i tō mātou paetukutuku kei www.cancernz.org.nz.

This section does not cover every side effect, but it will give you some ideas on ways to manage some of the common side effects to help you live well with advanced cancer.

More information on managing symptoms and side effects can be found on our website. If you are unsure about any symptoms you are experiencing, speak to your GP.

Fatigue

For many people, extreme and constant tiredness (fatigue) can be a significant problem. It can be very distressing for a person experiencing it and for those around them. Some people say tiredness is worse than pain and nausea.

Tiredness can be caused by things like:

- the effects of the cancer
- weight loss and changes in muscle tone
- anxiety
- not sleeping well
- medications and cancer treatments
- anaemia
- infection.

Fatigue is often confused with tiredness. Usually you know why you are tired and a good night's sleep solves the problem. Fatigue is overwhelming tiredness (physical and emotional) and is not relieved by rest or sleep.

Cancer-related fatigue is one of the most common side effects of cancer and its treatment. It can happen to anyone with any type of cancer.

Gentle exercise can help to relieve fatigue.

- If you need time to rest during the day, do not be afraid to say no to visitors.
- Other things that may help include planning ahead and pacing yourself, increasing your fluid intake, and having plenty of nutritious snacks on hand.



For more information on fatigue and suggestions on how to manage it, see the Cancer Society's website www.cancernz.org.nz

Loss of appetite

Changes in appetite can be normal due to the effects of your cancer, treatment, fatigue, pain, anxiety, or depression. Even though you may not feel hungry, your body still needs food to maintain your weight and support your recovery if you are undergoing cancer treatment. However, it is natural for the appetite to reduce gradually as cancer becomes more advanced. Towards the end of life people find they need very little food, and at this stage trying to eat more than the body needs can make people feel worse rather than better.

If you are concerned about losing weight or changes in eating, talk to your treatment team.

The following ideas may help.

- Eat small, regular meals and snacks throughout the day.
- Make the most of your appetite when it is good and you are most hungry.
- If you cannot face food, drink nutritious fluids such as smoothies, flavoured milk and supplement drinks.



People with advanced cancer may develop a muscle-wasting syndrome called cachexia. This is because the cancer can change the way the body uses the energy in food. Even if you are eating well you may lose weight and muscle. Your care team will discuss ways to manage cachexia. These may include exercise, nutritional supplements, and medicines such as appetite stimulants.



For more information, see our information on *Coping with eating problems*, at www.cancernz.org.nz.

Nausea (feeling sick)

If you have advanced cancer it is common to feel sick at some point. It can be caused by many different things including cancer treatments, pain, bowel problems, and anxiety.

People have found the following suggestions helpful:

- Eat small meals at frequent intervals.
- 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.



See more here: www.cancernz.org.nz

Managing pain

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

Pain depends on where the cancer is and how it is affecting your body. For example, your cancer may be pressing on bone, organs, or nerves. It may take a little time to find the most effective pain control for you. Pain management is now recognised as a specialised field for doctors and nurses. **Palliative care** services specialise in pain management.

People with advanced cancer may experience different types of pain.

There is a wide range of pain-relieving medications available to you, depending on the type of pain you have and how it is affecting you.

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

Breakthrough pain is a sudden increase in pain that some people experience even when receiving the right dose of regular pain medication. This may be related to an increase in activity or something like a coughing fit. You can be prescribed additional pain relief at these times.

It is important to remember that pain medications have side effects and these should be discussed carefully with your treatment team.



Read more in our information on *Managing cancer pain* at www.cancernz.org.nz

Breathing problems

Breathing problems are a common symptom for people with advanced cancer. You may find that you have a shortness of breath, tightness, or discomfort in the chest, fast or shallow breathing, or noisy breathing.

One of the common causes of breathing problems is a pleural effusion (a build-up of fluid around a lung). This fluid can press on the lung,



making it hard for you to breathe and causing a feeling of breathlessness. This is managed by removing the fluid.

There may be other reasons for breathlessness, such as the cancer itself, asthma, radiation side effects, anaemia, a clot on the lung, or a chest infection.

Always seek medical attention if breathing becomes difficult.

Treatment for breathing problems will depend on the cause of your shortness of breath. Your doctor may do some tests to find the cause, including a chest X-ray or measuring how much oxygen is making it into your bloodstream.

There are ways of managing long-term breathing problems, including:

- breathing techniques
- medication
- relaxation exercises.

See our information on [Breathlessness \(being short of breath\)](#), which offers suggestions for when you are having difficulty breathing on www.cancernz.org.nz

Difficulty sleeping

There may be times when you find it difficult to sleep. Side effects of cancer and treatment can cause this. Or it may be because you are anxious about treatment or worried about the future. Although you may feel you have been awake all night, you may have managed a few hours of good-quality sleep.

You may find regular exercise and bed-time routines helpful. It is OK to take a nap during the day, but try not to sleep all day. Avoiding stimulants, such as coffee and alcohol, in the evening is a simple step that may help.

You may find a referral for counselling, palliative care, or psychological support helpful.



See our information, *If you have difficulty sleeping* on www.cancernz.org.nz

A close-up photograph of a purple flower, likely a lily, with several yellow stamens protruding from the center. The petals are a deep purple color, and the background is a dark, muted green. The lighting is soft, highlighting the texture of the flower's parts.

LIVING WITH ADVANCED CANCER

Key points

- While having advanced cancer can mean living with uncertainty, some people live with their advanced cancer for many months and sometimes years.
- Learning to manage any uncertainty is an important part of staying healthy, and there are some things you can do to help you cope.
- Grief is a normal reaction to loss or a major change, and an advanced cancer diagnosis can lead to many changes in your life.
- Some people find strength and hope through talking to family/whānau, mindfulness, counselling, or spiritual practices. You may have your own ways of coping with tough times.
- Making healthy choices such as eating well, being active, not smoking, and limiting alcohol can help you live well with advanced cancer.

Te noho me te matepukupuku maukaha

Ngā pūwahi matua

- Ahakoa ka noho pōhēhē koe i te wā pāngia ana koe ki te matepukupuku, ka noho ora tonu ētahi tāngata me tō rātou matepukupuku maukaha mō te hia mārāma, hia tau hoki.
- He wāhanga nui mō te noho ora te ako ki te whakahaere i tō pōhēhē, ā, ara ētahi mea ka āhei koe ki te whakamahi hei āwhina i a koe ki te tū pakari.
- He hohenga noa te pōuri ki tētahi ngaronga, ki tētahi panoni matua rānei, a, ka nui ngā rerekētanga ki tō oranga nā tētahi tohumate matepukupuku maukaha.
- Ka puta ki ētahi tangata te kaha me te tūmanako mā te kōrero ki te whānau, mā te maharatanga, mā te whai tohutohu, mā ngā mahi wairua rānei. Tērā pea kei a koe ake o huarahi ki te tū pakari i ngā wā uaua.
- Mā te whai whiringa hauora pērā ki te kai pai, te whai korikori, te kore kai paipa, me te whakaiti ake i te inu waipiro, e āwhina i a koe ki te noho ora me te matepukupuku maukaha.

Living with uncertainty

Having cancer can mean living with uncertainty. This can be stressful.

You may have times when your cancer is stable and not causing too many problems. Some people live with their advanced cancer for many months or years. For others, the cancer develops more quickly and they have less time.

After a cancer diagnosis you may feel a lack of certainty about what the future holds. Your plans may need to change. You may worry that treatment will stop working. You may worry that you will lose your independence if you need to rely on others to support you.

For many people, having advanced cancer means they should stop driving. This may be because of the effects or risks of the cancer and treatments. Ask your care team about this.

This might be a time to think about 'a new normal' and look for ways to improve your wellbeing and maintain your quality of life.

Regular check-ups will become a routine part of life. It is common to feel anxious before appointments and while waiting for results.

“For me, the best remedy for the unknown future has been to actively work to control what I can, and to live purposefully and meaningfully at all times. Every day, I focus on actions towards goals that engage and motivate me, rather than on the prospect of further illness or death.”

Phil





Managing the ‘what ifs’

Learning to manage uncertainty is an important part of staying healthy. These tips may help you cope.

- It is important to ask for support. Talk with your treatment team about support and resources available to help you if you are struggling.
- Accept that there are things you can control and things you cannot.
- Talk to the Cancer Society or your GP about counselling services.
- Try a local support group or talk with a social worker at the hospital.
- Talk with family/whānau and friends. Tell them how you are feeling and how they can help.
- Learn as much as you can about the cancer and its treatment. Having the right information can help you know what to expect.
- Maintain your usual interests, friendships, and activities that give you time out from cancer.

The impacts of living with cancer long term

Advanced cancer can cause physical and emotional stress. You may be receiving treatments for the rest of your life. The cancer may go through cycles of growing and shrinking or seem to disappear. It is important to remember that, in most cases, advanced cancer may change but it is unlikely to go away completely.

The aim of ongoing treatment for cancer is to help people live as well as possible, for as long as possible. While living with cancer indefinitely is not easy, your treatment team and GP can help you manage the challenges of survivorship and extended treatment.

Your GP or primary care team has an important role in coordinating your care. Contact them first if you feel unwell. They will also provide follow-ups as you need them.

Understanding grief and loss

Grief is a normal reaction to loss or a major change. An advanced cancer diagnosis can lead to many changes in your life. You may grieve about the uncertainty of what lies ahead or the loss of your hopes and plans for the future.

We all express grief in different ways, and it is not as simple as going through stages. Some people describe it as 'waves' of grief and you may feel it at different times. It can affect you physically and emotionally.

People often find their own way to live well with the loss and grief of advanced cancer. A social worker or counsellor can help you and your family/whānau find ways to help you manage any feelings of grief and loss you may experience. The palliative care team can also provide grief support.



- See our information here on talking about grief and loss on www.cancernz.org.nz
- The Hospice New Zealand website has some good resources www.hospice.org.nz



Finding hope

Finding hope is having a sense of optimism about the future. Cancer treatments are improving and many people are living well, for longer.

It can be hard to stay hopeful about your future all the time, and what you hope for may change. It is OK to have days when you feel sad or scared about what lies ahead.

Talking to family/whānau and friends can be reassuring and uplifting. You may have your own ways of coping with tough times that may help you now. Some people find strength and hope through things like mindfulness and affirmations, and counselling can help them find new ways to view their situations.

Spiritual or religious practices can help some people adjust to the effects of cancer and its treatment. People who have a strong faith or spiritual beliefs tend to experience increased hope and optimism, and feelings of inner peace.

Some things that can help

Set the stage for hope — think about the things that bring you joy and take positive action to feel better. You might find you feel better listening to your favourite music, being with people who lift your spirits, or reading inspiring stories of others who have had cancer.

Manage stressful times — try reframing things that are stressful, such as waiting for the results of a scan. Recognising that uncertainty is part of having cancer can help you feel better.

Learn more — knowing more about the side effects of your treatment, how to manage them, and who to call for advice can help you feel more hopeful.

Talk about how you are feeling — for many people, cancer brings a sense of grief and loss. These feelings are normal. Finding trusted people to talk to — family/whānau, a close friend, a counsellor or your spiritual advisor — can be very beneficial.

Look forward — while living in the moment is great advice, having a goal to look forward to can play a role in your coping with the challenges you are facing.

Read inspiring stories — these are the stories of those who have been there and who give so much to others. People like our own local cancer survivors Phil Kerlake and David Downs.

Know that what you hope for can change — hearing bad news that perhaps your treatment is not working or your cancer has come back may mean that your hopes will change. Asking yourself, “What am I hoping for now?” may help you to focus on what is really important at this time.

“Hope boots me out of bed in the morning and lifts my eyes to the sunrise.”
Sophie Sabbage

Living well with advanced cancer

This is a good time to look for ways to stay as well as you possibly can. Eating well, exercising, and relaxing may help to reduce stress and improve your wellbeing. Making healthy choices such as not smoking, limiting alcohol, and reducing other cancer risks can help you live well with advanced cancer.

Ways to improve your wellbeing

- **Get some exercise** — exercising can boost your mood and improve your energy levels. Talk to your doctor or nurse about activities that would suit you best.
- **Keep a diary or journal** — writing can help you to express your feelings, especially if you are unable to talk about them with other people.
- **Try relaxation techniques** — breathing exercises, mindfulness, or meditation can help with anxiety. See the relaxation resources on our further information page 74.
- **Try complementary therapies** such as meditation, acupuncture, and massage that can help to relieve the symptoms and side effects of treatment and help you cope with fear and anxiety. Let your care team know if you are thinking about these therapies in case they could affect your cancer treatment.
- **Keep a part of your life cancer free** so that not all your life is about cancer. Depending on your energy levels, you might want to volunteer at a charity or follow a new interest.
- **Seek spiritual support** — for some people, praying or talking to a spiritual advisor/tohunga is a way to find strength and meaning in times of stress.
- **Try to live in the present** — one way to reduce stress and uncertainty is to make your plans day by day.
- **Plan ahead** — planning ahead is useful for everyone. Many people find it puts their mind at rest to have advance care plans in place and sort out legal and practical matters, even though they still hope to live for a long time.

- **Know that you are not alone** — if your feelings are overwhelming, it is important to get help. Counselling can be helpful if you are finding it hard to cope.
- **Set yourself goals about things you might like to achieve** — these might be personal or family/whānau related. They might or might not be ‘bucket list’ related. They may be things you have always wanted to achieve but not yet had the chance to.

If you are feeling overwhelmed, consider talking to family/whānau and friends, seeking professional help, or joining a support group. If you feel that you cannot talk to someone about your reactions, contact the Cancer Information Helpline **0800 CANCER (226 237)**.



For more information, see the Cancer Society website www.cancernz.org.nz, information on *Living well with cancer - Eating Well and Keeping Active*



A close-up photograph of a purple flower, likely a lily, with several yellow stamens protruding from the center. The background is a soft, out-of-focus green. The text "TALKING TO OTHERS ABOUT YOUR CANCER" is overlaid in white, bold, sans-serif font on the left side of the image.

TALKING TO OTHERS ABOUT YOUR CANCER

Key points

- How your family/whānau communicates about your cancer depends on how you have always spoken to each other.
- Sharing your anxiety and fear can make you feel stronger and help you through difficult times.
- Be prepared for people's responses when you first tell them you have cancer. People can react very differently when hearing distressing news.
- Your children will benefit from an open and honest approach. With support, most parents are able to talk to their children about cancer.
- For some people, meeting others who are in similar situations can help to decrease feelings of anxiety, isolation, and fear. Support groups or online communities offer you the opportunity to share your experiences.

Te kōrero ki ētahi atu e pā ana ki tō matepukupuku

Ngā pūwahi matua

Ka hāngai te āhua o tō whakawhitiwhiti kōrero me te whānau mō tō matepukupuku, ki te āhua o tō kōrerorero ki a rātou i ngā wā katoa. Mā te tuku i o āwangawanga, i ōu pōuritanga hoki, e kaha ake ai koe i ngā wā taumaha.

Kia mataara koe ki ngā urupare ā ngā tangata ka whakamōhiotia atu tuatahi e koe mō tō matepukupuku. He rerekē te urupare a tēnā, me tēnā, ka rongo ana i ngā kōrero whakakohuki.

He whai hua āu tamariki mēnā ka pono, ka tika tō kōrero ki a rātou. Mā te āwhina, e āhei ana te nuinga o ngā mātua ki te kōrero ki ā rātou tamariki mō te matepukupuku.

Mō ētahi tangata, ko te tūtaki ki ētahi atu e rite ana, he mea āwhina ki te whakaiti ake i te āwangawanga, i te tūhāhā, me te matakū. Whakarato ai ngā rōpū āwhina, ngā hapori a-ipurangi rānei, i te whai wāhitanga ki te kōrero mō ōu wheako.

Talking to family/whānau and friends

How your family/whānau communicates about your cancer depends on how you have always spoken to each other. Families/Whānau and friends who frequently share their feelings may be better able than others to talk about cancer and the changes it brings. Some relationships are more private or have one person playing the major role in decision-making.

Being able to share your anxiety and fear can make you feel stronger and help you through difficult times. Talking about your feelings with a family/whānau member or friend who is a good listener could be helpful.

“I did feel a great sense of uncertainty about the prognosis and how to tell my friends and family, in such a way they wouldn't get upset and how to let my work colleagues know.”
Jill

Your family/whānau and friends may have different ideas about your treatment. They may want you to have more aggressive treatment. Or they might try to stop you having certain treatments. If this happens, talk to your treatment team. They can help you talk to your family/whānau if you want them to.



Te kōrero ki tō whānau me ngā hoa

Ka hāngai te āhua o tō whakawhitiwhiti kōrero me te whānau mō tō matepukupuku, ki te āhua o tō kōrerorero ki a rātou i ngā wā katoa. He pai ake pea ngā whānau me ngā hoa kaha ki te toha i o rātou kāre-ā-roto, mō te kōrero mō te matepukupuku me ngā panoni ka puta ake. He āhua noho tapu ake ētahi hononga, kotahi rānei te tangata e kaha ana mō ngā wā whakatau.

Mā te tuku i o āwangawanga, i ou pōuritanga, e kaha ake ai koe i ngā wā taumaha. Tērā pea, he mea āwhina te kōrero ki tētahi o te whānau, tētahi hoa rānei pai rawa mō te whakarongo.

“I did feel a great sense of uncertainty about the prognosis and how to tell my friends and family, in such a way they wouldn't get upset and how to let my work colleagues know.”

Jill

Tērā pea, he rerekē ngā whakaaro a tō whānau, ou hoa e pā ana ki tō maimoatanga. Tērā pea ka hiahia rātou kia whai maimoa kaha ake koe. Tērā pea, ka huri kē rātou ki te whakamutu i tō whai i ētahi momo maimoatanga. Mehemea ka puta tēnei āhua, kōrero ki tō rōpū maimoa. E āhei ana rātou ki te āwhina i a koe ki te kōrero ki tō whānau mehemea ka pīrangi koe.

Suggestions for talking about your advanced cancer

Be prepared for people's responses when you first tell them you have cancer. People can react very differently when hearing distressing news. Some might withdraw and others may become closer.

- Provide clear and honest information and let them know what kind of support you need if this is appropriate.

- Often family/whānau and friends would like to provide support but are unsure how.
- Tell people about the diagnosis when you feel ready and in a way that you feel comfortable with.
- Family/Whānau or friends may be able to tell others what is going on if you cannot.
- People will want to ask you questions. You choose how much information you want to share.
- Many people know people who have had cancer. Some will want to share their thoughts and advice about cancer that you may find upsetting. It is OK to tell them you do not want to hear them right now.
- Let people know if you do not want your cancer details shared with others.



Read more in our information *Telling others about your diagnosis* on our website www.cancernz.org.nz

“Everyone had an opinion about my cancer and they didn’t mind sharing it in an unfiltered, non-thinking way. That was when I felt fear—friends rambling on about this or that person who’d had chemo and what it did to them. In the end I remember thinking I can’t have this ‘talk’ getting into my head, so I shut it down by saying, ‘Everyone is different so there is no reason to think I will experience what you are describing’—sometimes I had to say it more than once.”
Jill

Talking to your children about cancer

Children usually sense something is wrong even if they do not know what it is. Some people avoid telling their children they have cancer.

However, when they are not told what is going on, children may imagine the worst. They may also find out from someone else, which can make them feel angry and confused.

Your children will benefit from an open and honest approach. With planning, practice, and support from family/whānau or health professionals, most parents are able to talk to their children about cancer.

- Consider what you will say and how you will say it before the discussion.
- Talk to children in a language they understand—younger children need simple explanations, while teenagers and young adults might ask for more details.
- Reassure them that their needs are important.
- Communicating with children gives them the opportunity to ask questions and express their feelings.

Tell your family/whānau and other people close to your children (grandparents, friends, and school teachers) about your diagnosis and your plan for talking to your children, so that you all say similar things. Trusted family/whānau and/or friends can also talk to your children about cancer if you feel unable.



Find more information in *Cancer in the Family* on www.cancernz.org.nz

“I was 37 and my children were 1, 4, and 6 years old. My wife and I got some advice about what to tell them. We decided to tell them, ‘Dad is sick and needs some medicine to help him get well.’ We felt this was the right level for their age and ability to understand. Young children don’t need all the details and don’t know what it means anyway.”
Andrew

Getting support from others

It can be hard to ask for support, but it can also be a relief to have others help you.

- Let people know that sometimes all they need to do is listen.
- If you feel up to it, let them know they can feel free to ask questions and share their own feelings.
- Remind people you are the same person you have always been and are still interested in what is happening in the world.
- Respect someone's wishes if they choose not to talk about your cancer. For many people it is helpful, but it is OK if someone chooses not to.
- Think about practical things people can help you with. Be prepared with a list of these if people ask what they can do.
- You could try the Cancer Society's **Support Crew** platform. This will allow your family/whānau and friends to have a way they can easily coordinate help for you. **Support Crew** is a free online support platform www.supportcrew.co.nz

When people stay away

When people hear you have cancer, relationships can change. Some people will be very supportive, while others may withdraw.

People have their own reasons for staying away. They may not be able to cope with their feelings or they may not know how to respond. If you feel hurt by this sort of reaction, a conversation may clear the air. Sometimes accepting that people are unable to offer their support can help you move forward.

Talking to others

Sometimes different support is needed. For some people, meeting others who are in a similar situation can help to decrease feelings of

anxiety, isolation, and fear. Support groups or online communities offer you the opportunity to share your experiences. Counsellors and psychologists can help you talk about your feelings and the impacts a cancer diagnosis can have, and help you work on coping strategies.



The Cancer Society can link you with local support groups and services that you may find helpful. Phone the **Cancer Information Helpline 0800 CANCER (226 237)** for more information.

Looking forward

Living with advanced cancer will have many challenges. As new treatments are being developed, many people are living well with advanced cancer for a longer time. Looking after your physical, spiritual, and mental wellbeing can help your quality of life and enable you to enjoy the times you have with the people close to you.

Remember the simple things that give you joy — me aro tonu ki ngā mea māmā noa i ngākau harikoa ai koe.



**SUPPORTING
SOMEONE WITH
ADVANCED
CANCER**

Key points

- Your own health and wellbeing are important.
- Your role as a carer will depend on what the person needs and what you are able to offer.
- Find practical ways that family/whānau and friends can help you.
- Caring for your partner may affect the balance of your relationship. It can be helpful to know what supports are available to you, such as carer entitlements and respite care.

Te tautoko i tētahi kua pāngia ki te matepukupuku maukaha

Ngā pūwahi matua

- He mea nui tō hauora me tō toiora.
- Ka hāngai o kawenga hei kaitiaki ki ngā hiahia a te tangata me tērā e āhei ana koe ki te whakarato.
- Rapua ngā mahi whai kiko e āhei ana te whānau me ngā hoa ranei hei āwhina i a koe.
- Tērā pea ka paku raru tō hononga inā kei te tiaki koe i tō hoa moe. He mea nui kia mōhio koe mō ngā tautoko e wātea ana ki a koe, pērā ki ngā whakawhiwhinga kaitiaki me te atawhai tānga manawa.

Supporting someone close to you

Supporting someone with cancer can be one of the hardest things you can do, but also one of the most rewarding. There are different levels of care you might provide. You may be the emotional carer and/or the physical carer. You may now be the one who is doing all the cooking, looking after finances, and looking after children. You may be taking your loved one to treatments. Or you may be the one doing all the listening and supporting.

A carer is often closest to the person with cancer and knows them best. Every caring situation is different. Your role will depend on what the person needs and what you are able to offer.



We suggest you read *Supporting Someone with Cancer*, which is available on our website www.cancernz.org.nz

A Guide for Carers — this guide is a practical help for whānau, aiga, and carers who assist family/whānau members and friends who need help with everyday living because of a health condition, disability, or injury.
www.msd.govt.nz/what-we-can-do/community/carers

A Guide for Carers, Hospice New Zealand — information and support for people caring for someone with a life-limiting condition. It includes information on being a caregiver, caring for a loved one, circles of support, home nursing, and practical matters.
www.hospice.org.nz/wp-content/uploads/2019/03/A-Guide_for_Carers_WEB.pdf

Ways family/whānau and friends can help

As a family/whānau member or friend of someone who has been diagnosed with cancer, you may want to help but not know what to do.

Here are some suggestions that may be useful.

- Learn about cancer and its treatment. This will help you to understand what the person you are supporting is coping with.
- Be thoughtful about offering advice. Listening while they talk or just being there with them are good ways to show you care.
- Talk about your feelings together and be honest about what worries you.
- Offer to go to appointments with them. You can be there for support, to take notes or, when appropriate, to take part in the discussions.
- Provide practical support, such as preparing meals, doing housework, driving them to appointments, doing gardening, or providing childcare.

When your partner has advanced cancer

You may find yourself caring for your partner. This may affect the balance of your relationship as you take on different roles. This can make your relationship stronger, or it can show up problems that may already be there. Talk about things together so that you both understand what each other wants and needs.

Knowing what is available to you, such as respite care, counselling, carer support (in the home), and palliative care services, can help you manage at this time. Contacting these services early can help you get the support you need when you need it. Your GP is best placed to help you with this.

You may find the intimacy you have shared with your partner changes. You may find it hard to be a carer for your partner and think about them sexually. Talking openly can help you both feel closer.

It is important to take care of your own physical and emotional health.

Carer entitlements

If you are caring for someone else, Work and Income may be able to help you depending on your situation. The person you are caring for would need hospital, rest home, or residential care without you looking after them. Social workers are the best people to help you access your entitlements. GPs can also help to fill in Work and Income forms.



- Go to this page to find out what you might be entitled to if you or someone you care for need income support. You will need a medical certificate.
www.workandincome.govt.nz/eligibility/carers/care-illness-disability.html
- For practical assistance or respite care you will need a referral from a health professional to get an assessment from a Needs Assessment and Service Coordination service. Find out more on this here.
www.health.govt.nz/your-health/services-and-support/disability-services/getting-support-disability/needs-assessment-and-service-coordination-services

Self-care for carers

If you are caring for someone, your own health and wellbeing are important. Be clear with the person with cancer about what you can and cannot do to help them. Make the effort to take some time for yourself each day.

- Ask for help.
- Go to the doctor if you feel unwell.
- Get enough good food, sleep, and exercise.
- Think about joining a support group.
- Take time out when you need it.
- Keep up your social contacts where and when you can. Your local hospice may run a programme for carers.



Adjusting to change

Cancer is not just one stressful event to be dealt with and moved past — it is a series of changing situations and demands. You may need to:

- if you have young children, talk to their school about what is happening
- talk to your employer about what is happening at home and arrange some leave if needed
- talk to your bank about changing financial commitments to make them more manageable.

Changing roles

When someone close to you is diagnosed with cancer, there may be changes in family/whānau roles and routines. The person with cancer may not be able to manage all their usual roles and tasks. They may be more dependent on you. You may have to take on roles that do not come easily or that you find hard to manage.

At first, a shift in roles may be difficult for you both. Talk together about how you are both coping with these changes. You may decide to do less housework, simplify tasks where possible, or accept offers of help from family/whānau or friends.

When the going gets tough

Many people supporting someone with cancer say they have times when they feel they have had enough!

- Try to have one thing to look forward to every day, such as a catch-up with a friend, a coffee date, or some time to yourself to read or go for a walk.
- Do not be afraid to ask for help.
- It is OK to feel angry, to cry, and to let people see how you are feeling.
- Talk about your feelings with a close friend or relative or seek help from a counsellor.
- Some people find their religious and spiritual beliefs help them cope with their emotions.
- You cannot do everything, so do not expect to. There may be days when you need to leave certain things like the washing or cleaning.
- Remember — there are some things you just cannot change!



A GUIDE TO PRACTICAL THINGS

Key points

- This is a good time to make some practical decisions.
- You may want to think about things like planning funerals, tangihanga, organising financial and legal support, and making a will.
- Preparing an Advance Care Plan will guide your doctors and family/whānau in making decisions if you are unable to make them yourself.

He tohutohu ki ngā mea whai kiko

Ngā pūwahi matua

- I mua i te matenga o tētahi, he mea pai ki te whakarite i ētahi whakataunga whai kiko.
- Tērā pea, me whakaaro mō te tangihanga, mō te whakarite tautoko ā-ture, a-pūtea, me te whakarite wira.
- Mā te whakarite Mahere Atawhai Whakamua e ārahi i ō rata me te whānau ki ngā mahi whakataunga mehemea kāre e taea e koe te mahi.

Some decisions to make

This is a good time to think about making some practical decisions about things that are important to you. This may include planning funerals, deciding care for children, and what might happen to your things after death. It's a time to organise finances, insurance and unpaid debt.

It is useful to keep your important papers together in a safe place that your family/whānau or lawyer knows about, along with a list of your passwords. Some websites will let you set up proxy users in the event of your death, for example a Facebook legacy contact.

Advance care planning

Advance care planning helps you to think and talk about the end of your life, and about the treatments and care you might want. It gives you and your health care providers an opportunity to work together to ensure that your choices about treatment and care in the future are heard. An Advance Care Plan will guide your doctors and family/whānau in making decisions if you are unable to make them yourself. Advance care planning is voluntary—no-one can force you to do it.

For more information on advance care planning, visit this site:
www.hqsc.govt.nz/our-programmes/advance-care-planning

Financial and legal support

Financial support—benefits and entitlements

If you can no longer work because of the effects of your cancer, you may be entitled to receive income support from Work and Income. A social worker may be able to help you with advice and advocacy in this area.

Talking to your bank

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



For more information, visit these pages:

- Applying for KiwiSaver Hardship <https://sorted.org.nz/must-reads/applying-for-kiwisaver-hardship>
- See our information on *Benefits and entitlements and Benefits and entitlements: What happens when you apply for Work and Income support?* on our website www.cancernz.org.nz.

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.

What is 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 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 family/whānau, a friend, or a solicitor.

| Ordinary Power of Attorney | Enduring Power of Attorney |
|--|---|
| <p>This is used when you are still able to manage your own affairs.</p> | <p>There are two types of EPA.</p> <ul style="list-style-type: none"> • Property. • Personal care and welfare. <p>You must set them up while you are able to manage your own affairs.</p> |
| <p>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).</p> | <p>Property — authority can start immediately. You can nominate more than one person to manage your property.</p> |
| <p>You can have one or more people acting on your behalf.</p> | <p>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.</p> |



For more information, visit these websites.

- Community Law — www.communitylaw.org.nz
- Citizens Advice Bureau — www.cab.org.nz/vat/gl/roi/pages/powersofattorney.aspx

Making a will

A will states what will happen to your belongings when you die. For those left behind, a will simplifies matters, especially if you leave assets such as property or money.

It is best to get legal advice on writing your will from a solicitor or community law office. Do-it-yourself kits are available, but be aware they may not be legally binding.

Unpaid bills and debt

Most debts, such as credit card debt, mortgages, and loans, need to be paid back after you die. Things that you own, for example your house or car, could be sold to pay back your debt.

Your debt will not be given to your children, but they may miss out on their inheritance if you have debts that need to be repaid.

Planning your funeral

Some people want to plan their own funerals, memorial services, or other tribute events. Others may not. If you are ready, this is something you can do with your family/whānau and friends.



Find more advice at these sites.

- www.fdanz.co.nz/planning-a-funeral/prearrange-your-funeral
- www.bettersendoff.co.nz
- Tangihanga: www.communitylaw.org.nz/community-law-manual/chapter-16-a-death-in-the-family/funerals-and-tangihanga/tangihanga

More information on end of life



- www.govt.nz/browse/family-and-whanau/death-and-bereavement/what-to-organise-before-you-die
- endoflife.services.govt.nz/welcome

Further information

Cancer Council Australia — *Living with Advanced Cancer* (2017).
www.cancer.org.au

Hospice New Zealand — www.hospice.org.nz

Irish Cancer Society — Metastatic (Advanced) Cancer.
<https://www.cancer.ie/cancer-information-and-support/cancer-types/metastatic-cancer>

Kenzie's Gift — <https://www.kenziesgift.com>. This is a New Zealand site that supports children, young people, and families through serious illness, cancer, and/or grief.

Macmillan UK — *Coping with Advanced Cancer* (2019).

Phil Kerlake — *Life, Happiness... and Cancer*, Life Paths Publishing, Wellington, New Zealand (2006)

Sophie Sabbage — *The Cancer Whisperer: Finding Courage, Direction and the Unlikely Gifts of Cancer*, Hodder & Stoughton, United Kingdom (2017)

Sweet Louise — *A Guide to Life with Secondary Breast Cancer* (2018).
<https://sweetlouise.co.nz/wp-content/uploads/SL-GUIDE-Book-FINAL-H-WEB.pdf>

Wendy Schlessel Harpham — *Healing Hope—Through and Beyond Cancer*, Curant House, United States (2018).
Blog www.wendyharpham.com/writing

Wendy Schlessel Harpham — *Finding Hope that Heals* (2020).
Free e-book <https://www.nationalbreastcancer.org/resources/finding-hope-that-heals-ebook>

Podcasts

Cancer Council Australia:

Managing Fear

www.cancerCouncil.com.au/podcasts/episode-11-managing-fear

Coping with a Cancer Diagnosis

www.cancerCouncil.com.au/podcasts/episode-1-coping-with-a-cancer-diagnosis

Living Well with Advanced Cancer

www.cancerCouncil.com.au/advanced-cancer-podcasts/living-well-with-advanced-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

Domain Lodge
1 Boyle Crescent
Grafton
Auckland
09 308 0160

Daffodil House
73 Kamo Road
Kensington
Whangarei
09 437 559 360

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

Waikato/Bay of Plenty

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

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

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

Central Districts

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

3 Koromiko Road
Whanganui
06 348 7402

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

Morris Adair Building
Gisborne Hospital
Gisborne
06 867 1795

310 Orchard Road
Hastings
06 8767638

Addis House
135 Ruahine Street
Palmerston North
06 356 5355

Winchester House
112 Winchester Street
Levin

REAP Building
15 Gordon Street
Dannevirke

Wellington

52-62 Riddiford Street

Wellington

04 389 8421

27 Kāpiti Road

Paraparaumu

04 298 8514

37 Te Ore Ore Road

Masterton

06 378 8039

102 Hardy Street

Nelson

03 539 1137

The Forum Building

Market Street

Blenheim

03 579 4379

info@cancersoc.org.nz

Canterbury-West Coast

97 Fitzgerald Avenue

Christchurch

03 379 5835

98 High Street

Greymouth

03 768 9557

32 Memorial Avenue

Timaru

03 688 0124

6B Kidman Street

Rolleston

03 925 9708

122 Kermode Street

Ashburton

03 307 7691

contact@cancercwc.org.nz

info@cancercwc.org.nz

Otago and Southland

283 Great King Street

Dunedin

(03) 477 7447

SupportiveCare@cansoc.org.nz

Waitaki District Community House

100 Thames Street

Oamaru

(03) 434 3284 or 027 674 4200

Arcade 84

5/37 Clyde Street

Balclutha

(03) 418 3916 or 027 277 7632

Alexandra Community House Office

14-20 Centennial Avenue

Alexandra

(03) 440 0754 or 027 580 0640

Wanaka Community House

40 McDougall Street

Wanaka

112B Aurum House

1092 Frankton Road

Queenstown

(03) 442 4281 or 027 536 0066

Southland

149 Spey Street

Invercargill

(03) 218 4108

National Office

39 The Terrace

WELLINGTON

04 494 7270

admin@cancer.org.nz

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www.cancernz.org.nz

ANY CANCER, ANY QUESTION
0800 CANCER (226 237)
Cancer Information Helpline

