

Quick Links

Advanced Cancer

04 Introduction

06 Section 1:
Living with
advanced cancer

43 Section 2:
Towards the
end of life

51 Section 3:
Services and
information

52 Directory of
services

54 Questions checklist

56 Suggested reading
and websites

57 Glossary

59 Notes

61 Feedback



LIVING WITH CANCER

Advanced Cancer Matepukupuku Maukaha



A guide for people with advanced cancer



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Copyright © 2008, Cancer Society of New Zealand Inc,
PO Box 12700, Wellington 6011.
First Edition 2008 ISBN 0-908933-76-2

Publications Statement
The Cancer Society’s aim is to provide easy-to-understand and accurate information on cancer and its treatments and the support available. Our cancer information booklets are reviewed every four years by cancer doctors, specialist nurses, and other relevant health professionals to ensure the medical information is reliable, evidence-based, and up-to-date. The booklets are also checked by consumers to ensure they meet the needs of people with cancer.

This edition of *Advanced Cancer/Matepukupuku Maukaha: A guide for people with advanced cancer* includes new features in response to suggestions from those who review our booklets, and to meet the needs of our readers. Our key messages and important sections have been translated into te Reo Māori. Our translations have been provided by Hohepa MacDougall of Wharetuna Māori Consultancy Services, and have been peer reviewed by his colleagues. The personal quotes included in this booklet are from interviews with people who have been diagnosed with advanced cancer. We thank New Zealand writers Renée and Glenn Colquhoun and his publisher Steel Roberts for allowing the Cancer Society to reprint Glenn’s poem from his book *Playing God* in this edition.

Other titles from the Cancer Society of New Zealand /Te Kāhui Matepukupuku o Aotearoa

- Booklets**
Bowel Cancer/Mate Whēkau Pukupuku
Breast Cancer/Te Matepukupuku o ngā Ū
Chemotherapy/Hahau
Eating Well/Kia Pai te Kai
Got Water?/He Wai?
Lung Cancer/Matepukupuku Pōkahukahu
Melanoma/Tonapuku
Prostate Cancer/Matepukupuku Repe Ure
Radiation Treatment/Haumanu Iraruke
Secondary Breast Cancer/Matepukupuku Tuarua ā-Ū
Sexuality and Cancer/Hōkakatanga me te Matepukupuku
Understanding Grief/Te Mate Pāmamae
What do I tell the Children?/He Aha He Kōrero Maku Ki Āku Tamariki?

- Brochures**
Being Active When You Have Cancer
Questions You May Wish to Ask
Talking to a Friend With Cancer
When You Have Cancer



Advanced Cancer Matepukupuku Maukaha

A guide for people with advanced cancer



Contents

Introduction	4
A guide for people with advanced cancer	4
How cancer spreads	5
Cancer of an unknown primary	6
Section One: Living with advanced cancer	9
First reactions	10
Am I going to die?	10
What do I do now?	11
Hope	14
The emotional impact	17
Worry, anxiety, and panic attacks	19
Depression	20
Talking about it	22
Support groups	23
Taking care of yourself	24
Other people's reactions	26
Parenting with advanced cancer	28
Teenage children	31
Adult children	34
Parents	35
Partners	36
Changes in roles and routines	39
If you live on your own	40
Financial assistance	41
Sexuality and advanced cancer	42
Sites of secondary cancer	44
Bone secondaries	44
Liver secondaries	46
Lung secondaries	47
Brain secondaries	48
Symptoms that may occur with advanced cancer	49
Tiredness	49
Nausea (feeling sick)	53

Pain	54
Breathlessness	58
Lack of appetite	60
Treatment for advanced cancer	62
Chemotherapy	64
Surgery	66
Radiation treatment	67
Hormone therapy	68
Monoclonal antibodies	68
Bisphosphonates	69
Palliative care	70
Hospice care	71
Complementary therapies	72
Alternative therapy	73
Deciding about treatment	74
When treatment seems too much	77
Legal information	78
Your rights when receiving a Health or Disability Service	80
Section Two: Towards the end of life	83
Talking about death	84
How long have I got?	85
Facing death	87
Making a will	88
Planning your funeral	89
What is death going to be like?	93
Section Three: Services and information	99
Directory of services	100
Questions checklist	104
Suggested reading and websites	108
Glossary	110
Notes	114
Feedback	119

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Introduction

A guide for people with advanced cancer

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, metastatic, and progressive cancer. Whatever words used, it can be devastating to hear your cancer has advanced. This booklet offers general information about advanced cancer, telling you what might happen and where help can be found.

Being diagnosed with an advanced cancer is a very frightening experience. The aim of this booklet is to acknowledge this experience and the different things that advanced cancer means to each of us. For some it may be a slow progressing illness, for others it's more rapid.

Quotes in this booklet are from people with advanced cancer: how they described their illness and what has helped them. This booklet includes a section on the end of life that may not be relevant for you at this time.

Reading the booklet may stir up difficult feelings. You may want to read it with someone so you can talk things over as you go. Giving this booklet to others in the family may also be helpful.

The words in **bold** are explained in the glossary.

How cancer spreads

Sometimes, **cells** move away from the original (**primary cancer**) through the blood or **lymphatic system** and invade other organs. When cancer spreads from the place where it first grew to other parts of the body it is known as secondary, metastatic cancer or advanced cancer.

Advanced cancer usually cannot be cured. Often it can be treated to slow growth and spread and reduce symptoms.

An exception would be testicular cancer that has spread which is still often curable with modern chemotherapy. Cancers of the lymph glands (lymphoma) may arise in a number of sites at the same time but may be cured.

Knowing more about a type of cancer can help make sense of symptoms and the treatments that may be offered.

When a cancer spreads from a primary site, for example, prostate cancer to the bones, it is called secondary, metastatic, or advanced prostate cancer. The cells that make up the **tumour** in that bone are prostate cancer cells. Your doctor will still call it prostate cancer. This is very different from having a primary bone cancer.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



The difference between primary and **secondary cancer** is important for treatment. The treatment for secondary prostate cancer in the bone is designed to treat prostate cancer, while the treatment for primary bone cancer is designed to treat bone cancer.

If a primary cancer can be found, this helps doctors to decide what treatment to recommend. However, if a primary cancer can't be found, doctors can still recommend particular treatments. For example, if the cancer is only in one area, it might be treated with an operation or with radiation. If the cancer has spread to several areas of the body, generally, **chemotherapy** is recommended.

Cancer of an unknown primary

Sometimes cancer is found to have spread without us knowing where it started from (the primary site). Because doctors don't know where the cancer comes from, these cancers are difficult to treat.

Kupu whakataki

He aratohu mā ngā tāngata kua kaha rawa te mau o te matepukupuku.

He tino pai tēnei pukapuka mehemea kei te pāngia koe ki te matepukupuku maukaha ā, kei te kimi mōhiohio koe, kei te kimi tautoko rānei.

He maha ngā ingoa mō te matepukupuku kua kaha rawa te neke ki tua atu o ngā wāhanga tīmatatanga o te mate, pērā ki te matepukupuku maukaha (advanced), te matepukupuku tuarua, te matepukupuku metastatic me te matepukupuku pikihaere (progressive). Ahakoa ngā kupu ka whakamahia, he mea tino pōuri te rangona kua maukaha tō matepukupuku. He mōhiohio whānui kei roto i tēnei pukapuka e pā ana ki te matepukupuku maukaha rawa, e kōrero ana mō ngā āhuatanga tērā pea ka puta, me ngā huarahi e taea ai te āwhina.

He mea tino whakamataku te rangona kua pā te matepukupuku maukaha. Ko te whāinga o tēnei pukapuka ko te whakatau i tēnei wheako me ngā āhuatanga rerekē o te matepukupuku maukaha e ai ki tēnā, ki tēnā.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



He mate pōturi, he mate kauneke haere hoki tēnei mate mō ētahi o tātou. Mō ētahi atu, he tere kē te heke; ka mate ētahi i te matepukupuku, ko ētahi atu ka noho ora tonu.

I tangohia ngā kōrero whakahua kei roto i tēnei pukapuka mai i ngā ngutu o te hunga matepukupuku maukaha; ko tā rātou titiro ki tō rātou mate me ngā mea i āwhina i a rātou.

He wāhanga kei roto i tēnei pukapuka e pā ana ki te wā mate ai te tangata. Tērā pea kāore e hāngai ki a koe i tēnei wā.

Kāore e kore ka kōnatunatu ngā kare ā-roto i te pānuitanga i tēnei pukapuka. Tērā pea ka pīrangi koe ki te pānui i te pukapuka i te taha o ētahi atu kia pai ai tō kōrerorero me rātou. Tērā pea he pai noa iho te hoatu ki ētahi atu o tō whānau hei āwhina i a rātou.

He whakamārama kei te rārangi kupu mō ngā kupu kua miramirahia.

Section One: Living with advanced cancer

Te noho ora me te matepukupuku maukaha

04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



First reactions

Some people say the diagnosis of secondary cancer is more traumatic than when they were first diagnosed with cancer.

For people who did not even know that they had primary cancer, a diagnosis of advanced cancer can be a huge shock. It is very common to experience a wide range of thoughts and feelings. These may include shock, numbness, anger, blame, anxiety, fear, uncertainty, confusion, helplessness, hopelessness, denial, irritability, being overwhelmed, sadness, loneliness, disappointment, and disbelief.

Uruparenga tuatahi

E kī ana ētahi tāngata, he ngaukino ake te rongo kua pā te matepukupuku tuarua, ki tērā te wā i kitea tuatahi ai tō rātou matepukupuku.

Am I going to die?

While we all know we are going to die, the change that happens when you hear the news of your advanced cancer is that you fear that death will be soon. You may fear it will come with pain and suffering.

The challenge at this time is how to live with your cancer and how to get the most out of life.

“There is still a life to be lived, pleasures to be found and disappointments to be had. Living with advanced cancer is a different life, not a journey towards death.” **Judith**

Ka mate au?

Ahakoā tā tātou mōhio, ā tōna wā ka mate tātou katoa, ki te rongo mō te pānga o te matepukupuku maukaha, ka rerekē tō āhua nā te mea ka matakū koe kāore koe e ora roa. Ka matakū koe i te whakaaro mō te mamae me te hīwiniwini.

Ko te wero i nāianei, me pēhea te noho ora me tō matepukupuku.

“He oranga tonu kei mua, he nui tonu ngā mahi pārekareka me ngā mahi pāpōuri kei mua. Ko te noho me te matepukupuku maukaha tētahi mea rerekē, ēhara i te mea he haerenga tere ki tō mate.” **Nā Judith**

What do I do now?

Take time and allow the news to sink in. Hearing you have advanced cancer touches every part of your life. You may be unsure what to tell family 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 usual resilience will return.

Many people find that the more information they have the more they can feel in control of their situation. Don’t be afraid to ask questions. If you don’t understand or remember the first time, it is fine to ask again.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Some patients and families find it very useful to have some ideas of time. It is very hard for your doctor to give you accurate information as every person’s illness is different. This time frame will be the doctor’s best guess based on their experience of other people with similar disease in similar circumstances. There are so many differences, including what cancer you have, where it is, how old you are, previous treatments, and whether you have other illnesses.

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

For some people, going on with life as they normally would is what they feel most comfortable doing.

For other people, it’s thinking about what is most important for them, and perhaps making a list and prioritising. Maybe you have always wanted to paint, or learn te Reo Māori. If you are able to, why not do these things now? For some it will be spending time with family and friends. For others it will be getting their affairs in order, e.g. sorting out their photographs, making or updating their will, or planning their funeral. Other people will not want to do any of those things and prefer to live day to day.

“Although my diagnosis is an incurable cancer with **metastases** that won’t go away, I still have life and feel its quality can be improved with the right kind of encouragement even if this is temporary.” **Dorothy**

Me aha au i nāianeī?

I tō rangona mō tō mate, tukuna te wā kia rere – āta whakaarohia. Ka pā te rongo kua maukaha tō mate ki te katoa o tō āhua noho, tō āhua toiora hoki. Tērā pea kāore koe i te tino mōhio me pēhea te whakamōhio i tō whānau, i ō hoa hoki, ā, me aha hoki koe i te kāinga, i te mahi rānei. Tērā pea he uaua ki te pohewa ka pēhea tō pūkai i tō mate, heoi, kāore e kore ka pai ake inā ka waia haere koe.

Māu tonu e whakarite ko koe kē te mea nui. Whakaaro mō ngā wā i pēhia koe e te taumaha, e te ahotea, ka whakaaro ake mō ngā mea i āwhina i a koe i aua wā. Tērā pea ka taea e koe te whakamahi i aua rautaki i tēnei wā.

Mō ētahi tāngata, ko te whai tonu i tō rātou ake āhua noho i mua i te pānga o te matepukupuku, tā rātou e hiahia ana. Ko ētahi atu, ka whakaaro kē mō ngā mea hira mō rātou ake. Tērā pea, ko te whakarārangi i ngā mea hira te mea tuatahi, kātahi ka whakarite ko ēhea ngā mahi tuatahi hei whakatutuki. Tērā pea kua roa koe e hiahia ana ki te whāwhā i ngā mahi peita, i ngā mahi ako i te reo Māori, ki te haerere i te ao whānui rānei. Oti rā, ki te taea e koe, he aha te hē o te whakatutuki i ēnei wawata i nāianeī.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Ko ētahi atu tāngata, tērā pea ko te noho i te taha o ō rātou whanaunga, ō rātou hoa, te mea nui. Ko ētahi atu, ko te whakariterite i ō rātou kaipakihi arā, te whakatikatika i ō rātou whakaahua, whakahōu i tō rātou wira, whakarite i ngā āhuetanga mō tā rātou tangihanga. Arā anō ētahi atu tāngata, kāore e pīrangi ana ki te mahi i ēnei mahi katoa.

“Ahakoa kua kitea he mate kore oranga taku matepukupuku me te puta o ngā metastases kore wehe atu, ko te mea kē kei te ora tonu au, ā, mā te hāngai o ngā manawa tika, ka piki te kounga o taku oranga ahakoa he mea taupua noa iho.” **Nā Dorothy**

Hope

A sense of hope sustains us. We hope for things we’d like to achieve in the future; perhaps the birth of a child or a grandchild, a successful career, or an overseas trip. You may have many hopes and dreams for yourself and your family/whānau.

A key aspect of hope is that it leads us to the expectation of a better future. When you have advanced cancer you may feel robbed of hope and it might be difficult to trust in the future. However, in time and with support you may be able to redefine what you are hoping for, and focus on the things in life that matter most to you. You might explore new treatments or take part in a clinical trial as a way of helping yourself and others in the future. You might focus more on planning your life day by day.

Some people say that living in the present helps them get more out of each day than when they were always planning ahead. Using your supports: your close relationships and values can be satisfying. Hope is dynamic and while what you hope for may change as your circumstances change, it is important to keep hope alive.

“Hope is the thing with feathers that perches in the soul
And sings the tune without the words
and never stops at all.” **Emily Dickinson**

“You can turn your back on tomorrow and live for yesterday,
or you can be happy for tomorrow because of yesterday.” **Jill**

“At age 49, Ian had an operation to remove a tumour from his bowel, and soon after was diagnosed with cancer of the liver. While the rest of us struggled to come to terms with this news, he was planning his future. These plans didn’t merely stretch into the six months that the doctors had allotted for him.” **John**

“For me personally what kind of goals can I make? Where to go with life so as to continue to be of use to others and not become a recluse? If the cancer is advanced, inevitably, worse will come. Why project my fortune for today for what may happen weeks or months down the track?” **Dorothy**



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Tūmanako

Ko te tūmanako te mea e ukauka ana i a tātou. Ka puta te tūmanako mō ngā mea ka taea i ngā rā kei te tū: tērā pea ko te whai tamariki, mokopuna rānei, tērā pea ko te whai mahi angitū, ko tētahi haerenga rānei ki tāwāhi. Tērā pea he tini ōu tūmanako, ōu moemoeā mōu ake me tō whānau.

Ko te mea matua o tēnei mea te tūmanako, ko tōna kawē i ō tātou wawata kia tiro whakamua ki tētahi huarahi pai ake. Ka pāngia ana koe ki te matepukupuku maukaha tērā pea ka whakaaro koe kāore he take o ngā tūmanako ā, kāore koe e whakapono ana ka pai noa iho ngā rā kei mua i a koe. Heoi anō rā, mā te wā, me te whai haere i ngā tautoko, tērā pea ka āhei koe ki te tautuhi anō i ōu ake tūmanako, me te whakahāngai i tō aro ki ngā mea nui rawa atu mō tō oranga pai. Tērā pea ka titiro koe ki ētahi maimoatanga hōu, ka uru rānei koe ki ētahi whakamātauranga haumanu (clinical trial) hei huarahi ki te āwhina i a koe anō me ētahi atu. Tērā pea ka hāngai kē koe ki te mahere i ō mahi mō ia rā, ia rā anake.

E ai ki ētahi, he pai ake ki a rātou te noho ki roto i ngā mahi o ia rā, ia rā anake, i te mea ka nui ake te pai ki tērā o te mahere whakamua i ngā mahi i ngā wā katoa. Mā te whakamahi i ō kaitautoko, ō kaiwhaipānga tata, ka nanea koe i te piki o tō kaha me ō uara. He mea akiaki tēnei mea te tūmanako, nā reira ahakoa ka rerekē tētahi āhuatanga i tūmanakohia e koe ki tāu i whakaaro ai, ko te mea nui me whai tonu kia kaha tō whakaputa tūmanako ahakoa aha.

The emotional impact

It can seem easier to turn away from painful thoughts and feelings. There is no right or wrong approach.

“I saw the specialist and he said ‘I’m afraid to tell you it’s incurable.’ That word, ‘incurable!’ was so powerful. And I picked up a cancer booklet somewhere and there it was again, so it must be true. It took a long time to accept that.” **Viv**

For some, dealing with these strong emotions may help you see life in different ways.

“When I’m low, I often think I will scream if one more well-meaning person says ‘Be positive!’ However, even when I’m low, I can decide to take positive action.” **Kerry**

Advanced cancer can create a lot of uncertainty in your life and for many people this can be the hardest aspect to deal with. You may feel very concerned about your partner and family/whānau. You may be worried about how they are feeling and how they will cope in the future. It can be an extra strain if you have young children or other dependants.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Te papātanga wairua

Ko te whakaaro, he māmā noa iho te kaupare atu i ngā whakaaro mamae, ngā aronga mamae. Ēhara i te mea e mōhiotia ana he aha te arā tika.

“Kātahi au ka kite i te mātanga me tana kī mai, ‘Aroha mai, engari ko te kōrero, kāore he oranga mō tō mate.’ Te kaha ngau hoki o ngā kupu ‘kāore he oranga’. Kātahi au ka pānui i tētahi pukapuka matepukupuku, e hika, kei reira anō aua kupu rā, te āhua nei he pono aua kōrero. Roa tonu te wā kātahi anō au ka whakapono ki te kōrero.” **Nā Viv**

Mō ētahi tāngata, he āwhina pai kē te mahi whakatau i ēnei kare ā-roto, nā te kite i ngā taha rerekē o tō rātou toiora.

“I ngā wā ka heke taku wairua, ka whakaaro au ki te tioro (scream) atu ki ngā tāngata e mea ana ki a au ‘kia kaha rā!’ Oti rā, ahakoa kei te heke taku wairua, kei a au anō te tikanga ki te whai kia kaha ake au.”

Nā Kerry

Ka pāngia ana ki te matepukupuku maukaha, he maha ngā kumukumu (uncertainties) ka ara ake. Mō te nuinga, koinei te mea uaua rawa atu.

Tērā pea ka māharahara koe mō tō hoa rangatira, mō tō whānau hoki. Ka āwangawanga koe mō ō rātou whakaaro me tā rātou kawē i a rātou i ngā rā ki mua. Ka piki te taumaha mehemea he tamariki nohinohi āu, he tāngata atu anō āu e tiaki ana.

Worry, anxiety, and panic attacks

When you have been diagnosed with advanced cancer, it is natural to worry about what will happen. Sometimes the worry can be very intense, and more like fear or anxiety. Fear and anxiety are normal reactions to stressful situations.

Fear and anxiety may be present all of the time or may come and go. Sometimes the feelings can be very intense and difficult to cope with. You may find that you can’t concentrate, are irritable and easily distracted, sleep badly, and get tired easily.

If you are very anxious, you may have a panic attack. The fear and anxiety are almost overwhelming and you may feel very breathless, have a pounding heart, sweat, and shake. This can be very frightening, and some people worry that they will die during a panic attack.

If you feel your anxiety or worry is getting worse and interfering with your life, you may need to get help from your GP, counsellor, or psychologist. They can help you to look at the fear and find ways of coping with it.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Ngā māharahara, ngā manawapā, me ngā maurirere

I tō mōhiotanga kua pā te matepukupuku maukaha ki a koe, kāore e kore ka māharahara koe mō tō mate. I ētahi wā, he nui tonu ngā taumahatanga, ka matakū pea, ka manawapā hoki koe. Ko te tikanga i ngā wā taumaha pēnei, me puta te matakū me te manawapā.

Depression

It is not unusual to have times when you feel very low after a diagnosis of advanced cancer. Some people find their sadness gives way to a situation where their mood is low most of the time, and they are depressed.

Depression can usually be successfully treated and the first step to feeling better is getting appropriate help.

We all have days when our mood is low. Usually people or events can cheer us up, or after a few days our mood lifts.

Emotional symptoms of depression:

- very low mood for most of the time
- not feeling your usual self
- not being able to be lifted out of your low mood
- loss of interest or enjoyment in favourite activities
- feeling worse in the mornings

- problems getting off to sleep or waking early
- poor concentration and forgetfulness
- feelings of guilt/burden/blame
- feeling helpless or hopeless
- feeling vulnerable or oversensitive
- feeling close to tears
- irritability
- loss of motivation, being unable to start or complete jobs.

Physical symptoms of depression:

- low energy, fatigue
- physical aches and pains
- loss of or increase in appetite, with weight loss or gain
- loss of sexual interest
- anxiety or panic attacks.

Men are more likely to be aware of the physical symptoms rather than the emotional ones. Women tend to be more aware of the emotional symptoms.

It can be very difficult to know whether you are depressed. If your mood is low most of the time and you have even one or two of the other symptoms, talk to your doctor.





Try some self-help strategies and see if they help you to feel better (see page 72). You can ask to be referred to a counsellor, psychologist, or psychiatrist. For some people, anti-depressant medications can be helpful. Talk to your doctor about this.

Mate hārukiruki

He nui tonu ngā wā ka heke haere tō wairua whai muri i tō mōhio kei te pāngia koe ki te matepukupuku maukaha. Ko ētahi, ka kaha rawa te pōuri mō te wā āhua roa, ka mate hārukiruki rātou.

Ka pā ana tēnei mate hārukiruki, ka taea te whakaora te tāngata, heoi ko te mea tuatahi me whai āwhina hāngai.

Talking about it

Most people find they need help in learning to live with advanced cancer. It can be hard to share your feelings, and it can also be hard to know what words to use about your condition.

Finding the words that feel right for you can help you to talk about your situation. Keep trying until you find the sort of help that works for you.

Although you may not be in the habit of talking about your personal concerns, you may, at some stage, want to tell someone – a nurse, your doctor, or a counsellor – how it feels. Others may prefer to describe their feelings in writing.

Kōrero mō te mate

Mehemea he uaua mōu ki te kōrero mō ngā take whaiaro me kōrero kē koe ki tētahi atu – arā, ki tētahi tapuhi, tō tākuta, tētahi poutohutohu rānei – mō ō whakaaro. He pai ake pea mō ētahi ki te tuhi i ō rātou whakaaro. E ai ki te nuinga, nā ngā āwhina kē rātou i tau ai ki te noho me te matepukupuku maukaha. He mahi uaua tonu te kōrero mō ō kare ā-roto (feelings), he uaua hoki ki te kimi i ngā kupu hei kōrero i tō mate.

Mā te kite i ngā kupu tika mōu e āwhina i a koe ki te kōrero mō tō mate. Kia kaha tonu, kia taea rā anō te āwhina hāngai mōu.

Support groups

Many people are greatly helped by joining a support group.

“It’s good to be able to get together and just talk, like the support group I go to, where we were all living with secondary breast cancer. We can share our experiences, our different treatments, and the effect it is having on us.” Lyn

If you find a group that’s right for you, you may benefit from the close bonds with the other support group members.

People talk of the strength they have found in sharing feelings and facing reality. They also talk about the laughter that’s a big part of any group. For more information see page 101.

Groups are not for everyone, but are a support that is worth considering.

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Taking care of yourself

In the book *Handbook for Mortals* the authors Joanne Lynn and Joan Harrold describe the importance of taking care of yourself. This can be as simple as eating healthy food, exercising within your limits, and getting enough rest. It can also be doing the things you really enjoy, such as carrying on with your work if you are able, and helping others when you can.

Having fun is an important part of self-care. The value of humour as a therapy is increasingly recognised. Getting together with close friends to share memories and reminisce over photographs of good times together can be very enjoyable. Watching a comedy on TV or a funny DVD or reading an amusing book can be both a great diversion and good for your health.

“I hang on to my favourite daydream in which I receive a call from the oncologist who apologises profusely for misdiagnosing my condition. In this dream she tells me that, basically, all I have is a form of internal dandruff.” **Bridget**

Maybe you might find a new creative challenge – art, music, or writing. Some people find creating something for their family’s future very satisfying. You may choose to write your life story, or record your values, hopes, beliefs, and wisdom as a legacy of your life.

Telling ourselves the stories

“Those fabulous opening words, ‘Once Upon a Time’, never fail to cast their spell on me. I let go of everything else in my head, and settle into the story being told. That same magic is there when we tell our cancer story.

This alchemy operates on many levels. It informs others and, more importantly perhaps, informs us as well - sometimes it’s not till we write the words on a page that we (and others) realise the intensity of the journey we’re travelling.

There is the magic of putting words on a page, words which affirm, strengthen, and shed light. There are things we can tell - the story that we’ve never told anyone else, sometimes never thought about till we find the freedom of writing about them.

There is also a kind of triumph. We’ve told the story, the words are there - they will last longer than we do, will be part of the huge patchwork of stories which speak of our experiences in this new world. Our stories matter. There is a magic about that.”

Renée

Meditation and relaxation skills can help when you are feeling low or needing some quiet time. You may find gentle massage helps reduce stress and improves your wellbeing.

There are things you can do to find meaning in this difficult time, and give you strength and enjoyment in life.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Other people’s reactions

Some people worry that older people in the family or children will not cope with the news. It is usually best to tell your family/whānau and your closest friends about your cancer sooner rather than later. If you do not tell your family, they may sense that something is wrong.

You may find your friends and family don’t know what to say to you: they may also have difficulty with their feelings. Some people feel so uncomfortable they avoid you. Others expect you to lead the way and tell them what you need. You may feel able to approach your friends directly and tell them what you need, or you may prefer to approach a close family member or friend to act as an agent to speak for you.

The Elephant in the Room

“There’s an elephant in the room.
It is large and squatting,
So it is hard to get around it.
Yet we squeeze by with ‘How are you?’
and ‘I’m fine...’
And a thousand other forms of trivial chatter.
We talk about everything else - except the elephant
in the room.

There’s an elephant in the room.
We all know it is there.
We are thinking about the elephant
as we talk together.
It is constantly on our minds.
For, you see, it is a very big elephant.
It has hurt us all.
But we do not talk about the elephant in the room.”

An extract from “The Elephant in the Room” by Terry Kettering

Some people will want to tell you stories of relatives’ or friends’ cancers, or talk about alternative remedies or miracle cures. At times you may find this helpful, but if not, it’s okay to tell people you don’t want to hear their cancer stories right now.

While you are having treatment your needs should come first. Some friends are better at doing something practical to help than sitting and talking. Some find it so difficult that they may stop visiting for a while. Everyone is different.

“People have shown concern in so many ways: by holding my hand after surgery, letting me cuddle their babies and play with their kids, leaving messages on my answering machine, emailing their best wishes, and by not being too afraid to ask how I am.”
Joyce



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Parenting with advanced cancer

Should children be told?

- Children like to know about anything that affects the family.
- Children will pick up that something is wrong. If you protect them by saying nothing, they may have fears which are worse than the real situation.
- Not talking about cancer may suggest it is a subject too terrible to be discussed. This may lead to your children having an abnormal fear of cancer or other illness.
- Children may find out about your cancer from someone else, or get misleading information from other sources.
- Children can feel isolated if they are not told. They might feel they are not important enough to be included in a family matter.
- Children are good at noticing things but poor at understanding what they mean. For example: “Grandad died in hospital. Now Dad has to go into hospital. He is going to die too”, or “I was cross with Mummy when she told me to pick up my toys. Then she was ill. Maybe I made her ill.”
- Children who know the situation can be a comfort to you. You won’t need to feel secretive and isolated in your own family.

- Children have an amazing ability and capacity to deal with truth. Even very sad truths will relieve the anxiety of too much uncertainty. We cannot take their sadness away, but if we share our feelings and give them information about what is happening, we can offer them support in their sadness.
- Coping with cancer in the family can be an opportunity for children to learn about the body, cancer, treatment, and healing. They can learn about feelings and the strength of the human spirit in difficult times.

Children need assurance that there will be someone there to look after them when you get sicker. Talk to your children about who the adults are who will be there for them.

It is important to talk to their teachers about your situation so that they are aware of the changing needs of your child and can be prepared to address any questions and concerns your child may have.





Te matuatanga me te matepukupuku maukaha

Me whāki i ngā tamariki?

- Ka hiahia ngā tamariki ki te mōhio mō ngā take katoa e pā ana ki te whānau, ahakoa aha.
- Kei te mōhio tonu ngā tamariki mehemea he raruraru. Ki te kore koe e kōrero, tērā pea ka puta ētahi māharahara kino ake.
- Ki te kore e puta he kōrero mō te matepukupuku, kei pōhēhē rātou he kaupapa kino rawa hei kōrero. Kei puta te matakū mō te matepukupuku me ngā momo mate pēnei.
- Tērā pea kua rongo kē ngā tamariki mō tō mate mai i tētahi atu, ka hē rānei tā rātou rongo kōrero mai wāhi kē rānei.
- Ki te kore e whakamōhio ngā tamariki tērā pea ka noho tūhāhā (isolated) rātou. Kei whakaaro rātou kāore rātou e whai wāhi ana ki roto i ngā whakahere a te whānau.
- He tere te tamaiti ki te kite āhuatanga engari kāore e tino mārama ki ngā piki me ngā heke. Hei tauira atu, “I mate a koro i te hōhipera ā, i nāianei kua haere a pāpā ki te hōhipera, ka mate hoki ko ia” rānei, “I te riri au ki a māmā i tana tohutanga i a au ki te kohikohi i aku taonga tākaro. Kātahi ia ka mate. Nāku pea ia i mate ai.”
- Tērā pea ka noho āu tamariki hei oranga ngākau mōu ki te mārama rātou mō tō mate. Kāore koe e mate ki te huna i ō whakaaro, ki te noho tūhāhā rānei i tō whānau.

- He nui te āheinga o te tamaiti me te kaha o te tamaiti ki ngā mea e pono ana. Ahakoa te pōuri o te kōrero, he pai ake te kore mōhio. Kāore e taea te tango te āhuatanga o te kapua pouri, heoi anō rā, mā te kōrero mō ngā kare ā-roto me te hoatu mōhiohio, e taea ai te tautoko i a rātou i roto i te wā e pōuri ana rātou.
- He wā ako anō tēnei mā ngā tamariki ka puta ana te matepukupuku ki waenganui i te whānau. Ka ako rātou mō te āhua o te tinana, o te matepukupuku, ngā huarahi maimoatanga me ngā ahuatanga whakaora. Ka mōhio rātou mō tēnei mea te kare ā-roto me te kaha o te wairua tangata i ngā wā taumaha.

Teenage children

Adolescence is a time of exploration, experimentation, and introspection. Teenagers strive to be independent while still wanting to be taken care of by their parents.

When a parent is diagnosed with advanced cancer, it presents new and unique challenges to the teenager and his/her family/whānau.

1. Teenagers are unpredictable. Recognise that there is a variety of responses teenagers may have, and keep in mind that teenagers may be uncomfortable with some or all of their feelings and thoughts about your cancer.

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



2. Teenagers want detailed information. This is especially true when it comes to information about diagnosis, treatment, and **prognosis**. They may seek out further information on their own in addition to what you have provided.
3. Teenagers need to know the truth and may feel particularly sensitive to information they feel is incomplete or inaccurate.
4. Teenagers need privacy. They may or may not want to talk about the experience with their family. Reassure your teenagers that they can receive support from other sources, like an aunt, a friend's parent, a teacher, somebody from your church, or another member of their extended family/whānau.
5. Teenagers often write about and reflect upon their inner thoughts. Encourage your teenagers to share these feelings and concerns. They can also channel this energy into sport, writing a diary, or other creative arts.
6. Teenagers who want to contribute should be encouraged to participate in caring.
7. Encourage teenagers who want to accompany their family member to treatment in order to see the facility and meet the treatment team. This can help them feel more in control about how your medical care is provided.
8. Teenagers need consistency. Make an effort to ensure that they still attend usual activities and social events.

9. Teenagers struggle with the need for independence. A parent's illness may make this more difficult. Teenagers may need a break from the situation at home; for example, a family holiday, a trip with peers, or a regular night out.
10. Teenagers are often self-conscious. A teenager whose parent has cancer may feel different. To help your teenagers understand there are others going through a similar experience, you might suggest that they participate in a support group, peer-to-peer network, or online chat room.
(Source: CancerCare: www.cancercare.org)
11. Skylight (**0800 299 100**) is a national organisation which supports children and young people who are dealing with change, loss, and grief in their lives. For more information, visit Skylight's website (www.skylight.org.nz).

If you are a single parent it may be especially difficult to plan, and you might want to discuss your situation with someone who can offer expert advice, such as a lawyer or social worker. Your local Citizens Advice Bureau is able to refer you to low-cost legal advice.





Ngā taiohi

Ko te wā taiohinga te wā tūhuratanga, he wā whakamātautau, he wā tiro whakaroto. Konei te wā ka whai te taiohi kia tū motuhake ia ahakoa tana hiahia kia tiakina tonu ia e ana mātua. I te wā kua kitea kei te mate te matua i te matepukupuku maukaha, ka ara ake ngā wero hōu, ngā wero rerekē hoki mō te taiohi me tōna whānau.

1. Ka hiahia te taiohi ki te mōhio ki ngā kōrero katoa.
2. He mea nui kia mōhio ki ngā kōrero pono.
3. Me whai wā ki a ia anō.
4. He kiri hihira rātou (self-conscious) i te nuinga o te wā.

Adult children

Adult children will struggle too, particularly if they do not live in your town. You may feel you have to, or want to, carry on as the head of the family, reassuring everyone that things are the same as always.

Adult children can become aware of their own need to have their parent forever available.

“That night, while looking at my small daughter as she slept, I cried.

I thought, ‘No! Don’t you dare die Mum. I’m not ready for you to die yet. I still need you.’ Selfish thoughts? Maybe. But they were real ones.” **Sally**

Ngā tamariki pakeke

He mea uaua hoki anō hoki mō ngā tamariki pakeke tērā pea ka whakaaro koe me pīkau tonu koe i ō haepapa hei māngai mō te whānau, me tō whakaahuru i tō whānau, kei te rite tonu ngā mea katoa. Ka mārama te tamaiti pakeke ki tōna ake hiahia kia wātea mai tōna matua mō ake tonu atu.

“I a au e titiro ana ki taku kōtiro nohinohi e moe ana, ka tangi au. Ka whakaaro au, ‘Kāo! Kei noho koe ka mate Māmā. Kāore ano au kia reri kia mate koe. He mea nui tonu koe ki a au’. He whakaaro kaiapo (selfish) ēnei? Tērā pea. Engari he whakaaro tūturu.” **Nā Sally**

Parents

It is one of life’s most painful experiences to be the parent of someone with advanced cancer. It goes against nature to outlive your children. Your parents are likely to feel overwhelmed with sorrow and helplessness at first. It may take them a long time to adjust.

“I tried to tell Mum, but she blocked it, and I thought, so be it. She’ll feel the pain all in good time. Why force it on her now?”
Fiona



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Ngā mātua

Koinei tētahi o ngā wheako mamae rawa atu, ko te noho hei matua ki tētahi e mate ana i te matepukupuku maukaha. I te mea, kāore i te tika kia ora tonu koe i te wā matemate ai āu tamariki. I te tuatahi, pokea pea ōu mātua e te pōuri, e te koretake. Tērā pea he roa kē te wā mō rātou kia waia ki tō mate.

Partners

We use the word ‘partner’ to mean husband, wife, girlfriend, or boyfriend.

“We have faced many trials and traumas together, always managing somehow to get round, get over, or get under them. There had always been a way out. The diagnosis was ovarian cancer, giving a one-in-three chance of survival.” **Wayne**

Often, you may find that your thoughts and feelings are not ‘in synch’. This can cause frustration and misery, or it can help you to cope: as each new event presents itself, you may find that one of you expresses hope while the other is more pessimistic. Sometimes it can be hard for your partner to help you to make decisions about treatment. Your partner may overwhelm you by trying to protect you.

“My husband thinks if you talk a lot about it you worry more.” **Carol**

“When the outlook was reduced my husband went into himself. He was ‘brassed off’. He had visions of us growing old together. I had to tell him you don’t lie down; you go on with your life together otherwise you’re waiting to die really.” **Stephanie**

There may be role changes for each of you. It may be an opportunity to teach your partner new skills. Feeling frustrated about not being able to do what you used to is almost universal among people as their cancer advances.

It helps to work out what you need from your partner when things are tough and ask for it. Women often say that their biggest single need is for a sympathetic listener; many male partners acknowledge their difficulty providing this.

If your partner struggles with this don’t expect that he or she will be able to change, especially in a time of stress. Try to find someone else to provide this for you. If family and friends are not available there may be a counsellor, social worker, or support person available either through your hospital or local Cancer Society.

“I have often lacked the ability to encourage and to say the right thing at the right time.

On the plus side, I have become quite adept at using the washing machine and the clothes drier.” **Lloyd**



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Ngā hoa moe

He maha ngā wā, tērā pea kāore i te hāngai ō whakaaro, o kare ā-roto. Ko te otinga o tēnei ko te hōhā me te kōtonga (misery), ka āwhina kē rānei tēnei i a koe. I ngā wā ka ara ake anō he āhuetanga hōu, tērā pea kei te whai tūmanako tētahi o kōrua, kei te kārangirangi (pessimistic) kē tētahi atu. I ētahi wā he uaua pea mō tō hoa ki te āwhina i a koe ki te kōwhiri i tō maimoatanga.

Tērā pea ka huri whakatūnga kōrua. Tērā pea, he wā tēnei ki te whakaako pūkenga hōu ki tō hoa moe. Ko te kore āhei ki te mahi i nga mahi i tareka e koe i ngā rā ki mua tētahi mea hōhā rawa atu e kitea whānuitia ana i waenganui i te hunga e maukaha haere ana te matepukupuku.

Ka uaua ana, he pai te tiroiro ki ngā mea e pirangi ana koei tō hoa moe, kātahi ka pātai i a ia. I te nuinga o te wā, ka kī ai ngā wāhine, ko te taringa pūaroa (sympathetic listener) te mea nui ki a rātou; he mea uaua tēnei ki ngā tāne. Mehemea kāore i te pai tēnei ki tō hoa, kaua e whakaaro ka huri ia, he wā taumaha anō hoki māna.

Me huri ki te kimi i tētahi atu hei taringa whakarongo mōu. Ki te kore tētahi o tō whānau e watea, tētahi hoa rānei, tērā pea kei te wātea tētahi poutohutohu, tētahi tauwhiro, tētahi tangata tautoko rānei i tō hōhipera, i tō Kāhui Matepukupuku ā-Rohe rānei.

Changes in roles and routines

When someone is diagnosed with advanced cancer, routines and family roles change. The person who was the major source of income might now be unable to work and may be dependent on others.

A partner who was sharing chores may now have to take on extra tasks or get a job. Maintaining your usual social life, hobbies, and interests may be difficult or impossible for a while.

There are a number of ways that may help you manage:

- preparing simpler meals
- being more relaxed about housekeeping standards
- if you have children, asking them to help more around the house
- when neighbours, friends, or relatives ask what they can do to help, you could ask for a specific task to be done for your child; such as taking them to sports practice.

“I have friends that allow me to talk. I don’t have to actually protect them all the time. I don’t have to protect my husband. I hand over things that I always took control of. I was the one to ferry the kids around, organised the meals, but they can do it.”

Colleen



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



If you live on your own

Being unwell can make you feel lonely and isolated even though you may strongly value your independence. If your energy is low it can be hard to manage the practical aspects of running a home, going to hospital appointments, and coping with treatment.

You may not be used to asking others for help. However, if people close to you – friends, neighbours, colleagues – offer to help, they will appreciate the opportunity to assist you. It is often easier to give them a specific task to do; such as shopping, cooking occasional meals, or mowing the lawn.

You may find it tiring to answer frequent enquiries about how you are. It can help to have an answer phone installed or to ask a friend to coordinate an email update for you.

Knowing who to contact when you feel unwell is vital. A list of key phone numbers, e.g. GP, district nurses, displayed by your phone is useful.

You could also enter the numbers into your phone or cell phone.

Many people choose to have a medical alarm system, which is activated for quick contact with assistance when you feel unwell. Ask your district nurse or social worker about local alarm services. You may be eligible for funding for this.

(Source: CancerBackup: www.cancerbackup.org.uk)

Financial assistance

You might feel concerned about the financial impact of your advanced cancer. You may need advice about negotiating leave from work or obtaining an early superannuation payment, or cashing in life insurance (see page 102).

Short-term financial help is available through the Sickness Benefit and longer-term help is provided through the Invalids Benefit. You may qualify for extra help through accommodation supplements and assistance with medical bills.

If you need to travel some distance to your medical appointments you may qualify for transport and accommodation costs. Your treatment centre or local Cancer Society can advise you about what sort of help is available.

For information on your entitlements contact Work and Income on **0800 559 009**. The Cancer Society has an Information Sheet on “Benefits and Entitlements”. Visit our website (www.cancernz.org.nz) to read or receive a copy.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Pūtea āwhina

Kāore e kore ka puta te āwangawanga mō te taha moni e pā ana ki tō matepukupuku maukaha. Tērā pea me whai tohutohu koe e pā ana ki te tango matuatanga (leave), ki te whiwhi tere i ō utu penihana kaumātua rānei, ki te whai moni rānei i ō inihua toiora (life insurance).

Ka taea he pūtea mō te wā poto mā te penihana māuiuitanga, arā atu anō tētahi pūtea mō te wā roa ake, arā, ko te penihana hauā (invalid benefit). Tērā pea he āwhina tāpiri mā ngā penihana tāpiri mō te noho kāinga me ētahi āwhina mō ngā utu ā-hauora.

Mō te roanga ake o ngā kōrero e pā ana ki ngā āwhina e tika ana mōu, whakapā atu ki te Tari Hiringa Mahi i te nama waea **0800 559 009**. Kei te Kāhui Matepukupuku ngā wharangi kōrero e pā ana ki ngā momo penihana.

Sexuality and advanced cancer

It is very difficult to predict accurately how advanced cancer and its treatment will affect your sexual relationships. For most people there are changes which require them to adapt and develop new ways of giving and receiving sexual pleasure. Advanced cancer does not mean your sexuality will be destroyed.

With clear communication, you may still enjoy a fulfilling sexual relationship.

“Sex is sometimes the only escape from a world of worry and misery, and to maintain a sense of normality.”

Dr. Robert Buckman 1998

In many relationships one partner may be more interested in sex than the other. Advanced cancer can exaggerate this. Many people with cancer say that they feel washed out and almost completely without energy. This may be to do with the cancer itself, or sometimes the treatment. In this situation you might not want to bother to do anything at all about sex.

Discuss this with your treatment team or for more information, phone the Cancer Society on **0800 CANCER (226 237)** and ask for the booklet *Sexuality and Cancer/Hōkakatanga me te Matepukupuku*.

Te hōkakatanga me te matepukupuku maukaha

Ehara i te mea māmā te matapae ka pēhea te pānga o te matepukupuku maukaha me ngā maimoatanga ki ō hononga hōkakatanga. Mō te nuinga, ka rerekē. Ka mate rātou ki te urutau me te kimi huarahi hōu kia pai ai ngā mahi reka o te ai. Ehara i te mea ka patua tō hōkakatanga e te matepukupuku.

Mā ngā kōrero mārama, tērā pea ka taea tonu te haere pai o ngā hononga hōkaka. Me whakaara pea i tēnei kaupapa ki waenganui i tō kāhui hoatu maimoatanga mēnā ka hiahia tohutohu koe.

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Sites of secondary cancer

Bone secondaries

Some people experience few or no symptoms, but secondary 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
- fracture (breaking) of the bone.

A secondary cancer in the bone may gradually damage some of the bone **tissue**, causing the bone to become weaker. Early treatment by **radiation treatment**, drugs, and surgery may prevent fractures.

For more information visit the Cancer Society’s website (www.cancernz.org.nz) and read the Information Sheet on “Secondary Cancer in the Bone” or call **0800 CANCER (226 237)** for information.

Hypercalcaemia (high levels of calcium in the blood)

Calcium sometimes seeps into the blood when bones are damaged by advanced cancer. Hypercalcaemia is diagnosed by a blood test and is usually easily treated.

Symptoms may include headache, nausea, increased urination, excessive thirst, dehydration, constipation, feeling disorientated and drowsy. You may be admitted to hospital for short-term treatment with bisphosphonates. This quick treatment should make you feel much better within a couple of days. Treatment can be repeated as often as necessary.

Spinal cord compression

The spinal cord is the large nerve that runs from the base of the brain to the bottom of the back. It is protected by the bones of the spine (vertebrae). If advanced cancer is present in the vertebrae it may cause pressure on the spinal cord.

Although advanced cancer in the vertebrae is quite common, only a small number of people will actually develop spinal cord compression.

Symptoms may include pain or damage to the nerves at the level of the compression. If the nerves are damaged in the lower part of the spine this may lead to tingling or numbness, or loss of power and movement in one or both legs.

If damage is higher in the spine there may be a loss of power and sensation in one or both arms or hands. Because the nerves of the spinal cord control the bladder and bowel there may be difficulty urinating or changes in bowel function.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Report any of the following symptoms to your doctor as soon as they occur:

- tingling or numbness in arm(s), hand(s), or leg(s)
- difficulty walking
- trouble passing urine
- constipation or diarrhoea.

Early treatment – usually steroids, radiation treatment, or surgery, or a combination of these – offers the best chance of avoiding permanent damage to the spinal cord.

Liver secondaries

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)
- swelling of the abdomen.

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

Ascites

Ascites is a swelling of the abdomen caused by fluid build-up.

The membranes lining the abdomen (peritoneum) produce a fluid that acts as a lubricant allowing the abdominal organs to glide smoothly over one another. Sometimes too much of this fluid can build up between the two layers and this is called ascites.

To relieve the ascites, fluid may be drained, or a drug may be used or, very occasionally, a shunt which helps remove the fluid may be used. A shunt is a plastic tube that drains the fluid from the abdomen.

Lung secondaries

Symptoms may include:

- shortness of breath
- dry cough
- tiredness
- chest pain.

Cancer within the lungs or on the lining of the lungs may cause the above symptoms. 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.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Seek medical attention immediately if you experience breathing problems or cough up blood. Medication can be put between the two layers to stop fluid building up again.

Brain secondaries

Symptoms may include:

- headaches – such headaches 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 (rare).

The brain is a large organ which, like the liver, will often work very well even when part of it is affected by advanced cancer.

Many of the symptoms described above can be treated with appropriate therapy.

Diagnosis is made by CT scan or MRI.

Symptoms that may occur with advanced cancer

Some symptoms are a side effect of treatment while others are caused by the cancer itself.

Tiredness

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

Tiredness can be caused by a range of things:

- progression of the cancer
- treatments
- poor nutrition causing loss of weight and muscle tone
- anxiety
- inadequate sleep
- drugs, such as **analgesics**, anti-depressants, and sedatives
- anaemia
- infection.

Unfortunately, treating tiredness successfully is not straightforward.

“It was a strange tiredness. It was a feeling of being totally drained of energy: as if someone had pulled out the plug connecting me to my power source.” **Lydia**



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Good things to do when you experience tiredness are:

- Talk about the tiredness to your friends, relatives, and supporters: it helps them to understand how you feel.
- Plan to do things at the time of day when tiredness is least severe. Morning is best for many people.
- Plan your activities so that you conserve your energy for the things you really want or need to do.
- Take short naps during the day. Naps allow you to feel better, yet still sleep at night.
- Take gentle exercise, like walking to the letterbox or sitting out of bed for meals. This preserves muscle tone and a sense of normality.
- Have high-calorie, high-protein drinks. This may slow weight loss and help maintain muscle strength.

Tell your doctor or nurse if you become weaker or more fatigued. The cause may be something treatable, like anaemia.

Ngā tohumate tērā pea ka ara ake i te matepukupuku

Ko ētahi, ka puta i te taha nā runga i ngā maimoatanga ā, ko ētahi atu, nā te matepukupuku tonu.

Te matemoe

Mō te nuinga ka puta he tino raruraru i te mea ka pā te kaha matemoe (te ngenge) i ngā wā katoa. He mea tino whakakohuki mō te tūroro me ngā tāngata tata ki a ia. Ki ētahi, he kino ake tēnei i te mamae, i te ruaki ranei.

He maha tonu ngā take pā ai te hiamoe:

- te pikihaere o te matepukupuku
- ngā maimoa
- te kore kai pai me te heke o te taumaha me ngā uaua
- te mānukanuka
- kore pai te moe
- anaemia
- ngā pōauau pērā ki ngā analgesics, ngā rongoa patu i te hārukiruki me te kore moe
- ngā mate noa.





Ko te raruraru kē, ehara i te māmā te kimi maimoa angitū mō te hiamoe.

Ko ngā mahi pai ka pā ana te matemoe:

- Me kōrero mō tō hiamoe ki ō hoa, ki ō whanaunga me ō kaitautoko: hei āwhina i a rātou kia mārama ai ki ō kare ā-roto.
- Me mahere ō mahi i te wā o te rā e kore koe e tino hiamoe. Ko te ata te wā pai mō te nuinga.
- Maheretia ō ngohe (activities) kia pai ai tō tiaki i tō pūngao mō ngā mea e tino hiahia ana koe kia mahia.
- Whakamātauria te hopu moe i waenganui i te rā. He pai te moemoe i te rā, ā, ka moe tonu koe i te pō.
- Whāia ētahi korikori tinana māmā, pērā ki te hīkoi ki te pouaka mēra, te puta i tō moenga mō te kai. Mā ēnei e āwhina te āhua o ō uaua.
- Me kaha te inu i ngā inu pūngoi kaha (high-calorie) ngā inu pūmua kaha (high protein) hoki. Mā tēnei pea e āwhina kia kore e tere heke tō taumaha, hei pupuri hoki i te kaha o ō uaua.

Nausea (feeling sick)

There is a range of anti-sickness drugs that work in different ways. Let your doctor know if you feel sick, or if the drug is not working. Most anti-nausea drugs take about 20 to 30 minutes to work.

The following suggestions may be helpful:

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

Whakapairuaki (te hia ruaki)

He nui tonu ngā momo whakapōauau kapi i te whakapairuaki. Whakamōhiotia tō rata mēnā ka pāngia koe ki te whakapairuaki, ki te kore rānei ngā whakapōauau e mahi pai. Ka āhua 20 ki te 30 meneti te roa i mua i te mahinga o ngā whakapōauau kapi whakapairuaki.

04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Ki ētahi tāngata, he pai ngā whakaaro e whai ake nei:

- Kia paku noa iho te kai engari me maha ake ngā wā.
- Me karo ngā kai mōmona, ngā kai parai.
- Me whakatā i mua i te kai, i muri hoki i te kai.
- Kaua e takoto papatahi i te wā e kai ana.
- Me kaha te inu kūtore (fluids).
- Me kōrero ki tētahi mātanga kai, ki tētahi tapuhi rānei mō ngā kai tōtika.
- Whakamātauria ētahi korikori pārore.
- Me whakauru ki tētahi mea pai ki a koe, hei āwhina i a koe.

Pain

Not everyone with advanced cancer has pain. If you have pain, in most cases it can be controlled. Pain may come and go. It may be worse on some occasions or it may be always there.

People with advanced cancer do not necessarily have more severe pain as the cancer progresses.

Pain depends on the location of the cancer and its size. 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.

There are many ways to manage pain, including:

- pain-relieving drugs like paracetamol, codeine, and **morphine**
- pain-relieving procedures, such as ‘**nerve block**’ and ‘vertebroplasty’ (see page 66)
- treating the cause of the pain with chemotherapy, surgery, and radiation treatment, alone or together.

A combination of these methods may achieve the best results. How and where the pain is felt, and how it affects your life, can change. Regular reviews by pain management experts will ensure the best results are achieved.

Pain-relieving drugs

There is a range of pain-relieving drugs (analgesics). Some may be mild, like paracetamol; moderate, like codeine; or strong, like morphine. Pain-relieving drugs may be taken in tablet form (orally), as suppositories, syrups, infusions, patches (like skin patches), and injections.

Other drugs may also be prescribed, such as non-steroidal anti-inflammatory drugs (NSAIDs), and bisphosphonates (see page 69) for bone pain. For nerve pain (neuropathic pain) other treatments include anti-depressants and anti-convulsants, or a nerve block, used singly or in combination. Steroids may be used to relieve pain due to cancer pressing on a nerve, cancer in the brain, or cancer in the liver.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



“For me there came a time when the pain killers I was taking were no longer sufficient and I found the decision to start morphine difficult to make. Having made it I have been taking the slow release morphine tablets for 18 months with no appreciable side effects. Without the morphine the pain would now be too debilitating for me to continue doing all the things I do now.” **Peter**

Morphine

Morphine is one of the best drugs we have to help people with severe pain. People often worry about morphine because of stories they have been told about it. They wonder whether they will become addicted, have their life shortened, or be offered it because they are dying. It comes in quick-acting and long-acting tablets, or as syrup. It also may be administered into the skin via a syringe driver.

- If morphine is taken in controlled doses to relieve pain it is not addictive.
- Morphine is a very effective pain reliever. It can be taken for a long time in increasing doses. It doesn't have to be kept for 'when the pain gets really bad'.
- The 'drowsiness' effect of morphine decreases after a couple of days and people can continue to carry on normal activities and be pain free.
- Morphine causes constipation. Regular laxatives can relieve or prevent this.

- Morphine is most effective when taken regularly, even if the pain is not present. It is better to stay pain free rather than wait to treat the pain when it returns.
- Occasionally people cannot tolerate morphine. Other drugs can be as effective.
- Some people are nauseated when first taking morphine. The nausea usually passes, and can be treated.

“I finally came to terms with the concept of being morphine dependent when the **oncologist** pointed out that nobody thinks that diabetics are drug addicts because they need insulin.” **Lucy**

For some people morphine is not helpful and in this case there are many other ways of controlling the pain.

Mamae

Ehara i te mea ka pā te mamae ki te katoa e māuiuitia ana e te matepukupuku maukaha. Oti rā, mehemea kei te rongo koe i te mamae, ka taea te whakaiti tēnei i te nuinga o te wā. Ka piki ka heke tēnei mea te mamae i ētahi wā ka kaha mamae, i ētahi wā he iti noa iho, i ētahi wā ka rongo tonu i te mamae i ngā wā katoa. Ehara i te mea ka kaha ake te mamae mō te hunga matepukupuku i te wā e kauneke haere ana te mate.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Mā te wāhi puta ai te matepukupuku me tōna rahi e tohu mehemea ka pā te mamae. Ā tōna wā, ka kitea te inetanga tika hei pupuri i te mamae.

Kua mārama i nāianei he mea mātanga kē te mahi whakaiti mamae mō ngā rata me ngā tapuhi. He mea mātanga ngā ratonga taurima mō te whakahaere mamae.

Breathlessness

Some people with advanced cancer experience breathlessness. Your breathing rate goes up or you feel you can't catch your breath.

Treatment will depend on the reason for your breathlessness; for example, you can be short of breath if there is fluid around your lungs (this is called pleural effusion, (see page 47). This may need to be drained, or medication may be prescribed if you have an infection. Or it could be caused by the cancer itself, scarring from radiation treatment, or pressure from a swollen abdomen.

Asthma or emphysema might be present. Whatever the cause, anxiety can increase breathlessness.

Te Hēmanawa (uaua te whakahā)

Ka pā ngā āhuatanga uaua mō te whakahā ki ētahi tāngata e mate ana i te matepukupuku maukaha. Ka piki te tere o tō whakahā, ka kore rānei e mau tika tō whakahā.

Ka hāngai ngā maimoatanga ki te take o tō kore whakahā tika, arā hei tauira, ka poto tō whakahā mehemea he kūtere kei ō pūkahunuka.

Ko te tango i te kūtere pea te otinga, ko ētahi rongoā rānei mō kua pā he tahumaero. Tērā pea nā te matepukupuku tonu, nā te maimoatanga iraruke, nā te pupuhi o te puku rānei.

Tērā pea kua pā kē te kume, te mate miru pupuhi (emphysema) rānei. Ahakoa he aha te take, ka piki te kore whakahā i te mānukanuka (anxiety).

Relaxation can help:

- You may want to practise breathing techniques, alone or with someone else.
- To slow down your breathing, try breathing with someone else. You might like to practise this when you are not breathless.
- Sit up to ease your breathing or lean forward resting on a table.
- Listening to a relaxation tape or CD can be helpful.
- Have a fan in the room or open a window and get a draught of air moving near your face.
- Your doctor may prescribe a small dose of morphine which can be taken for the relief of breathlessness. Ring **0800 CANCER (226 237)** for a copy of the booklet and CD “Living with Cancer-related Breathlessness”.

It is important to discuss any concerns you have about your breathing with your doctor.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Mā te mahi pārore e āwhina:

- Tērā pea ka hiahia koe ki te whakaharatau (practise) takitahi ētahi mahi whakahā, ki te taha rānei o tētahi atu. Tērā pea me whakaharatau kē koe i te wā kāore koe i te mate i te kore whakahā.
- Mā te whakarongo ki tētahi rīpene pārore, ki tētahi kōpae pūoro rānei hei āwhina.
- Me whakatū he pūrere whakahuri hau (fan) ki roto i te rūma, ka whakatuwhera rānei i te wini kia pupuhi te hau ki tō kanohi.
- Tērā pea ka tonoa he toha pakupaku morphine hei whakapai i te uaua o te whakahā. Waea atu ki te nama **0800 CANCER (226 237)** mō tētahi kape o te puka me te kōpae pūoro “Living with Cancer-related Breathlessness”.

Lack of appetite

Many people who have advanced cancer lose their appetite and lose weight. This can be the most obvious sign that you have advanced cancer.

Tensions may arise because you don’t feel like eating what others have prepared. You may feel guilty because you can’t eat it.

Letting others know how you feel and what foods and snacks appeal may be helpful.

Some ideas that may be useful to improve your appetite are:

- Eat small meals and snacks frequently.
- Use a small plate and serve dessert in a wineglass.
- Eat moist food, such as scrambled eggs.
- Add ice cream or fruit to a drink to increase calories and nutrients.
- Drink from a smaller glass.
- Try food supplements such as Complan, which is available from a supermarket.
- Lemon juice and salt may give flavour to food when it tastes bland.
- You may prefer to sip clear liquids and then follow these with biscuits or something light.
- Avoid fatty foods or heavy, sugary food.
- Cold foods are easier to tolerate than hot.
- Eat more of your favourite foods.
- If you are not eating properly because you have a sore mouth, tell your doctor or nurse.

Speak to a dietitian with a special interest in cancer. For Cancer Society booklets, *Eating Well/Kia Pai te Kai* and *Got Water?/He Wai*, call **0800 CANCER (226 237)**, or call your local Cancer Society, or download them from our website: www.cancernz.org.nz



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Te kore hiakai

He nui ngā tāngata e mate ana i te matepukupuku maukaha, kāore e hiakai ana ā, ka heke rā te taumaha. Koinei pea te tino tohu kei te mate koe i te matepukupuku maukaha.

Ka ara ake pea he raruraru i tō kore hiahia ki ngā kai kua whakatakahia e tētahi. Tērā pea ka whakamā koe i tō kore kaha ki te kai. He pai pea ki te whakamōhio i ētahi atu e pēhea ana ōu whakaaro ā, ko ēhea o ngā kai me ngā ngaungau e pai ana ki a koe.

Kōrero ki tētahi mātanga kua whai mōhiotanga motuhake mō te matepukupuku.

Treatment for advanced cancer

The sort of treatment you are given for your cancer depends on the type of cancer you have, where it has spread to, and where it began. Your doctor will discuss treatment with you, taking into consideration your general health and how you feel about treatments.

You may be treated at a cancer centre by an oncology team, which may include specialist palliative care services. Palliative care provides care and support so that people with advanced cancer can live as fully and as comfortably as possible (see page 70).

Treatments for your cancer may include:

- chemotherapy (drug treatment)
- surgery
- radiation treatment
- hormone treatment
- monoclonal antibodies (see page 68)
- bisphosphonates (see page 69)
- palliative care
- **hospice** care
- complementary therapies, such as massage and self-help strategies (see page 72 for more detail).

Ngā maimoatanga mō te matepukupuku maukaha

Ka whiriwhiria te maimoa tika e ai ki te momo matepukupuku kua pā ki a koe, tae noa ki te āhua o tōna rauroha me te wāhi i tīmata ai te matepukupuku. Ka kōrero tō rata ki a koe mō tō maimoatanga me tōna whakaaro nui mō tō hauora whānui tae noa ki ōu whakaaro mō ngā momo maimoatanga.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Chemotherapy

Chemotherapy is the most widely-used treatment when cancer has spread. It is the use of particular drugs to kill cancer cells or slow their growth.

The chemotherapy that you may be offered is dependent on the cancer that you have and how it is affecting you. There is no ‘one size fits all’. The length of treatment is in part determined by how successful it is in helping you feel better.

Chemotherapy may be given as tablets (oral) or through a vein (intravenous). Several drugs may be given at the same time (known as combination chemotherapy). Discuss with your doctor anything you do not understand about the treatment, its side effects, and benefits.

Chemotherapy drugs damage normal cells as well as cancer cells, leading to side effects which may include:

- feeling sick and vomiting, which can often be prevented with anti-nausea drugs
- hair loss – any hair lost as a result of chemotherapy will grow back within a few months after treatment finishes. It is possible your new hair may be a different texture or colour
- tiredness
- lack of appetite
- diarrhoea or constipation
- most chemotherapy drugs can affect the bone marrow which produces the blood cells
- sore or dry mouth.

If the function of the bone marrow is damaged by chemotherapy, side effects may include:

- lowered resistance to infection
- bruising or bleeding even from minor cuts (an occasional side effect).

You will have regular blood tests throughout chemotherapy treatment to check your blood count. If you have a low white blood cell level you are at risk of infection. If you develop an infection you will be given antibiotics and your next treatment may be delayed to allow your bone marrow to recover. Blood transfusions can be given if your platelet levels or red blood cells are low, or your doctor may delay the next treatment to allow the marrow to recover.

If you develop a fever (if your temperature is 38 degrees or over) or you feel unwell, whatever it is, even with a normal temperature, don’t wait to see what happens – take action quickly. Contact your cancer nurse or doctor and follow the advice given.

If you want more information about chemotherapy, ask your local Cancer Society for our booklet *Chemotherapy/Hahau* or download it on our website www.cancernz.org.nz. Copies can also be obtained by phoning **0800 CANCER (226 237)**. For more information on individual chemotherapy drugs you may like to visit the CancerBackup website: www.cancerbackup.org.uk/Treatments/Chemotherapy/Individualdrugs



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Hahau

Ko te hahau te maimoatanga e whakamahia whānuitia ana mehemea kua rauroha te matepukupuku. He whakamahi whakapōauau hāngai te hahau, hei patu i ngā pūtau matepukupuku, hei whakapōturi rānei i te tipu.

Surgery

It may seem logical to have an operation to remove your cancer. Often, though, this is not possible. It may be in a position where it cannot be safely removed. In some instances surgery is offered to relieve symptoms, and occasionally to prolong life.

Sometimes it may be possible to remove a small secondary cancer in the lung, liver, or brain. Surgery may be offered to strengthen a weakened bone or stabilise a broken bone.

Some people with secondary bone cancer may be offered a vertebroplasty. Vertebroplasty is a minimally invasive surgical procedure in which bone cement is injected directly into the collapsed vertebrae (the bone in the spinal column). The purpose of this is to stabilise a fracture and reduce pain.

Hāparapara

I ētahi wā ka whakamahia te hāparapara hei whakamāmā ake i ngā tohumate hei whakaroa ake rānei i te oranga.

Radiation treatment

Radiation for advanced cancer is usually used to relieve symptoms such as pain from cancer in bones. There are many other instances where radiation treatment may be offered and these will be discussed with you as necessary. Radiation treatment uses high energy rays to kill or injure cancer cells. These rays can be precisely targeted onto cancer sites in your body. Treatment is carefully planned to do as little harm as possible to your normal body tissues.

Any side effects from radiation are dependent on where it is given and how much is given. Usually, effects are mild when given for advanced cancer.

For more information on radiation treatment read the Cancer Society's booklet *Radiation Therapy/Haumanu Iraruke* on the Society's website (www.cancernz.org.nz) or phone **0800 CANCER (226 237)** to receive a copy.

Maimoatanga iraruke

Whakamahia ai te rongoā iraruke hei whakakapi i ngā tohumate pērā ki te mamae nā runga i te matepukupuku i roto i ngā kōiwi. He nui anō ngā wā e whakamahia ai te maimoa iraruke ā, ka kōrerotia ēnei ki a koe i te wā e tika ana.

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Hormone therapy

Cancers that grow in response to hormones can often be slowed by taking drugs to suppress the body’s production of the hormone.

For women, certain hormonal drugs cause menopausal symptoms, whatever your age. For men, hormone treatments can produce hot flushes and mood swings.

Monoclonal antibodies

Monoclonal antibodies (called this because they come from a single cell) work by recognising the protein on the surface of the cancer cell and then locking onto it (like a key in a lock). They destroy the cancer by either:

- triggering the body’s immune system to attack the cancer cell and causing the cell to kill itself, or
- attaching a cancer drug or a radioactive substance to the antibody, which delivers them directly to the cancer cell because they target those specific cells (targeted therapy).

Examples of monoclonal antibodies are trastuzumab (Herceptin) and rituximab (Mabthera).

Bisphosphonates

Bisphosphonates are drugs which are mainly used in the management of cancer which has spread to the bone (secondary bone cancer).

People with cancer in the bone have abnormally high levels of osteoclasts (cells which break down bone). When osteoclasts break down and absorb old bone faster than new bone is formed, fractures (breaks), bone pain, osteoporosis (bone thinning), and hypercalcaemia (high levels of calcium in the blood) can occur.

Bisphosphonates reduce the activity of osteoclasts and help protect and strengthen bone. They can help reduce pain and are used as part of the treatment of hypercalcaemia.

The side effects of bisphosphonates may include headaches, nausea, and flu-like symptoms, which usually subside within 48 hours of the infusion. Jaw problems have been reported as a very rare side effect. It is important to tell your dentist that you’re having this treatment.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Palliative care

Palliative care is an approach to caring for people with cancer and their family that focuses on improving their quality of life and not just about care at the end of life. This can be offered in a hospital, rest home, at home, or by hospice.

Palliative care may be used during:

- times when your illness is causing discomfort; for example, bothersome pain, shortness of breath, or nausea and vomiting
- periods when your thoughts and feelings are distressing
- occasions when your illness may be having a big impact elsewhere in your life – maybe with your partner, children, family/whānau, work, or perhaps financial affairs.

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

You may also be faced with decisions and choices that are confusing or difficult to make during your illness. The palliative care team may be able to help explain things to you, and help you find answers.

Maimoa taurima

He arunga te maimoa taurima mō te tiaki tāngata e mate ana i te matepukupuku me ō rātou whānau, me tōna hāngai ki te whakapai ake i tō rātou kounga toiora, ehara anake mō te wā whakamatemate ai. Ka whakaratoa tēnei momo atawhai i roto i te hōhipera, i ngā kāinga whakangā, i te kāinga, ki te whare manaaki (hospice) rānei.

Ka kōrerohia te maimoa taurima i te wā tuatahi ka mōhiohia ai kua maukaha tō matepukupuku. Kō ngā wā ka whakamahia ai te maimoa taurima, ko:

- ngā wā hēmanawa ai koe i tō mate, pērā ki ngā wā kaha te mamae, poto tō whakahā, me te hiaruaki
- ngā wā ka taumaha rawa tō wairua.

Hospice care

Hospice care (depending on where you are in New Zealand) may be offered as home-based community care, in-patient care, or a combination of both.

Reasons for in-patient hospice care may be to:

- control your symptoms
- give the person looking after you a break
- spend your last days.

Many people go into hospice for a short time and then return to their home.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



“We must not lose the chance of making good on a great deal of untidiness in our lives, or of making time to pack our bags and say ‘Sorry, goodbye and thank you’.”

Dame Cicely Saunders, pioneer of the modern hospice concept

Complementary therapies

Complementary therapies can increase your sense of control over what is happening to you, reducing your feelings of helplessness, decreasing stress and anxiety, and improving your mood.

- Some people find that meditation and other relaxation techniques can be calming and sometimes helpful in easing pain.
- Yoga, T'ai Chi, and guided imagery may also relieve you of the stresses.
- Massage, too, can be a great release, but find out from medical staff if there are areas of your body that shouldn't be massaged.
- Hypnotherapy is another technique that can help to relieve anxiety and deal with pain.
- Art therapy can be helpful in allowing you to express strong emotions, which may be difficult to talk about.

Complementary therapies can be part of your treatment plan. For example, palliative care treatment can be arranged to include complementary therapies.

“Prayer and meditation have become part of my coping strategies. I have tuned into my need to explore my sense of the spiritual. This was blocked out before I had cancer because it was something I thought I might get around to, but was always too busy for.” **John**

Most complementary methods will cost money. You could enquire at your nearest palliative care service or Cancer Society to see what they offer free of charge or for a small fee per session.

If you use a private practitioner and have private health insurance, check with your health plan to see if there is a rebate for the service.

Alternative therapy

Alternative therapy is a term used to describe any treatment or therapy that may be offered as an alternative to conventional treatments. It includes things like:

- homeopathy
- naturopathy
- Chinese herbs.

Alternative therapies are sometimes promoted as cancer cures. However, they are unproven as they may not have been scientifically tested or if tested they were found to be ineffective. Be especially wary of websites or literature that advertise unorthodox cancer ‘cures’ or treatments that they say the medical establishment want to suppress.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Other drawbacks of alternative therapies:

- they can be expensive
- they are often unavailable in New Zealand
- they can be physically stressful
- they often require major changes in lifestyle.

It is important to let your doctor know if you are taking any complementary or alternative therapies because some treatments may be harmful if they are taken at the same time as conventional treatments.

You may find that seeking out different forms of treatment can give you a sense of control. You may not wish to ‘leave any stone unturned’.

“I want to be satisfied that I’ve tried everything.” Jane

Deciding about treatment

Some people are happy to have whatever treatment their doctor recommends, but others like to know as much as possible before starting any course of treatment.

It is usually possible to take a bit of time to think about the treatment options, and discuss them with the people closest to you and the doctors and nurses looking after you. Your oncologist (cancer specialist) is the best source of accurate medical information.

Your doctor may suggest that there is no further treatment that can be given to control your cancer. This does not mean that ‘nothing more can be done’, but rather that the aim of treatment is changing. Rather than trying to shrink the cancer, the aim will now be to ease troublesome or distressing symptoms. This will make sure that you are comfortable and will give you the best possible quality of life.

It is important that you make the decision that feels right for you about which treatment, if any, you are prepared to have; even if your family or doctors may recommend otherwise.

Don’t feel under pressure from your family and friends to accept or refuse treatment. The final decision must be your own.

Te whiriwhiri ko tēhea maimoa

He mea nui, māu anō hei kōwhiri te maimoatanga e whakaaro ana koe he tika ake mōu, inā ka hiahia koe, ahakoa te kōrero a tō whānau, a tō rata rānei.

Kaua e mahara mō ngā pēhitanga a tō whānau me ngā hoa ki te whakaae, ki te whakahē rānei i te whai maimoa. I te mutunga, kei a koe kē te kōrero whakatau.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



These questions and suggestions may help you make treatment decisions.

1. What is the aim of the treatment?
2. What will receiving this treatment give me?
3. If it improves my quality of life will it impact on the length of my life?
4. If it extends my life what will it do for the quality of my life?
5. What if I don't accept treatment?
6. What's causing the symptoms?
7. What are the side effects of treatment?
8. What can be done about side effects?
9. Who will be supervising my care?
10. Who do I call in the evenings or after hours?
11. Do the oncologists, doctors, nurses, and palliative care team communicate about my care?
12. Taking notes during the session can help.
13. You may find it useful to take a family member or friend with you to take part in the discussion, take notes, or simply listen.
14. Some people find it helps to record the session.

When treatment seems too much

Sometimes you will ask yourself if the treatment is worth it.

- Before you stop treatment, give yourself time to think about it.
- Are you feeling bad from the side effects of the treatment, from advancing disease, or from emotional overload? Some or all of these can be treated.
- Talk with others, particularly your doctor and those close to you.
- If you feel uncertain, you can speak to someone less closely involved – a counsellor, social worker, or call **0800 CANCER (226 237)**. These people may be able to help you to weigh up what is best for you.

“She hadn’t any further wish to be jabbed and scanned or struggle to keep appointments. She simply preferred to enjoy her time with me and inspired her visitors with her carefree determination and religious belief.” **William**

“If I was told I had six months, but with a certain treatment I could extend it to one year, first off I would say, ‘What kind of side effects will I feel from the treatment?’

If they said my quality of life would be compromised greatly, I would say, ‘Forget it.’ I have had enough side effects to last me two lifetimes, I wouldn’t want any more.

Now that doesn’t mean I would be giving up, far from it. I would be fighting with every ounce of life left in my body.” **Bess**



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Te wā kua rahi rawa te maimoatanga

I ētahi wā, ka puta te pātai mēnā kua rahi rawa te maimoa.

- I mua i tō whakamutu i te maimoatanga, āta whakaarohia.
- Kei te kino koe nā runga i ngā pāpānga i te taha o te maimoatanga, o te kaha mau rānei o te mate, o te kaha poke rānei o te mate i tō ngākau? Ka taea pea te whakatikatika i ētahi o ēnei.
- Me kōrero ki ētahi atu, tae noa ki tō rata me ngā tāngata tata ki a koe.
- Mehemea kei te rangirua koe, ka taea te kōrero ki tētahi atu kāore e pātata ana ki a koe pērā ki tētahi poutohutohu, ki tētahi tauwhiro rānei, mā te waea atu rānei ki **0800 CANCER (226 237)**. Tērā pea ka taea e rātou te āwhina i a koe ki te whāwhā ko tēhea te huarahi pai mōu.

Legal information

Enduring power of attorney

In the same way that treatment can prolong life, medical intervention can delay death.

There can be choices and decisions to be made about continuing treatment. It is difficult to know what you may want ahead of time. Some people have strong wishes and may want to know that these will be respected.

There are two types of enduring power of attorney. The one discussed here relates to personal care and welfare.

You may appoint an enduring power of attorney (personal care and welfare) and someone whom you trust to make medical decisions for you should you become unable to make competent medical decisions because of illness. You can get information about this from the New Zealand Law Society, your lawyer, or social worker. The point about an enduring power of attorney is that it comes into effect only when you are unable to make decisions for yourself.

Refusal of medical treatment

New Zealand law allows for the refusal of medical treatment if you wish, including palliative care, pain relief, and food and drink.

If you have appointed someone to act as your enduring power of attorney, he or she can refuse medical treatment on your behalf. For more information on both enduring power of attorney and refusal of medical treatment visit the web addresses that follow:

www.lawyers.org.nz/pubaboutlaw.asp

The New Zealand Law Society:
www.lawyers.co.nz

The New Zealand Medical Association:
www.nzma.org.nz



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



You may be asked to discuss your wishes about **resuscitation**. It may be helpful to read the section on CPR on the CancerBackup website (www.cancerbackup.org.uk/ResourceSupport/Advancedcancer/CPRforpeoplewithcancer).

If you do not have internet access, call **0800 CANCER (226 237)** for their assistance.

Your rights when receiving a Health or Disability Service

Whatever your decision is about treatment at any stage, you have the right to be treated according to the Code of Rights for Health and Disability.

Your rights are:

1. To be treated with respect.
2. To be treated fairly without pressure or discrimination.
3. The right to dignity and independence.
4. To receive a quality service and to be treated with care and skill.
5. To be given information that you can understand in a way that helps you communicate with the person providing the service.

6. To be given the information you need to know about your health or disability; the service being provided and the names and roles of the staff; as well as information about any tests and procedures you need and any test results

In New Zealand, people are encouraged to ask questions and to ask for more information to help them understand what is going on.

7. To make your own decision about your care, and to change your mind.
8. To have a support person with you at most times.
9. To have all these rights apply if you are asked to take part in a research study or teaching session for training staff.
10. You have the right to complain and have your complaint taken seriously.

(Source: www.hdc.org.nz/theact/theact-thecode)

For more information phone the Health and Disability Commissioner's Office on **0800 112 233**.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Notes

Section Two: Towards the end of life

Ka tata haere ana ki te wā hemo

04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



It is quite common to avoid talk of death and dying. If that is how you feel, leave this section until you feel ready.

Talking about death

There will be times when your morale slumps and you feel terrible – physically and emotionally. At other times, you may feel optimistic about your situation. Talking about these feelings may be hard for you and for your listeners. It will be especially hard for the people who love and know you best. They will need time to adjust.

“People saying, ‘You’ll get well’ makes me really cross. I know I won’t be well. I want to say to them, ‘I am going to die and don’t you dare deny me this business of dying’.” **Doris**

You may come to terms with your situation faster than those who love you. While your family and friends adjust, it might help to share your feelings with the doctors, nurses, or others who are looking after you.

“I’m not worried about dying. I know that when the time comes, it will be my time, this body will be worn out.” **Stan**

I te nuinga o te wā, he uaua ki te kōrero mō te hemonga. Mehemea he uaua mōu, waihotia tēnei wāhanga kia reri rā anō koe.

Te kōrero mō te hemonga

He nui ngā wā ka heke tō wairua, me te anuanu o tō āhua ā-kiko, ā-wairua hoki. I ētahi wā, ka whakaaro pai koe mō tō mate. Tērā pea he uaua mōu ki te kōrero mō ōu kare-ā-roto ki ētahi atu. Ka tino uaua mō ngā tāngata e tino mōhio ana, e tino aroha ana ki a koe. Mā te wā rā anō e pai ake ai.

Tērā pea ka tere ake tō whakatau i tō mate, ki ērā e tino aroha ana ki a koe. I te wā e whakariterite ana rātou, tērā pea he pai ki te kōrero i ō kare-ā-roto me ngā rata, ngā tapuhi me ērā atu e tiaki ana i a koe.

How long have I got?

“It was like appearing in court expecting a death sentence and discovering the judge didn’t want to commit himself.” **Joyce**

It may be tough if you are told that your time is short. Your mind and feelings may become focused and you may find yourself making decisions about things that are important to you.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



“The doctors said, ‘You haven’t got much time. Do what you have to do, do what you want to do.’ Suddenly they were talking weeks not months. That was a very difficult time. At night I wouldn’t know if I was going to wake up. I didn’t know when somebody left if that was the last time I’d see them.

I made very certain everybody knew how important they were to me. I wanted people to feel free and released from any unfinished business between us.” **Roy**

You can feel uneasy or unsettled if you live past the expected time, not quite knowing what you should do now.

“Last year I was living thinking I was dying, making the most of it, not planning anything for the future. In a funny sort of way it was quite easy. You can plan to die. This year is different. When I kept on living it was a problem. What on earth is this for?”

Jane

“I’d made a will and left money for my cat to be looked after. I’d given away all my Led Zeppelin CDs. Now the cat’s dead and I’d really like to play one or two of those songs.” **Harry**

Pēhea te roa mōku?

He uaua mehemea ka whakamōhiotia koe he poto noa iho te wā mōu. Ka hāngai pea tō hinengaro ā, tērā pea ka taea noa iho e koe ngā whakatau e hira ana mōu.

Tērā pea ka manawapā koe mehemea ka roa ake tō oranga ki tērā i whakaarohia, me tō kore mōhio me aha rā i nāianei.

Facing death

“When I was told, ‘You’re going to die’, it made me ask myself what dying means. I decided nobody really knows. Nobody sends you a postcard from Heaven to tell you what it’s like.” **June**

Where do you go for help in sorting out your feelings about this new stage of your life? Facing death means losing people, places, and things you hold dear. It is natural to grieve for their loss. And it is natural to want to share your hopes and fears with an understanding listener.

People living with advanced cancer say how important it is to say goodbye to people – work colleagues as well as family and friends – and to make arrangements for the future care of their pets.

Te aro hāngai atu ki te hemonga

Ki hea rā koe e haere ai ki te kimi āwhina e pā ana ki ō kare ā-roto mō tēnei wāhanga hōu o tō toiora? Ko te tikanga o te aro hāngai atu ki te hemonga, ko te mōhio ka ngaro atu katoa ngā tāngata, ngā wāhi me ngā mea tino hira ki a koe. Kāore he aha mō te tangi mō ēnei mea ka ngaro ki a koe. Kāore hoki he aha ki te kōrero ki tētahi e whai taringa mai ana ki ōu tūmanako, ki ōu whakamataku hoki. E ai ki ngā tāngata e noho ana me te matepukupuku maukaha, he mea nui ki te poroporoaki i ō hoa mahi, tae noa ki tō whānau me ō hoa, me te whakariterite mā wai e tiaki ō mōkai.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Making a will

“The oncologist told us that there was no more treatment for John. He said we should go home, write a will, and then do whatever we wanted - enjoy ourselves. We already had a will, but we rewrote it to say who should be guardians for our children if something should happen to me as well.” **Phyllis**

A will states what is to happen to a person’s belongings when he or she dies. For those left behind, a will simplifies matters, especially if a person leaves assets, such as property or money. A will also helps to ensure that ‘special things’ are given to the right people after death.

If you had made a will before your cancer diagnosis, you may wish to review it to make sure it reflects your current wishes.

If your assets are substantial, or the division of them will be complex, for example, if your main relationship is not fully recognised by law or if you have children from a previous relationship, it is advised that you seek the assistance of a solicitor or trustee firm.

Alternatively, you may like to try a ‘do-it-yourself’ will, especially if the division of assets is straightforward. Will kits are available from many bookshops. If you live in a city there may be a community law office that can assist.

Te whakarite wira

Ko tā te wira mahi, he tohutohu ka ahatia ō mea katoa ka mate ana koe. Ka māmā ake mō rātou e ora tōna ana tēnei mea te wira, tae noa ki te wā ka waiho rawa te tāngata mate, pērā ki ngā whenua me ngā moni. Mā te wira e āwhina kia tae ngā “mea motuhake” ki te tangata e tika ana kia whiwhi. Mehemea i whakaritea e koe tō wira i mua i te pānga o te matepukupuku, tērā pea ka hiahia koe ki te arotake anō kia hāngai ki ōu hiahia o nāianei.

Planning your funeral

“I’m planning my funeral to have the music I want. It is the music that has been a special part of my life. I also intend to leave a tape to be played at the service - they haven’t heard the last of me.

My two closest friends are going to have something to say about my life - warts and all. I hope my funeral will be a celebration of life.” **Peter**

Planning your own funeral or at least talking with your family about your wishes can be therapeutic for you and helpful for your family. Your family will not have to try to ‘guess’ what you would have wanted. It is probably not easy for most of us to hear or think about the reality of what is involved in funerals. However, there can be a satisfaction in leaving your mark on the occasion. Sometimes it is something that you can have some control over at a time when you may feel you don’t have much control at all.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Some of the things for you to think about are:

- Which funeral director to use.
- Whether you’d like to be embalmed.
- Whether you want to be buried or cremated.
- What venue you would like used.
- What form the service will take.
- Who will conduct it.
- What music you’d like.
- Who you would like to speak.
- What you may want read.

Do talk to your family as they may have ideas and this is something that children can be involved in. They often benefit from the opportunity to have a role in planning and also in participating in the funeral service. You can lodge a plan with the funeral company of your choice well before it is needed.

If you feel you need to make preparations but you can’t do the work, or prefer not to, consult a social worker or pastoral care worker who will help you work out what you can do.

The Funeral Directors Association of New Zealand can provide a listing of funeral directors, estimates of funeral costs, and provide a kit, *My Life, My Funeral*. To receive this kit you can telephone **04 473 7475**, or view the kit’s contents online at www.fdanz.org.nz or email fdanz@xtra.co.nz for a copy.

For an environmentally friendly funeral, phone Living Legacies **03 528 5220** or visit the website www.livinglegacies.co.nz

“I didn’t know Penny very well. She was dying when I joined the support group and I didn’t realise. I missed the meeting when she came to say goodbye. I was awed when I heard that her kids decorated her coffin in their garage while she was still alive.”

Trish

“I remember Fred saying he hoped he lived long enough so the twins would remember him.” **Moana**

People who work with the dying say that pain in mind and body can be lessened when fears and hopes are talked about. Conversations can be a precious memory for those involved.

If you have last messages for people, you can make a point of passing them on now. That way, there is a chance for dialogue – time for people to listen and respond.

If you have children, consider making a ‘moral will’ – a letter, tape, or DVD telling them what you would like them to know. This could include your memories of them as a child and growing up, how it feels leaving them, your wishes for their future, and how much you love them.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



There is no ‘right’ way or place to die. You and your family will go through it in your and their own way when the time comes.

“When patients ask about the dying process, I describe it as the physical and emotional experience of gradually becoming weaker and letting go of their attachment to living.” (Occasionally, people die unexpectedly.) **Phillip**

Whatever your belief is about what happens after death, you can make the most of the time you have now. A palliative care doctor suggests: Maintain purpose for living and express feelings. Don’t aim to stay alive, but to live.

“Keep planning and setting goals, however small or big. Keep your mind active. I’m always planning for the next thing: someone to love, something to do, something to look forward to.” **Judith**

There are positive things you can do, for yourself and for those close to you. If you have strategies to get you through the more difficult situations, you’ll have a sense of being in control of your life. For example, if you live alone, you could call on home help and palliative care services sooner rather than later.

The aim is to feel free to do whatever you can. Perhaps it is just enjoying small things in your daily life, even if this is no longer an active one. Being able to live in the moment is a gift, but it can also be learnt. Whether the moment is especially good, utterly ordinary, or even painful, you can live it to the full.

Te mahere i tō tangihanga

He mea tino haumanu mōu me tō whānau te mahere i tōu ake tangihanga, te kōrero rānei ki tō whānau mō ōu hiahia. Kia kore rātou e mate ki te kimikimi, he aha rā ō hiahia. Tērā pea, ehara i te mea māmā ki te rongo, ki te whakaaro tūturu rānei mō ngā āhuatanga o te tangihanga. Heoi anō rā, tērā pea, ka nui tō koa i te mōhio, āe, ka maumaharatia koe nā runga i ōu whakariteritenga. I ētahi wā, koinei tētahi mea ka taea e koe te whakahaere, ahakoa tō whakaaro kāore noa iho i a koe te mana ki te whakahaere.

Ahakoa he aha tō whakapono ka ahatia koe whai muri i tō hemonga, ko te mea kē kia kaha tō whai i ngā āhuatanga mō te wā e toe ana ki a koe. E ai ki tētahi rata maimoa taurima: kia hāngai ki te take e ora tonu ana koe, kia kaha hoki te whakaputa whakaaro. Kaua e whai kia ora tonu koe engari, whāia te ora.

What is death going to be like?

As you approach death, you may become unconscious. Some people lapse into and out of consciousness and are able to talk at times to people around them. Some people stay alert almost until the end.

If you are unconscious, the people around you will see and take notice of things that you may not be aware of. Your breathing will sound different and your appearance will change. It may seem to the people watching that it is an effort for you to breathe, but experts think that people do not experience it this way.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Death is as much a process as an event, so your body will ‘shut down’ bit by bit. It seems that hearing is the last sense to go (although we cannot be sure about this). With this in mind, the people caring for you will tell you what they’re doing; for example, turning you on your side to make you more comfortable, and moistening your lips.

No one really knows how a dying person experiences the moment of death. We each imagine it differently. Some people see it as a moment of release from suffering and care; others imagine falling into a blissful sleep. People with religious faith look forward to the time after death, when they will reach Heaven or Paradise.

Some people believe that their ‘life force’ will leave their body and become a part of a greater life force. Perhaps death is the last and greatest experience of them all.

“You lay there
Not so much sleeping as leaving
Many of those who loved you
Stood or sat around you...
That fearful tearful moment was not far away
Yet
The room was alive with love
Pain had succumbed to peace
Ending surrendered to beginning.”

Bill

Ka pēhea rā ka hemo ana?

Ka tata haere ana koe ki te hemonga, tērā pea ka mauri moe (unconscious) koe. Ko ētahi, ka mauri moe, ka oho ake anō, ka mauri moe, ka mauri ora anō, ā i ētahi wā, taea noa iho e rātou te kōrerorero ki ngā tāngata kei reira. Ko ētahi, ka noho mataara tae noa ki te hemonga.

Mehemea kei te mauri moe koe, tērā pea ka kite atu ngā tāngata kei rera, i ētahi āhuatanga kāore koe i te mārama. Ka rerekē tō whakahā, ka rerekē tō āhua. Tērā pea ka whakaaro te hunga e mātaki ana, he uaua mōu ki te whakahā, heoi anō, e ai ki ngā mātanga, kāore tēnei whakaaro i te tika.

He whai hātepe, he tukanga te hemonga nā reira ka āta kati haere tō oranga. E ai ki te kōrero, ko te āhei rongo te mea mutunga ki te kati (Ahakoa, kāore e taea te kī pono, kei te tika tēnei). Nā tēnei whakaaro, ka kōrero ngā tāngata e manaaki ana i a koe kei te aha rātou. Hei tauira atu, ka hurihuri ana i a koe kia hāneanea tō takoto, ka whakamākūkū ana i ō ngutu, kua kōrero atu ki a koe. Kāore tētahi e paku mōhio ana, he aha ngā wheako o te tāngata e te wā e hemo ana ia. Kei tēnā, kei tēnā ōna whakaaro. Ki ētahi, he wā kua kore e pā te mamae me te māharahara; ki ētahi atu, kua moe te tāngata.

Ko te hunga whakapono ki te atua, he wā anō i muri i te hemonga, arā te wā ka tae rātou ki te tūrangahakoa (Paradise). Ki ētahi, ka wehe atu tō rātou mauri i te tinana ka hono ki tētahi atu mauri nui rawa atu. Tērā pea ko te hemonga te wheako nui rawa atu o ngā mea katoa.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



The not getting better

When the tide goes out you will
see bit by bit the bottom of her life,

Crabs and shells and old tyres which
hold her up, her bare bones drying,

Holes which gulp quickly
their last drops of water.

There will be a less crisp line between the blue
and the white and the sun in the sky

Fewer people will lay on the sand.

There will be a field of grey to walk on.

There will be a line of seaweed
to remind you of when the tide was full,
a line in the sand to say:

‘Here is as much as this man took for granted’.

Between it and the water will be the other
landscape of his life, a place to find old bottles
and tins and pieces of wood covered by snails
and oysters and mud,

Bubbles where things live underneath,

All that the water hides.

Some will sit silently and wait
for the sea to return.

Some may walk in the mud with bare feet
and look under rocks for treasure.

Glenn Colquhoun



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Notes

Section Three: Services and information

Ngā ratonga me ngā mōhiohio

Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Directory of services

This is a brief listing of some of the major services available in New Zealand.

Cancer Society of New Zealand/ Te Kāhui Matepukupuku o Aotearoa

Local Cancer Societies provide confidential information and support.

The Cancer Society has an Information Service where you can talk about your concerns and needs with specially trained nurses. Contact the Cancer Society on **0800 CANCER (226 237)** or call your local Cancer Society.

Local Cancer Society centres offer a range of services for people with cancer and their families/whānau. These may include:

- volunteer drivers providing transport to and from treatment
- support and education groups.

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

Cancer support groups

Cancer support groups offer mutual support and information to people with cancer, and often to their families too. It can help to talk to others who have gone through the same experience. Support groups can also offer many practical suggestions and ways of coping. Ask your hospital or local Cancer Society for information on cancer support groups in your area.

Funerals

The Funeral Directors Association of New Zealand can provide a listing of funeral directors, estimates of funeral costs, and provide a kit, *My Life, My Funeral*. To receive this kit you can telephone **04 473 7475**, or view the kit’s contents online at www.fdanz.org.nz or email fdanz@xtra.co.nz for a copy.

To explore environmentally friendly funerals. Phone **03 528 5220** or visit their website www.livinglegacies.co.nz

Grief support

Grief support is offered by many different services, e.g. hospice or palliative care, social workers, or Skylight. Contact your local Cancer Society for information on the support available in your area or call **0800 CANCER (226 237)**.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Home help

You may be entitled to assistance with household tasks. For information on the availability of this assistance, contact your hospital social worker or Community Health Service. Private home help is also available through nursing agencies, which can be found in the Yellow Pages phone book.

Legal advice and information

See your lawyer. If you do not have a lawyer, contact the Law Society in your area or the local Community Law Office.

Life insurance

If you are terminally ill, you may be able to receive a partial or full claim from your insurer. This procedure requires an opinion from your specialist. Check with your insurance company about your eligibility for this type of insurance claim. For more information on insurances contact the Financial Planning & Insurance Advisers Association, phone **04 499 8064**. For insurance disputes contact The Office of the Insurance and Savings Ombudsman (www.iombudsman.org.nz) or phone **0800 888 202**.

Medical equipment

Equipment for home care may be available through your local Community Health Service. Ask your GP or nurse. Equipment is also available for hire. Ask your local Cancer Society for details of local services.

Nursing

Nursing care is available at home through district nursing or your local hospital, hospice, or palliative care service. Your doctor or hospital can arrange this. There is no cost to patients and families for this service.

Private nursing care is available through nursing agencies.

Palliative care

The doctor or nurse will provide information about palliative care and hospice facilities and services in your area.

Respite care

Your local hospice, palliative care services, community services, or hospital social worker will also be able to advise you about services in your area.

Social and pastoral care workers

Pastoral care workers are able to discuss practical and spiritual concerns (from all religious and non religious viewpoints). Contact your local hospice, palliative care services, community services, or hospital social worker for advice about services in your area.

Work and Income

For information about income support phone the Work and Income Contact Centre on **0800 599 009**.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Questions checklist

The following questions are suggestions only. You may find it helpful to compile your own list to take with you when you visit your doctor.

My cancer

- What is my cancer called?
- What is going on with my cancer?
- What are the chances of controlling my cancer?
- Will the cancer progress?
- What can I expect in the future?
- What symptoms may occur in the future, and what should I do if they arise?
- Will I be in pain?
- Will my pain and other symptoms be controlled in the future?
- What are the worst days going to be like?
- What are the best days going to be like?
- How long am I likely to live?

Treatment for advanced cancer

- What is the aim of the treatment?
- What are the side effects of treatment?
- How likely are side effects to occur?
- What can be done about side effects?
- What’s causing the symptoms?
- What can be done about the symptoms?
- Who will be supervising my care?
- Who do I call in the evenings or after hours?
- Do the oncologists, doctors, nurses, and palliative care team talk to each other about my care?

Living with advanced cancer

- What can I expect to be able to do?
- How much activity or exercise is too much and how much is too little?
- What activities may help me to enjoy life more, e.g. massage, meditation?
- How can I make the most of my life?
- What kind of food should I eat?
- How important is my diet?
- Can you advise me if and when I can return to work?
- Can you advise me about the timing of a holiday or trip I wish to take?
- Is it okay for me to drive?





Ngā pātai – rarangi tohu

He whakaaro noa iho ēnei e whai ake nei. Tērā pea, he pai ake mōu ki te whakarite i tōu ake rārangi pātai hei hari i te wā ka haere koe ki tō rata.

Taku matepukupuku

- He aha te ingoa o taku matepukupuku?
- He aha ngā piki me ngā heke o taku mate?
- Ka taea te whakamau taku matepukupuku?
- Ka kauneke te matepukupuku?
- He aha kei mua i a au?
- He aha ngā tohumate ka puta i ngā rā e tū mai ana, me aha au ka ara ake ana?
- Ka mamae au?
- Ka taea te whakahaere taku mamae me ērā atu tohumate i ngā rā ki mua?
- Ka pēhea ngā rā e tino kino ana au?
- Ka pēhea ngā rā e tino pai ana au?
- Ka pēhea te roa o taku toiora?

Ngā maimoa mō te matepukupuku maukaha

- He aha te whāinga o te maimoatanga?
- He aha te kōrero mō te puta o ngā tūpono raruraru (side effects) o te maimoatanga?
- Ka auau te puta o ngā tūpono raruraru?
- Ka taea he rongoā mō ngā tūpono raruraru?
- Nāā te aha i puta ai ngā tohumate?
- Ka ahatia ka puta ana ngā tohumate?
- Ma wai e arataki te mahi tiaki i ahau?
- Ka waea atu au ki a wai i ngā ahiahi, i te pō rānei?
- Ka kōrero tahi ai ngā tohunga mātāi matepukupuku, ngā rata, ngā tapuhi me te kāhui taurima ki a au e pā ana ki ngā mahi taurima?
- Te noho me te matepukupuku?



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Suggested reading and websites

Reading

- Linda Blachman. *Another Morning: Voices of hope and truth from mothers with cancer*. Seal Press, USA 2006.
- Jean Shinoda Bolen. *Close to the Bone: Life-threatening illness and the search for meaning*. Touchstone Books, USA 1998.
- Jimmie Holland and Sheldon Lewis. *The Human Side of Cancer: Living with hope, coping with uncertainty*. HarperCollins, USA 2000.
- Joanne Lynn and Joan Harrold. *Handbook for Mortals: Guidance for people living with serious illness*. Oxford University Press, USA 1999.
- Thomas Moore. *Care of the Soul: A guide for celebrating depth and sacredness in everyday life*. HarperPerennial, USA 1994.

Websites

- CancerBackup – coping with advanced cancer:
www.cancerbackup.org.uk/Resourcessupport/Advancedcancer/Copingwithadvancedcancer
- National Cancer Institute – when cancer returns:
www.cancer.gov/cancertopics/When-Cancer-Returns
- Palliative Care Australia
‘Asking Questions can Help’ – An online booklet for patients and families – to view this click ‘publications’ to link to the booklet: www.pallcare.org.au
- Skylight
Skylight helps children and young people deal with change, loss, and grief.
www.skylight.org.nz



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Glossary

Most of the words listed here are used in this booklet; others are words you are likely to hear used by doctors and other health professionals who will be working with you.

advanced cancer – secondary/metastatic and primary cancer that is unlikely to be cured.

anaesthetic – a drug given to stop a person feeling pain. A ‘local’ anaesthetic numbs part of the body; a ‘general’ anaesthetic causes temporary loss of consciousness.

analgesic – a drug that relieves pain.

benign – not cancerous. Benign cells are not able to metastasise like cancer cells.

carer – a person who provides physical and emotional support to someone who is ill or disabled.

cells – the ‘building blocks’ of the body. A human is made of millions of cells, which are adapted for different functions. Cells are able to reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.

chemotherapy – treatment of cancer with drugs that destroy cancer cells or prevent or slow further growth.

hospice – a place which provides comprehensive care for people with incurable disease. This includes inpatient medical care, respite care, and care of the dying person if he or she is not able to die at home. Hospices also offer day care facilities and home visiting teams.

lymphatic system – the lymphatic system is part of the immune system, which protects the body against ‘invaders’, like bacteria and parasites. The lymphatic system is a network of small lymph nodes connected by very thin lymph vessels, which branch into every part of the body.

malignant – cancerous. Malignant cells can spread (metastasise) and can eventually cause death if they cannot be treated.

metastases – also known as ‘secondaries’. Tumours or masses of cells that develop when cancer cells break away from the original (primary) tumour and are carried by the lymphatic and blood systems to other parts of the body.

morphine – a strong and effective painkiller which is used commonly to treat people with cancer who have pain.

nerve block – a procedure sometimes used for pain control. Nerves are ‘blocked’ by injecting them with alcohol or a local anaesthetic.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



oncologist – a doctor who specialises in the study and treatment of cancer.

palliative care – treatment which aims to promote comfort, relieve symptoms, and maximise quality of life.

primary cancer – the original cancer. At some stage, cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers may form.

prognosis – an assessment of the course and likely outcome of a person’s disease.

radiation treatment – the use of radiation, usually X-rays or gamma rays, to kill cancer cells, or injure them so that they cannot multiply. Radiation can be directed at a tumour from outside the body, or a radioactive source may be implanted into the tumour and its surroundings.

randomised clinical trial – a trial where people are put into groups by chance. One group is given the best current treatment or a placebo and their progress is compared with those having the treatment that is being tested. People are usually selected for each group by a computer.

recurrent cancer – a cancer which grows from cells of a primary cancer which evaded treatment. Recurrent cancer may appear up to 20 years after the primary cancer was treated, depending on the type of cancer.

respite care – alternative care arrangements which allow the carer and person with cancer a short break from their usual care arrangements.

resuscitation – the process of reviving someone who appears to be dead; for example, by heart massage or artificial respiration.

secondary cancer – cancer metastases.

tissue – a collection of cells.

tumour – a new or abnormal growth of tissue on or in the body.

voluntary euthanasia – choosing to die rather than suffer from the possible effects of treatment or disease.



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Notes

You may wish to use this space to write down any questions you want to ask your doctors, nurses, or health providers at your next appointment.

Whakamahia tēnei wāhi wātea hei tuhi pātai e hiahia ana koe ki te pātai i tō rata, ngā tapuhi, ngā kaiwhakarato hauora rānei mō te wā e hoki atu ai koe.



Quick Links	
Advanced Cancer	
04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Notes

Cancer Society of New Zealand Inc.

National Office

PO Box 12700, Wellington 6011
Telephone: (04) 494-7270

Auckland Division

PO Box 1724, Auckland 1023
Telephone: (09) 308-0160
Covering: Northland

Waikato/Bay of Plenty Division

PO Box 134, Hamilton 3216
Telephone: (07) 838-2027
Covering: Tauranga, Rotorua, Taupo,
Thames, and Waikato

Central Districts Division

PO Box 5096, Palmerston North 4410
Telephone: (06) 364-8989
Covering: Taranaki, Wanganui, Manawatu,
Hawke’s Bay, and Gisborne/East Coast



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



Wellington Division

52-62 Riddiford Street, Wellington 6021
Telephone: (04) 389-8421
Covering: Marlborough, Nelson,
Wairarapa, and Wellington

Canterbury/West Coast Division

PO Box 13450, Christchurch 8011
Telephone: (03) 379-5835
Covering: South Canterbury, West Coast,
and Ashburton

Otago/Southland Division

PO Box 6258, Dunedin 9016
Telephone: (03) 477-7447



Feedback

Advanced Cancer/Matepukupuku Mauhaka

We would like to read what you thought of this booklet:
whether you found it helpful or not. If you would like to give
us your feedback please fill out this questionnaire, cut it out
and send it to the Information Manager at the address at the
bottom of the following page.

1. Did you find this booklet helpful?

Yes ☐ No ☐

Please give reason(s) for your answer.

2. Did you find the booklet easy to understand?

Yes ☐ No ☐

Please give reason(s) for your answer.

3. Did you have any questions not answered in the booklet?

Yes ☐ No ☐

If yes, what were they?



04	Introduction
06	Section 1: Living with advanced cancer
43	Section 2: Towards the end of life
51	Section 3: Services and information
52	Directory of services
54	Questions checklist
56	Suggested reading and websites
57	Glossary
59	Notes
61	Feedback



4. What did you like the most about the booklet?

5. What did you like the least about the booklet?

6. Any other comments?

Personal information (optional)

Are you a person with cancer, or a friend/relative/whānau?

Gender: Female ☐ Male ☐ Age

Ethnicity (please specify):

Thank you for helping us review this booklet. The Editorial Team will record your feedback when it arrives, and consider it when this booklet is reviewed for its next edition.

Please return to: The Information Manager, Cancer Society of New Zealand, P.O. Box 12700, Wellington 6011.



Information, support, and research

The Cancer Society of New Zealand offers information and support to people with cancer and their families. Information is available on specific cancers, treatment, and living with cancer. The Cancer Society is a major funder of cancer research in New Zealand. The aim of research is to determine the causes, prevention, and effective methods of treating various types of cancer. The Society also undertakes health promotion through programmes, such as those encouraging SunSmart behaviour, healthy eating, physical activity, and discouraging smoking.

We would appreciate your support

The Cancer Society receives no direct financial support from Government so funding comes only from donations, legacies, and bequests. You can make a donation by phoning 0900 31 111, through our website, or by contacting your local Cancer Society.

The Cancer Society provides all its information (booklets, leaflets, and sheets) free of charge to health providers distributing them to the public.

Acknowledgements

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

Dr Jonathan Adler

Palliative Care Services, Wellington Hospital

Tom Marshall

Clinical Psychologist, Spinal Unit, Burwood Hospital, Christchurch

Marie Glenys

Grief Counsellor, Christchurch

Associate Professor Chris Atkinson

Medical Oncologist, Oncology Service, Christchurch Hospital and the Cancer Society of New Zealand's Medical Director

Meg Biggs, Julie Holt, Liz Wright

Cancer Society Information Nurses

Sarah Stacy-Baynes

Information Manager

We also thank the people who reviewed this edition and offered many valuable suggestions. Thanks to our Cancer Society volunteers who agreed to be photographed for our booklet covers.

Photography

Cancer affects New Zealanders from all walks of life, and all regions of our beautiful country.

This cover photo was taken by Lindsay Keats in the Botanical Gardens, Wellington.

Cancer Society of New Zealand Inc. (2008)

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the prior permission of the publisher.





www.cancernz.org.nz

For cancer information and support
phone the Cancer Information
Helpline 0800 (226 237)

