



## Prostate Cancer Matepukupuku Repeure



Understanding Cancer A guide for men with prostate cancer

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

Your general practitioner: phone

Your cancer team: phone

Your local Cancer Society:\_\_

24-hour emergency phone 111

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You can get copies of Cancer Society booklets and information sheets from your local Cancer Society, by phoning the Cancer Information Helpline 0800 CANCER (226 237) or by downloading them from our website (www.cancernz.org.nz).

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

More information about the Cancer Society can be found in the back of this booklet.

We value your feedback on the information we provide, such as this booklet. There is an online form you can fill in here:

www.cancernz.org.nz/cancer-information/other-links/feedback.

## About this booklet

When you hear you have prostate cancer you may have a lot of questions. This booklet will answer your questions about what it is, how it is treated, and living well while you have prostate cancer.

The words in **bold** in the text are explained in the glossary (what this word means) at the end of this booklet. Key points are written in Māori.

Ka rongo ana koe kua pāngia koe ki te matepukupuku tērā pea, ka nui ngā pātai ka ara ake. Ka whakautu tēnei puka i ō pātai e pā ana ki te mate nei, pēhea te maimoa i tēnei mate, me te noho ora i te wā o tō matepukupuku repe ure.

Whakamāramatia ai ngā kupu kua miramirahia, ki roto i te rārangi kupu (he whakamārama kupu) kei te mutunga o te puka nei. Kua whakamāoritia ngā tohu (tikanga) matua.



Knowing what information you can get, the questions you should ask, and where to go for support and more information on treatment you could understand. It would have helped me to have this before I saw the urologist.

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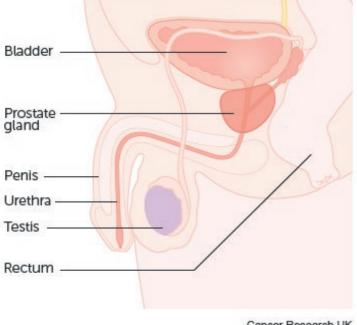
## SECTION ONE: UNDERSTANDING PROSTATE CANCER

## Key points

- The prostate is a small gland, about the size of a ping pong ball, just below the bladder. The prostate produces most of the fluid that mixes with sperm to make semen, and also produces a protein called prostate-specific antigen (PSA).
- Early prostate cancer often has no symptoms. A raised PSA level may lead to a biopsy of the prostate. A biopsy is the main way prostate cancer is diagnosed.
- Prostate cancer occurs most often in men over 50 and is the most common cancer diagnosed in New Zealand men.
  - He repe iti noa iho te repe tātea, āhua rite ki te rahi o te poikōpiko, ka noho ki raro tata i te tōngāmimi. Ka whakanao te repe tātea i te nuinga o te wai tinana ka whakaranu me te tātea ki te mahi i te waitātea, me tōna whakanao i tētahi pūmua e kīia ana ko te prostate-specific antigen (PSA).
  - I te nuinga o te wā, kāore he tohumate mō te matepukupuku repe ure puta moata. Tērā pea, ka whakamahia he unuhanga ki tō repe tātea Inā kua piki te taumata o tō PSA, Ko te unuhanga te huarahi matua mō te whakatau i te matepukupuku repe ure.
  - Ka puta te matepukupuku repe tātea, i te nuinga o ngā wā, ki ngā tāne pakeke ake i te 50 tau, ā, koinei te matepukupuku kiteatia nuitia ai ki roto i ngā tāne o Aotearoa.

## The prostate

The prostate is a small gland about the size of a ping pong ball. It sits just below the bladder and surrounds the upper part of the urethra the tube that carries urine from the bladder and semen from the testicles to the outside of the body through the penis.



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## What does the prostate do?

The prostate produces most of the fluid that mixes with sperm to make semen. During sex the muscles of the prostate help force prostate fluid and sperm into the urethra via ejaculation.

The male sex **hormone**, **testosterone**, made in the testicles, controls how the prostate works.

The prostate also produces a protein called prostate-specific antigen (PSA). This helps to make semen watery.

## Prostate cancer

Early prostate cancer is contained within the prostate gland and is called localised cancer.

The spread of the cancer through the capsule (the outer covering) of the prostate is known as extracapsular spread or locally advanced cancer.

Prostate cancer can sometimes spread to other parts of the body, such as the bones and lymph glands. This is called metastatic, secondary or advanced cancer. Cancer **cells** can move through the **lymphatic system** or bloodstream.

## How common is prostate cancer?

Prostate cancer occurs most commonly in men over 50 years and is the most common cancer among New Zealand men. Around 3,400 men are **diagnosed** with prostate cancer in New Zealand each year. Of this number around 7% are Māori.



## Causes of prostate cancer

The causes of prostate cancer are not fully understood. But we know that the chance of getting prostate cancer increases as you get older and doubles if your father or a brother have had it.

## Prostate symptoms

Men with early prostate cancer are unlikely to have any symptoms, as these only occur when the cancer is large enough to put pressure on the urethra.

In men over the age of 50, the prostate gland often gets larger due to a non-cancerous condition called **benign prostatic hyperplasia** (BPH).

The symptoms of BPH and prostate cancer are similar and can include any of the following:

- difficulty passing urine
- passing urine more frequently than usual, especially at night
- pain when passing urine
- blood in the urine or semen.

If you have any of these symptoms, get them checked by your GP.

Ko te tikanga, kāore ngā tāne e pāngia ana ki te matepukupuku repe ure e whai tohumate, i te mea, puta noa iho ēnei i te wā kua rahi rawa te matepukupuku, kua pēhi hoki i te taiawa mimi.

Mō ngā tāne e 50 tau te pakeke, neke atu rānei, he nui ngā wā ka āhua rahi ake te tipu o te repe tātea nā runga i tētahi āhuatanga kore-matepukupuku e kīia ana ko te b**enign prostatic hyperplasia** (BPH).

He rite ngā tohumate o te BPH me te repe ure, ā, tērā pea ka puta ko tētahi o ēnei:

- uaua te mahi mimi
- ka nui ake ngā wā mimi, tae noa ki ngā wā o te pō
- ka mamae i ngā wā mimi
- ka puta he toto i roto i te mimi, i te waitātea

Ki te whai koe i t $\bar{e}$ tahi o  $\bar{e}$ nei tohumate, he mea nui kia tirohia koe e t $\bar{o}$  rata.



## SECTION TWO: DIAGNOSING PROSTATE CANCER

## Key points:

- You will be given a prostate specific antigen (PSA) blood test to measure the level of PSA in your blood. A raised PSA indicates that your risk of having prostate cancer is higher than it would be for a person with a normal PSA.
- A raised PSA can be raised for reasons other than cancer so a PSA test on its own cannot be used to diagnose prostate cancer.
- Other tests include a digital rectal examination, **ultrasound** and biopsy.
- If your biopsy sample contains cancer it is **graded** using the ISUP scale (based on your Gleason score).
- Grading is a way of describing what your cancer cells look like, how quickly they are growing and how likely they are to spread.
- You may have other scans such as **CT** or **MRI**, and sometimes a bone scan.
- The results of the tests and scans are used to work out the stage of your cancer how large it is and if it has spread.
- Knowing the stage of your prostate cancer helps your treatment team to plan your treatment.

- Mā te mōhio ki te wāhanga o tō matepukupuku repe ure, e āwhina i tō rōpū maimoa ki te whakamahere i ō maimoatanga.
- Ka whakaritea he whakamātau toto prostate specific antigen (PSA) ki te ine i te taumata PSA kei roto i tō toto. Mehemea kua piki tō PSA, he tohu tēnei kua piki ake te mōrea o tō whai i te matepukupuku repe ure, e ai ki te tangata whai taumata PSA pai.
- Ara anō ētahi atu take, atu i te matepukupuku, piki ai te PSA, nō reira, kāore e taea te whakamahi i te whakamātautau PSA anake ki te whakatau i te matepukupuku repe ure.
- Ko te whakamātautau ā-mati tou, ko te pāorooro, ko te unuhanga ētahi atu whakamātautau.
- Mehemea kei roto te matepukupuku i to tauira unuhanga, ka tauinetia mā te whakamahi i te tauine ISUP (whakaritea ai ki tō kaute Gleason).
- He huarahi te mahi tauine ki te korero i te momo ahua o ou putau matepukupuku, te tere o ta ratou tipu, me te ahua o tona kaha ki te horapa ki wahi ke o te tinana.
- Tērā pea ka whakahaerehia ētahi atu titiro whakatau pērā ki te CT, ki te MRI rānei, ā, i ētahi wā, he titiro whakatau ā-kōiwi.
- Ka whakamahia ngā putanga o ngā whakamātautau me ngā titiro whakatau ki te kārawarawa i te wāhanga taumata o tō matepukupuku - tōna rahi, me tōna kaha rauroha.

I was very upset at first. I prepared myself for the worst and got it. I was confused but as I settled down I decided to take a positive view and that helped.



# Tests to diagnose prostate cancer

## A blood test for PSA

PSA is a protein made by both normal and cancerous prostate cells. The PSA blood test measures the level of PSA in the blood. PSA levels may rise for many reasons, such as BPH, **inflammation** or infection of the prostate gland, and prostate cancer.

A raised PSA can show that your risk of having prostate cancer is higher than it would be for a person with a normal PSA. In many men a small rise in PSA level may be normal.

A PSA test alone cannot be used to diagnose prostate cancer. Some men can have prostate cancer with normal PSA levels, while others with high PSA levels may not have prostate cancer. Other tests will be needed to confirm a diagnosis. PSA levels can vary so more than one PSA test may be needed. I felt upset when I was first diagnosed and concerned about what happened next. It came as a shock as no real signs were evident - not even a high PSA.

## **Digital rectal examination**

Your GP may check your prostate gland by putting a gloved finger into your anus to feel your prostate through the wall of your **rectum**. If they have any concerns, further tests may be needed.

## Biopsy and ultrasound examination

A biopsy is the most common way to confirm a diagnosis of prostate cancer.

If you are diagnosed with prostate cancer, the information from your biopsy will also help you and your cancer treatment team to make decisions about the treatment and management of your prostate cancer.

A biopsy removes small samples of tissue from different parts of the prostate. You will be given either a general or a local **anaesthetic**, depending on the procedure, to help manage any discomfort.

Ultrasound is used to guide a needle into the prostate, through either the rectum or the **perineum**. After a biopsy of your prostate, many men may have blood in their urine for a few days. Some men also notice blood in their semen.

Antibiotics are given before and after the biopsy to prevent infection, and pain relief may be prescribed to relieve any discomfort.

Tissue samples will be looked at under a microscope to see if there are any cancer cells present.



# Grading your prostate cancer

Grading is a way of describing what your cancer cells look like. It provides an indication of how quickly the **tumour** is growing and how likely it is to spread.

Your biopsy samples will be viewed under a microscope by a pathologist to see what any cancer cells look like. The cells will be given a grade from 3 to 5. Grade 3 tumours look relatively similar to normal prostate cells, whereas grade 5 cells look very different.

The two most frequently occurring grades seen in the biopsy samples are added together to give a **Gleason score**, which ranges from 6 to 10. The higher the Gleason score, the more active the cancer and the more likely it is to spread.

#### The new ISUP grading system

There is a new grading system for prostate cancer known as the ISUP grading system (named after the International Society of Urological

Pathology). This new system grades the cancer between 1 and 5 depending on your Gleason score. The lower the grade, the less likely the cancer is to spread. This helps your treatment team to plan your treatment.

#### Grading of prostate cancer

ISUP grade	Gleason score	Description of the two patterns		
1	3+3=6	The cancer cells found in the biopsy are likely to grow slowly.		
Note the difference between 3+4 and 4+3, which are both Gleason score 7				
2	3+4=7	Most of the cancer found in the biopsy looks likely to grow slowly. There are some cancer cells that look more likely to grow at a more moderate rate.		
3	4+3=7	Most of the cancer cells found in the biopsy look likely to grow at a moderate rate. There are some cancer cells that look likely to grow slowly.		
4	4+4=8	All of the cancer cells found in the biopsy look likely to grow at a moderately quick rate.		
Note the difference between 4+5 and 5+4, which are both Gleason score 9				
5	4+5=9	Most of the cancer cells found in the biopsy look likely to grow at a moderately quick rate. There are some cancer cells that are likely to grow more quickly.		
5	5+4=9	Most of the cancer cells found in the biopsy look likely to grow quickly.		
5	5+5=10	All of the cancer cells found in the biopsy look likely to grow quickly.		

## Other tests for prostate cancer

If you are diagnosed with prostate cancer, your treatment team may recommend other tests. These may include a bone scan, CT (computerised tomography) scan, MRI (magnetic resonance imaging) scan or PSMA (prostate-specific membrane antigen) PET-scan.

#### Bone scan

A bone scan is used to see if any cancer has spread to your bones.

A small dose of radioactive liquid is injected into a vein. You will need to wait for up to four hours for the liquid to travel around your body and collect in your bones. The liquid tends to collect in areas where bone is breaking down and repairing itself. It is these areas (called hot spots) that can be seen on the scan.

#### CT scan

A CT scan - previously known as a CAT scan - is a series of X-rays from different angles that provides more detailed information than a normal X-ray.



#### MRI scan

This is a scan that uses radio waves and magnetic fields to produce images of the inside of a body.

#### PSMA PET-scan

This new technology is a scan that is available privately in some New Zealand centres. It uses a radioactive solution that attaches to prostate cancer cells so they can be seen in a scan. It is used to identify the spread of prostate cancer beyond the prostate.

# Staging your prostate cancer

Knowing the stage of your prostate cancer helps your treatment team to plan your treatment. Staging is based on the results of the tests you have had and describes the size of your cancer and if it has spread to other parts of your body.

Prostate cancer may be:

- localised confined to the prostate
- locally advanced extended beyond the prostate to nearby areas
- advanced spread to other parts of the body.

While the Gleason score describes what the cancer looks like under the microscope, the stage of the cancer describes where the cancer is found. Staging is done using the TNM (tumour, node and metastases) system.

Ko tā te kaute Gleason, he kōrero i te āhua o te matepukupuku i raro i te karu whārahi, ko tā te wāhanga taumata o te matepukupuku, he whakamārama i te wāhi kitea ai te matepukupuku. Whakamahia te wāhanga taumata mā te pūnaha TNM (tumour, node and metastases).

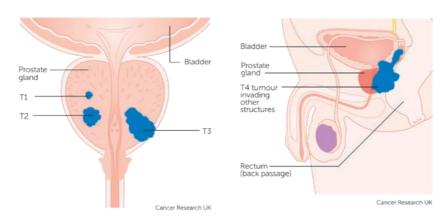
## TNM staging of prostate cancer

The TNM system is used all over the world. It separately assesses the tumour (T), lymph nodes (N) and secondary cancer **metastases** (M).

#### Prostate cancer stages:

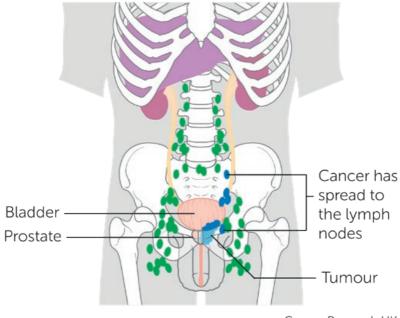
#### Tumour (T) - the size of the primary cancer (tumour)

Stage	How far the cancer has spread
T1	The cancer cannot be felt by the doctor or detected on ultrasound.
T2	The doctor can feel the cancer but it does not appear to have spread beyond the prostate.
Т3	The cancer feels as though it has spread beyond the prostate into surrounding tissues.
T4	The cancer has grown into surrounding organs such as the bladder or the rectum.



## 2. Lymph nodes (N) - the number of nearby lymph nodes that have cancer

- NX lymph nodes cannot be assessed
- N0 nearby lymph nodes do not contain cancer cells.
- N1 there are cancer cells in the lymph nodes near the prostate.

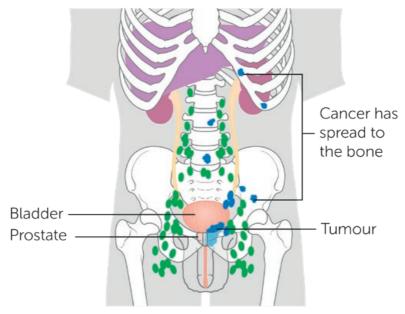


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## 3. Metastasis (M) - describes whether the cancer has spread to a different part of the body

M0 - the cancer has not spread to other organs.

M1 - the cancer has spread to other parts of the body beyond the pelvis.



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### **Questions you might like** to ask your treatment team

You may want to think about the questions you want to ask your treatment team before you see them. Think about asking:

- how advanced and at what stage your prostate cancer might be
- what treatment they might advise and why they advise that treatment
- what other treatment choices you might have
- what the risks and possible side-effects of each treatment might be
- how long the treatment might take and if you might have to stay in hospital
- how the treatment might be provided and when it will begin
- what the cost might be if you are treated privately
- if you will be able to continue working, and if not, when you might be able to return to work
- how frequent your check-ups might be.

## SECTION THREE: MAKING TREATMENT DECISIONS

## Your treatment team

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

- your GP your family/whānau doctor who will often be the first person you see
- a **urologist** a doctor who specialises in the care of men with prostate cancer, providing medical and surgical care
- medical oncologists doctors who are responsible for prescribing targeted therapies, immunotherapy, chemotherapy and other aspects of cancer care
- radiation oncologists doctors who specialise in the use of radiation treatment
- radiation therapists people who plan and give you your radiation treatment
- a cancer nurse coordinator and/or clinical nurse specialist a
  person who acts as a point of contact for you in different parts of
  the health service. They support and guide you and your family/
  whānau to keep you fully informed about your care
- **outpatient nurses** nurses who work alongside doctors during their clinics.

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

Have faith in the professionals and be confident that modern treatment options are effective.



## Talking to your cancer treatment team

When you first learn you have cancer you may have many questions. We suggest that you think about the questions you would like to have answered and what you do not want to be told, before you visit your cancer treatment team. There is a lot of information to take so it can be helpful to have a support person with you when you visit.

Ka nui pea ō pātai ka mōhio ana koe kua pā te matepukupuku. Ko tā mātou ki a koe, me ata whakaaro koe i ngā pātai ka hiahia koe kia whakautua, me ngā mea kīhai koe e hiahia ana ki te rongo i mua i tō haerenga ki te kite i tō rōpū maimoa matepukupuku. He nui ngā pārongo ka rongo koe, nō reira, he mea nui kia hari tangata tautoko koe i te wā haere ai koe.

## You can ask for a second opinion

You may want to ask another doctor about your cancer or treatment. You can ask your treatment team or GP to refer you to another cancer doctor. You are entitled to a second opinion if you want one.

I had prostate cancer and had a radical prostatectomy. My PSA was zero but there were 3-4 years I didn't have my levels tested. My levels have gone up again and I don't know why I wasn't tested earlier.

I had to ask my doctor for another PSA test, otherwise he wouldn't do it and I wanted to know I was OK.

## Talking with others

Once you have discussed treatment options with your doctor and family/whānau, you may want to talk them over with someone else. Talking it over can help you to decide what choice is right for you.





You may be interested in Cancer Connect, run by the Cancer Society. This is a free telephone peer-support programme. For more information on this programme, phone the Cancer Information Helpline 0800 CANCER (226 237).

I got my first prostate cancer diagnosis seven years ago. It's my second time round and I go to see the nurses at the Cancer Society. They are supportive and up to date with what is happening with treatments so I know what to expect.

### **Finding out more from your** cancer treatment team

You may like to learn more from your cancer treatment team. Consider asking questions about:

- the possible advantages and disadvantages of different treatments
- the difference that waiting would make
- what would happen if you do not have treatment
- how long your treatment might last and how often you will have to have it
- how your treatment will be given
- if you will need to stay in hospital
- how treatment might affect your day-to-day life now and in the future
- how likely it is that the treatment will work for your situation
- if there is anything you need to be particularly careful about during and/or after treatment
- the effects on your erectile function and what that might mean.

## SECTION FOUR: TREATING YOUR PROSTATE CANCER

## Key points:

- The treatment choices you are offered will be based on all the information your treatment team has about your cancer and what is right for you.
- Treatments for prostate cancer include:
  - active surveillance
  - surgery
  - radiation treatment
  - hormone therapy
  - a combination of the above.
- If the cancer has not spread beyond the prostate, the whole gland can be surgically removed.
- Radiation treatment is the use of high-energy radiation to destroy cancer cells or prevent them reproducing. There are three types of radiation treatment for prostate cancer:
  - external beam radiotherapy
  - low-dose-rate brachytherapy
  - high-dose-rate brachytherapy.
- Prostate cancer needs the male hormone testosterone to grow. There are a number of ways to slow down or shrink the cancer by reducing the body's testosterone levels through hormone treatment.

- Ka hāngai ngā whiringa maimoa ka hoaturia ki a koe, e ai ki ngā pārongo katoa e möhiotia ana e tō rōpū maimoa e pā ana ki to matepukupuku, me ngā mea e tika ana mōu.
- Ko ētahi o ngā maimoatanga mō te matepukupuku repe ure, ko ēnei:
  - te ngangahau o te titiro
  - te hāparapara
  - maimoa iraruke
  - haumanu taiaki
  - he whiringa o ēnei i runga ake nei
- Mehemea kāre anō te matepukupuku i rauroha ki tua atu o te repe ure, ka āhei te tango ā-hāparapara i te repe katoa.
- Ko te whakamahi i te iraruke pūngao- nui te maimoatanga iraruke hei whakamate i ngā pūtau matepukupuku, ki te ārai rānei i tō rātou hanga hou. E toru ngā momo maimoa iraruke mō te matepukupuku repe ure
  - hihi ā-waho haumanu iraruke
  - brachytherapy horopeta iti
  - brachytherapy Horopeta nui.
- Me whai rawa te matepukupuku repe ure i te testosterone taiaki tāne e tipu ai ia. He maha tonu ngā ara hei whakatōmuri i te tipu haere, hei tīngongo rānei i te matepukupuku mā te whakaiti i ngā taumata testosterone o te tinana.

Your cancer treatment team will advise you about the best treatment for your prostate cancer. Depending on the stage of your cancer, treatment may include surgery, radiation treatment, hormone therapies, chemotherapy and/or palliative care. If you have early-stage prostate cancer you may be offered treatment options - active surveillance (close monitoring), surgery to remove your prostate, or radiation treatment. Before making a decision about treatment it can be helpful to talk to both a urologist and a radiation oncologist.

Mehemea kua pāngia koe ki te matepukupuku repe ure wāhanga-moata, tērā pea ka whakaratoa koe me ngā whiriwhiringa maimoa - te tirotiro ngangahau (aroturuki tata), te hāparapara ki te tango i to repe ure, te haumanu iraruke rānei. I mua i tō whakatau ko tēhea o ngā maimoatanga me whai koe, he mea pai ki te kōrero ki tētahi kaimātai roma mimi, me tētahi mātanga matepukupuku iraruke.

### **Treatment summary**

Stage	Treatment options
Early stage	Active surveillance (close monitoring), surgery or radiation treatment. Cryotherapy (limited availability).
Locally advanced	Surgery and/or radiation treatment, and hormone treatments.
Advanced	Hormone, chemotherapy, radiation treatment, immunotherapy and monitoring with regular follow-up through GP or clinic. Palliative care may also be provided.

In my case the chance of getting all the cancer out with surgery made the decision easier. Some information provided was helpful but then other information was contradictory.

## Active surveillance to manage prostate cancer

If your cancer has a low or very low risk of spreading, you may be offered active surveillance. This is a way of managing your cancer, where the cancer is not immediately treated but is very closely monitored with regular PSA testing (three- to six-monthly), repeated biopsies and MRI scans.

If there is evidence of your cancer becoming active your treatment team will discuss treatment options with you. Active surveillance is often used, as low-risk cancer can pose a low threat to your health.

Some things you might want to discuss with your treatment team:

- who will be doing the monitoring
- how often you will be monitored
- what changes would lead to needing treatment.

I felt very healthy when I was diagnosed and it was very difficult to hear I had a disease I might not recover from.

## Surgery for prostate cancer

If the cancer has not spread beyond the prostate and you are in good general health, the whole prostate gland can be surgically removed. This is called a radical prostatectomy and aims to cure your prostate cancer.

Surgery may also be an option if your cancer has spread to the area just beyond the prostate (locally advanced prostate cancer). This will depend on how far the cancer has spread.

You will need to stay in hospital for a few days after your surgery, and it is normal to go home with a **urinary catheter** in place for a short time. For most men the recovery time is around six weeks.



Surgery for prostate cancer may be performed using different surgical techniques. Some options are only available through private hospitals.

In each of the procedures, your surgeon will try to save the two bundles of nerves (nerve-sparing radical prostatectomy) attached to the prostate that help you get erections. This surgery is only possible if the cancer is not in or close to these nerves.

Problems with erections are common, even with nerve-sparing surgery. For this reason this procedure is more suitable for younger men with good erectile function and lower-grade prostate cancer.

**Open radical prostatectomy:** Surgery is performed through a cut in the lower abdomen.

#### Laparoscopic (keyhole) radical prostatectomy:

Small surgical tools are inserted into several small cuts in the abdomen. A small camera at the tip of a tool allows the surgeon to see what they are doing on a screen. Recovery is often quicker after keyhole surgery than it is if other techniques are used.

# **Robotic-assisted radical prostatectomy:** Your surgeon uses a robotic device during the operation, which allows them to use more advanced surgical tools.. This is only available privately in New Zealand.

### Removing lymph nodes

Removing lymph nodes around the area of the prostate is sometimes done for men with high-risk prostate cancer as part of the treatment.

## Side-effects of prostate cancer surgery

The following are possible side-effects of surgery. Talk to your cancer treatment team about how they might affect you. See page 53 for ways to manage them.

#### Nerve damage

The nerves needed for erections and bladder control lie close to the prostate. During surgery these nerves may be damaged, causing problems with erectile function and bladder control.

#### Erection problems (impotence)

Many men have problems with getting and keeping an erection after prostate surgery. Your ability to have an erection may take up to two years to recover. Some men do not get strong erections again. Men who have had good sexual function before surgery, are young, have small cancers and have nerve-sparing operations are less likely to have problems with erections after surgery.

#### Problems with bladder control

It is normal to have **urinary incontinence** (loss of bladder control) for a short time after your urinary catheter has been removed. This usually improves over time, particularly if you do regular pelvic floor exercises. A small group of men have longer-term issues with incontinence.

#### Infertility

After your prostate has been removed, semen is no longer ejaculated during orgasm. This is called a dry orgasm and results in **infertility**.

## Lymphoedema

If you have lymph nodes removed, fluid may build up in the surface tissues just under the skin on your body. In prostate cancer it may affect the legs, and it can also affect areas including the penis and testicles. It may occur months or years after treatment.

## Shortening of your penis

You may notice that your penis becomes shorter after surgery, but this may resolve with time.

# Cryotherapy surgery for prostate cancer

Cryotherapy is a procedure that uses needles to apply freezing gases to your prostate. The freezing destroys your entire prostate, including cancer cells. It is used when your cancer is in one place within your prostate. This treatment is only available privately in Tauranga.

## **Radiation treatment**

Radiation treatment uses radiation beams to destroy cancer cells or stop them growing. Radiation treatment only affects the part of the body at which the beams are aimed.

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

## When is radiation treatment offered?

If the cancer has not spread beyond the prostate and you are in good general health, you may be offered radiation treatment. Radiation is an alternative to surgery, with similar cure rates but different sideeffects. Radiation treatment may be offered:

- if you are not well enough for surgery
- if you have had surgery for locally advanced prostate cancer but there are signs that not all the cancer has been removed
- to relieve pain caused by secondary cancer in the bones
- to shrink obstructions in your lymphatic or urinary system
- where radiation treatment is your preferred treatment option.

Treatment is carefully planned to do as little harm as possible to your normal body tissue. The length of treatment will depend on the size and type of the cancer and on your general health.

## Where radiation treatment is provided

Radiation treatment is available in specialist treatment centres in Auckland, Hamilton, Tauranga, Palmerston North, Wellington, Christchurch and Dunedin. Help may be available for transport and accommodation costs through the National Travel Assistance Scheme. Your treatment centre or your local Cancer Society can advise you on what help may be available.

## Types of radiation treatment

There are three types of radiation treatment for prostate cancer:

- external beam radiotherapy
- low-dose-rate brachytherapy
- high-dose-rate brachytherapy.



A room equipped with a machine used for high-dose-rate brachytherapy.

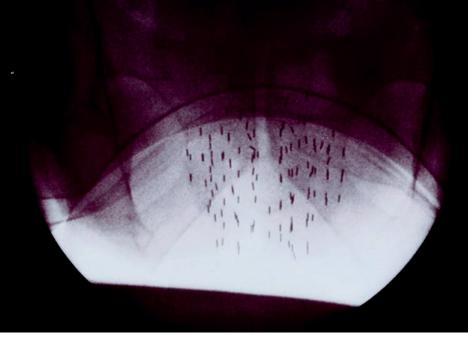
#### 1. External beam radiotherapy

External beam radiotherapy is given from outside the body by a machine called a linear accelerator, onto the area affected by cancer. This is the most commonly used type of radiation treatment for prostate cancer.

Treatment is usually given daily, for five days each week, for a period of four to eight weeks. The machine is on for only a few minutes and the total amount of time spent in the treatment room is usually 10 to 20 minutes.

# 2. Low-dose-rate brachytherapy (permanent implant)

Low-dose-rate brachytherapy is suitable for low-risk cancer that is confined to the prostate gland. Radioactive seeds are inserted permanently into the prostate gland. This is only available in a few private centres in New Zealand.



After your treatment you will be radioactive and you will need to take special precautions at home. Your radiation treatment team will explain what to do.

Whai muri i tō maimoatanga ka noho ira rukeruke koe, nō reira, me ata whakarite whakatūpato i tō kāinga. Mā tō rōpū maimoa iraruke e whakamārama, he aha ngā mahi.

I can't believe they put 123 of those little seeds of different strengths at different locations in something the size of a ping pong ball.

# 3. High-dose-rate brachytherapy (temporary implant)

In high-dose-rate brachytherapy, hollow needles are placed in the prostate and radioactive sources are temporarily placed into the prostate down the needles.

High-dose-rate brachytherapy is usually used in combination with external beam radiotherapy to treat higher-risk prostate cancer. It may also be used alone to treat low-risk prostate cancer.

## Side-effects of radiation treatment

You may experience the following side-effects when undergoing radiation treatment:

## Erection problems

Some men find they slowly develop ongoing erection problems after they have radiation treatment. The nerves needed for erections can be damaged.

## Infertility

Radiation treatment usually results in infertility. You may find ejaculation uncomfortable and some men notice that they ejaculate less or not at all. You may experience dry orgasms (where no semen is produced). Your orgasms may feel different from those you are used to.

## Urinary problems

Radiation treatment can irritate the lining of your bladder and your urethra and you may experience increased urination frequency, a burning sensation while urinating, or difficulty with flow. Some men experience incontinence (leakage) after radiation treatment.

## Bowel problems

Radiation treatment can irritate the lining of your bowel and rectum (proctitis). You may notice you pass more wind than usual, your bowel motions may be looser and more urgent, and you may feel your bowels have not emptied properly. Occasionally, you may experience pain and bleeding. These effects usually reduce after the end of treatment. With modern radiation techniques, bowel problems are much less common than they used to be.

#### Tiredness and fatigue

You may become increasingly tired during your radiation treatment as your body copes with the impacts. Fatigue is extreme tiredness that can affect your everyday life, energy levels, motivation and emotions. Fatigue and tiredness may last for several months after radiation treatment finishes.



# Hormone treatment for prostate cancer

Hormone treatments are used for men with locally advanced or advanced prostate cancer.

Prostate cancer needs the male hormone testosterone to grow. Most of a man's testosterone is produced in the testicles. There are a number of ways to slow the growth of or shrink your prostate cancer by reducing your body's testosterone levels.

Hormone treatments may also be called 'androgen deprivation therapy'. Androgens (including testosterone) are the hormones that give men their 'male' characteristics.

Types of treatment include: Luteinising hormone-releasing hormone (LHRH), anti-androgen (hormone) tablets, abiraterone, and orchidectomy.

### Luteinising hormone-releasing hormone

Luteinising hormone-releasing hormone (LHRH) lowers the amount of testosterone made in the testicles. LHRH therapy is usually given as a monthly or three-monthly injection.

## Anti-androgen tablets

Anti-androgen (hormone) tablets stop testosterone stimulating the growth of prostate cancer. They are normally used when LHRH therapy is becoming less effective (when the PSA level is rising).

#### Abiraterone

Abiraterone is a hormone therapy that stops your body making testosterone. This treatment is used for men with advanced prostate cancer where other treatments are no longer working.

## Orchidectomy

An orchidectomy is a small operation where the testicles are removed. This is a permanent procedure. This treatment is not commonly used.

## Side-effects of hormone treatment

You may find you experience the following side-effects with hormone treatment. Ways to manage your side-effects are described on page 62.

## Changes in your sex life

You may feel less interested in sex and have difficulty gaining or maintaining an erection. Your testicles and penis may also shrink.

## **Body changes**

Hormone treatment can cause weight gain and you may find it causes your breasts to become tender and start to swell. You may notice a loss of strength and muscle mass.

You may also experience hot flushes and sweats.

### Mood changes

You may feel more emotional than you have before. Hormone treatment may increase your risk of depression. If your mood remains low, you lose interest in things or your sleep patterns or appetite change, visit your GP as these can be signs of depression.

Tiredness is also a common side-effect.

## Long-term side-effects

If you take hormone treatment for a long time, your bones may begin to weaken (due to the loss of bone density), and your risk of having a heart attack or stroke may increase.

Through the treatment I lost all my sex drive. It's a real downer. Luckily I can talk to my wife about this. Brent

# **Combined treatment**

For men with locally advanced or high-risk prostate cancer, hormone treatment may be given to shrink the cancer before giving radiation treatment. This is known as **neo-adjuvant treatment** and may last for six months or more.

Hormone treatment may also be given after surgery or radiation treatment. This is known as **adjuvant treatment** and may last for up to two years.

# Treatment for advanced prostate cancer

If your cancer has spread beyond your prostate, your treatment team may offer you radiation, hormone treatment and chemotherapy. Immunotherapy treatments may also be provided.

## Chemotherapy

Chemotherapy may benefit men with advanced prostate cancer when hormone therapies are no longer working. It is not used for early-stage prostate cancer.



It may also be used as a first treatment if you are diagnosed with advanced prostate cancer. It can be given alongside hormone treatment.

Chemotherapy is the use of medication to kill cancer cells while doing the least possible harm to normal cells. It is usually given intravenously to the bloodstream.

Common side-effects of chemotherapy include tiredness, hair loss and increased risk of infection.

## Immunotherapy

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

It is possible that immunotherapy will become an important treatment option for men with prostate cancer in the future.

You can read more about chemotherapy and immunotherapy in our booklet: *Chemotherapy, Immunotherapy and Targeted Treatments* on our website www.cancernz.org.nz.



## Other medical treatments

Other treatments include:

- surgery called transurethral resection of the prostate, which is the removal of prostate tissue that is pressing on the urethra and causing an obstruction
- radiation treatment to painful areas in the bone
- bone-strengthening treatments.

## Palliative care

Palliative care focuses on improving quality of life - it is not just about care at the end of life.

Care can be offered in a hospital, a rest home, at home or in a hospice. Coordinated care is provided by specialist doctors, nurses, social workers, spiritual care workers and cultural health services.

Palliative care will help:

- you to enjoy the best quality of life you can for as long as possible
- to make sure that your physical, practical, emotional and spiritual needs are looked after as well as possible
- to manage symptoms of your cancer
- to manage side-effects of treatment
- to help you feel in control of your situation
- to make your time as positive as it can be for you and your family/ whānau.

It is a good idea to ask for palliative care early. Dealing with concerns early rather than waiting until they become difficult to manage can help to reduce stress for both you and your family/whānau.

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



For more information on advanced cancer, see the Cancer Society's booklet *Advanced Cancer/Matepukupuku Maukaha* on our website, www.cancernz.org.nz.

# Taking part in a clinical trial

There are many new and emerging treatments for cancer. There may be clinical trials available that you could join. Sometimes these trials give you access to better medications than would be available outside a study.

Trials are also used to test the effectiveness and side-effects of medications that have not been widely used so that they may be used in the future. You should discuss this with your cancer treatment team.

Clinical trials are a vital part of the search to find better treatments for cancer, to test new and modified treatments, and to see if they are better than existing treatments. In randomised clinical trials you will either receive the standard treatment currently available or the new treatment being tested.



Many people all over the world have taken part in clinical trials that have improved cancer treatments, but not all medications tested in trials turn out to be helpful. If you are asked to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for your treatment. The decision to take part in a clinical trial is yours.

# Other treatments

# Complementary and alternative therapies

Complementary therapies are massage, meditation, acupuncture and other relaxation methods that are used alongside medical treatments. They may help you to feel better and cope more easily with your cancer treatment.

Alternative therapies include some herbal and dietary methods that are used instead of medical treatment. Many are promoted as cancer cures. However, none of these methods has been proven to be effective in treating cancer.

It is important to let your treatment team 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 medical treatments.



For more information on complementary and alternative therapies, see the Cancer Society's booklet *Complementary and Alternative Medicine* on our website, www.cancernz.org.nz.

## **Traditional treatments**

## Traditional Māori healing

Traditional healing has been an integral part of Māori culture for generations. Values, belief systems and teachings from kaumātua and tohunga alike have seen Māori focus on total wellbeing encompassing taha tinana, taha hinengaro, taha wairua and taha whānau (the physical domain, the domain of mind and behaviour, the spiritual domain and the family/whānau or social domain).

When Māori are faced with tough decisions on health care or treatment, some opt for traditional healing methods. These can include rongoā Māori, romiromi or mirimiri to name a few customary remedies based on native plants, massage therapy and spiritual healing.

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

## Pacific traditional healing

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

## **Questions you might like** to ask your treatment team

You might like to find out:

- if treatment will affect your sex life and your fertility, and if so, what can be done to help manage these side-effects
- if your diet needs to change and who to talk to about it
- what other side-effects you might experience
- if you will be able to drive after treatment
- if your cancer is likely to be hereditary
- what the chances might be of your cancer coming back after treatment(s)
- what you can do to help improve your outcome
- how your PSA levels and your prostate cancer will be monitored after treatment.

# SECTION FIVE: LIVING WELL WITH PROSTATE CANCER

# Key points

- You will be given regular appointments to monitor your PSA levels following treatment. How often you are seen will get less over time depending on your results.
- Following treatment you may experience a number of side-effects. This section talks about ways to help manage these, such as improving continence through pelvic floor exercises, using sex aids, dietary changes and keeping active.
- Prostate cancer and its treatment can affect your sex life and your mind, body and relationships. There is help to manage these side-effects.
  - Ka hoaturia he whakaritenga auau mōu ki te aroturuki i ō taumata PSA whai muri i te maimoatanga. Ka iti ake ngā wā ka tirotirohia koe huri noa i te wā, e ai ki ngā hua ka puta.
  - Tērā pea, ka rongo koe i ētahi papātanga ki te taha whai muri i te maimoatanga. Ka korero tēnei tekiona mo ngā huarahi ki te whakahaere i ēnei, pērā ki te whakapai ake i te mahi mimi me te tiko mā ngā korikori ā-papatoiake, te whakamahi i ngā āwhina mo te mahi ai, te panoni i te kai whakaita, me te noho kakama tonu.
  - Ka whai papātanga tō kaha ai, tō hinengaro, tō tinana, me ōu hononga, nā te matepukupuku repe ure me ngā maimoatanga. Tērā ētahi āwhina, hei whakahaere i ēnei papātanga ki te taha.



# Monitoring your PSA levels after treatment

You will be given regular appointments to monitor your PSA levels following treatment. Your treatment team or your GP will also ask how well you are feeling and if you have any symptoms. How often you are seen will get less over time depending on your PSA results.

Your PSA level should drop to very low or be undetectable following surgery. To limit your anxiety, ask your treatment team what changes in PSA level they would be concerned about.

PSA levels following radiation tend to drop slowly and may not reach their lowest level until two or more years later.

PSA monitoring during treatment for advanced prostate cancer can help show how well the treatment is working.

I had prostate cancer and had a radical prostatectomy. My PSA was zero but there was 3-4 years where I didn't have my levels tested. Now my levels have gone up again and I don't know why I wasn't tested earlier.

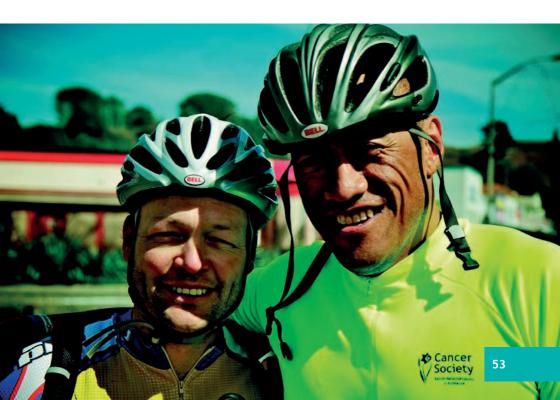
## Managing side-effects of prostate cancer treatments

Following treatment you may experience a number of side-effects. These include incontinence, changes in your sex life and your fertility, bowel changes and hormonal changes. This section talks about ways to help manage these.

## Incontinence

Incontinence refers to the leaking of urine. The amount of urine leaking can vary. For the majority of men it is temporary, and should resolve within a year.

A small number of men continue to have significant incontinence on a long-term basis. If incontinence is worrying you, talk to your specialist about having an assessment. There are options available to treat or better manage your incontinence.



#### Wearing pads or absorbent underwear

Wearing pads or absorbent underwear will help. Ask your GP for a referral to the continence services at your local DHB for help with the supply of the most appropriate product for your leakage.

Urinary sheaths, bed protectors and hand-held urinals may be available through your continence service.

## Pelvic floor exercises

Regular pelvic floor exercises, which involve exercising the muscles of the pelvic floor, help many men to regain bladder control after prostate surgery. It is best to start these exercises before treatment as normal pelvic floor muscle sensations may be altered for several weeks afterwards. Ask your treatment team for information about pelvic floor exercises.

It is normal to have stress incontinence (urinary leakage associated with movement and activity) after your catheter is removed after surgery. This may persist for many months but usually improves over time.

#### Further support



Specialist continence nurses can help with advice and equipment. A small number of men may need further support if incontinence persists or worsens. Most urology departments have pelvic floor physiotherapists. Ask for a referral, ideally before surgery.

For more information on continence and pelvic floor exercises, see Continence NZ's website, www.continence.org.nz.

## Changes in your sex life

Prostate cancer and its treatment can affect your sex life and your mind, body and relationships. Treatment can affect:

- your ability to get an erection, ejaculate and have an orgasm
- your desire to have sex (libido)
- your ability to have children (fertility)
- how you feel about your sexuality
- how your body looks
- your relationships.

## Erection problems and loss of interest in sex

As you get older, it usually gets more difficult to have and maintain an erection. Adding the effects of prostate cancer treatment, it can be even more difficult.

For some men, difficulty gaining an erection might not be a big concern for them or their partners. For others it may be very important.

You may want to try different ways to achieve a non-penetrative orgasm, either with or without a partner. It will probably take longer to reach orgasm, which means there will be more time to enjoy the pleasure of intimate body contact. Keep in mind that no matter what kind of cancer treatment you have, you will almost always be able to feel pleasure from touching.

Going through treatment and coping with the effects of changes on your hormones can have big effects on how you feel about yourself and your interest in sex.

## Talking about how you are feeling

If you have a partner, talking together about how you are both feeling can be very helpful.



If you find changes in your sex life upsetting, or you (or your partner) are finding it difficult to share your feelings, it may be helpful to discuss this with your treatment team. They may be able to refer you to someone who can help.

It could be worthwhile talking to a counsellor about the changes that you (or your partner) are experiencing and the effects on your life.

There may be an erectile dysfunction service in your area. Some specialist services are available through physiotherapists, or are attached to urology private practices.



Talking to other men who have experienced changes in their sexual function due to prostate cancer can be helpful. You can contact the Cancer Society's Cancer Connect Service by phoning 0800 CANCER (226 237) and asking them about any prostate cancer support groups in your area.

After being impotent for 18 months, the fitting of a penile implant gave me back my confidence and brought back the intimacy to my relationship.

#### Managing problems with erections

There are practical ways to help overcome erection problems.

#### **Physical devices**



**Physical devices** such as vacuum pumps use suction to draw blood into the penis and can help you to strengthen and keep a natural erection. They are either manual or battery operated.

After the pump is removed a constriction ring can remain in place for up to 30 minutes to help you keep an erection.

Constriction ring.

#### Oral medications and injections



**Oral medications** such as Viagra, Cialis and Levitra are options to discuss with your GP. These medications cannot be used if you take nitrate-based medicine for heart problems. Make sure you take these as prescribed for best effect.

Injections given straight into the penis are available on prescription. You will be provided with syringes that are pre-filled with medication, and you will be taught how to use them. The needle is very fine and usually does not cause much discomfort. The medicine makes the blood vessels of your penis expand. The vessels fill with blood, creating an erection that can last up to an hour. Most men find this works for them.



#### Penile implants

**Penile implants** are usually only used when other treatments are not effective. Flexible rods or small, inflatable cylinders are put into your penis during a short operation. Whilst effective, implants may be expensive.

If rods are inserted, they are placed into the part of your penis that becomes erect. Your penis will remain erect but the rods have joints that allow you to position your penis.

If you have inflatable cylinders inserted, an erection is achieved through a small pump that is placed in your scrotum.

#### Sex therapy

Getting an erection also relies on your thoughts and feelings, so tackling any worries or relationship issues, as well as having medical treatment for erection problems, often works well.

#### Self-help

Keeping a healthy weight, stopping smoking and doing pelvic floor exercises may help improve your erections.





## Infertility and dry orgasms

Men who have treatment for prostate cancer can expect to be infertile. Talk to your treatment team about sperm banking before treatment if you wish to have children in the future.

#### Other resources

Websites that will be helpful:

- www.atouchysubject.com
- www.andrologyaustralia.org
- www.prostatecanceruk.org look under sex in the search box
- www.sextherapy.co.nz
- www.prostate.org.au



You may find also the Cancer Society's booklet, Sex and Cancer/Hokakatanga me te Matepukupuku helpful.

# Bowel function after treatment for prostate cancer

Men who have had radiation treatment are more likely to have problems with their bowels and bowel motions (poo). You may experience:

- diarrhoea
- gas and bloating
- blood in your poo or passing blood
- bowel incontinence.

These problems may occur months or years after treatment and are caused by radiation irritating the lining of the lower part of your bowel. Modern radiation techniques are less likely to cause these side-effects.



#### Ways to manage these side-effects

- Keep yourself hydrated by drinking plenty of fluids (water is best).
- Avoid spicy and fatty foods.
- Try some gentle exercise each day.
- Talk to your GP about medications that may help.
- Consider talking to a dietician about what you eat if diarrhoea is an ongoing issue.
- If you have incontinence you may want to speak to an incontinence specialist for further advice.

## Coping with fatigue

Fatigue is often confused with tiredness. Usually you know why you are tired and a good night's sleep solves the problem.

Fatigue is overwhelming tiredness (physical and emotional) and is not relieved by rest or sleep. Cancer-related fatigue is one of the most common side-effects of cancer and its treatment. It can happen to anyone with any type of cancer and at any time, during and after treatment. Gentle exercise can help to relieve fatigue.



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

# Managing mood changes and depression

Having prostate cancer can cause worry, stress and sadness, making it seem an effort to keep active and connect with family/whānau and friends. This can lead to isolation and may make it harder to manage the effects of treatment. Some treatments for prostate cancer, such as hormone treatments, can put men at a greater risk of experiencing mood changes, anxiety and depression.

My wife was a trained nurse but even she found coping with my post-surgery depression extremely difficult. The nature of the disease meant I was self-focused and spent little or no time considering the emotional needs of loved ones.

Two key signs of depression are constantly feeling down or hopeless, and having little pleasure in doing the things you used to enjoy (www.depression.org.nz; retrieved 10/4/19).

Remember that your mental health is as important as your physical health. If you are concerned about yourself or someone else, talk to your GP or treatment team. There's a lot that can be done that can make a difference. Me maumahara, he rite te hira o tō hauora hinengaro ki tō hauora tinana. Mehemea kai te māharahara koe mōu ake, mō tētahi atu rānei, me kōrero ki tō GP, ki tō rōpū maimoa rānei. He nui tonu ngā āhuatanga ka taea te whakamahi, e puta ai te rerekētanga.



Mindfulness programmes, relaxation, meditation and exercise are all helpful things to try when you are feeling low. Talk to a trained counsellor about how you are feeling. Contact the Depression Helpline on 0800 111 757.

Information on anxiety and depression for men is available at www.beyondblue.org.au. You can also find good information at www.depression.org.nz.

Support from my wife, family and friends helped me cope. And exercise helped the mind.

## Dealing with hormonal changes

When I was on hormone therapy I didn't know what the side-effects would be or how to deal with them. I put on a lot of weight and felt like crying for no reason, and then you get to the things nobody talks about like my penis shrinking and loss of sex drive.

Hormone treatment can cause a range of side-effects that change the quality of men's lives. These include hot flushes, weight gain and breast swelling.



#### Managing hot flushes

Some men find their hot flushes reduce as their bodies become used to the treatment, while others may have ongoing problems. You can help manage these by:

- keeping to a healthy weight
- stopping smoking if you smoke
- · drinking plenty of fluids and limiting alcohol and caffeine
- · reducing the amount of spicy food you eat
- keeping your room at a cool temperature and using a fan
- using cotton rather than synthetics. If you sweat a lot at night, try using a cotton towel on top of your sheet when you sleep
- having lukewarm baths or showers
- talking to your GP about any medications that might relieve symptoms.

Some men have found that acupuncture or hypnotherapy helps.

## Weight gain and loss of muscle strength

Resistance exercise, such as lifting weights, can help with muscle strength, while regular walking can keep your weight stable and also help with muscle strength. Eating in a healthy and balanced way will also help with weight management. The Ministry of Health recommends:



#### Changes in bone density

Men on hormone therapy should discuss ways to preserve their bone density with their treatment teams. Bone-strengthening medication may be suggested, and regular exercise that increases your heart rate and builds muscle strength can be helpful. Men on anti-androgen therapy who are at risk of osteoporosis should try to include calcium in their diets. Good sources of calcium include:

- dairy products
- green vegetables
- nuts
- tofu
- tinned sardines with the bones
- whole grain foods, such as bread, rice and cereals.

#### Breast swelling or tenderness

Some hormonal treatments cause breast swelling or tenderness. If this causes discomfort, talk to your treatment team about the options that might help to reduce the side-effects. Some men get benefits from a single dose of radiation treatment to the breast area. This usually works best if given before hormone treatment starts. Sometimes low-dose tamoxifen is used to help with this side-effect.

## Joining a support group

For some people, meeting others who are in a similar situation can help to decrease feelings of anxiety, isolation or fear. Support groups offer you the opportunity to share your experiences and learn different ways of dealing with problems.

Prostate cancer support groups are available nationwide to assist you and are run by the Prostate Cancer Foundation. These can be found on their website: www.prostate.org.nz/support-groups.

My piece of advice if you have this condition, talk to others who have had it, read widely and find a local prostate group to attend. David



## How families/whānau can help

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

- Learn about prostate cancer and its treatment. This will help you to understand what the person you are supporting is coping with.
- Be thoughtful about offering advice. Listening while they talk or just being there with them, are good ways to show you care.
- Talk about your feelings together and be honest about what worries you.
- Offer to go to appointments with them. You can be there for support, take notes or, when appropriate, take part in the discussions.
- Respect that your family/whānau member or friend may want to talk to their treatment team alone.



The Cancer Society offers a range of resources to support you. We suggest you read *Supporting Someone with Cancer* which is available on our website www.cancer.org.nz.

# Lifestyle changes to help you cope with cancer

Cancer can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is also very important.

Research indicates that regular, gentle exercise may help with fatigue and lift your mood. Talk with your cancer treatment team about what exercise is best for you.

## It's good to know where the support networks are after going to the Urologists.



A number of support services are available to you if you are having difficulty coping with your cancer diagnosis or adjusting to the lifestyle changes your cancer diagnosis may bring.



For more information, see the Cancer Society booklets Coping with Cancer and Eating Well During Cancer Treatment/Kia Pai te Kai te wā Maimoatanga Matepukupuku, and our pamphlet Being Active When You Have Cancer on our website, www.cancernz.org.nz.

# Cultural and spiritual support

Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural and advocacy needs. They may include Māori and Pacific health workers who will work with you and your family/whānau. Hospital chaplains are available to offer support through prayer and quiet reflection.



Community health workers based at your local marae or community-based Pacific health service may be a good source of support.

## **Interpreting services**

New Zealand's Code of Health and Disability Services Consumers' Rights states that everyone has the right to have an interpreter present during a medical consultation.

If you do not speak English as your first language or you are deaf, you may find it helpful to use an interpreter when you have your hospital appointments. Speak to a member of your health care team about arranging interpreters in your local area.

# Advance care planning

Advance care planning is about helping you to think and talk about the end of your life, and about the treatments and care you might want. This gives you and your health care providers an opportunity to work together to ensure that your choices about treatment and care in the future are heard. An advance care plan will guide your doctors and family/whānau in making decisions if you are unable to make them yourself.

Advance care planning is voluntary - no-one can force you to do it. For more information on advance care planning, see the Advance Care Planning website, www.advancecareplanning.org.nz.

# Appendix 1: What is cancer?

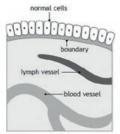
Cancer is a disease of the body's cells. It starts in our genes. Our bodies are constantly making new cells to allow us to grow, replace worn-out cells and heal damaged cells after an injury.

The process of making new cells is controlled by certain genes - the codes that tell our cells how to grow and behave. Cancer is caused by damage to these genes.

In a very small number of families/whānau, damaged genes may be passed through the generations. While these people have an increased risk of developing cancer, it does not mean they will definitely get cancer.

## How cancer starts

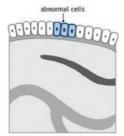
Tumours can be benign (not cancerous) or malignant (cancerous). Benign tumours do not spread to other parts of the body.



1. Normal cells



3. Abnormal cells multiply



2. Abnormal cells



4. Malignant or invasive cancer

## How cancer spreads

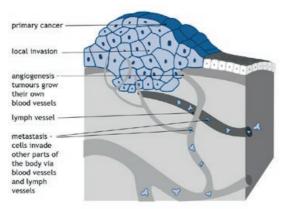
A malignant tumour is made up of cancer cells. When it first develops, the malignant tumour is usually confined to its original site. This is known as the primary site. Some tumours can become quite large within their organs of origin. With growth, the tumour may spread beyond the original organ boundaries and into surrounding tissues. This is called locally advanced cancer.

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

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

Treatment for cancer includes surgery, radiation treatment and chemotherapy. Immunotherapy and targeted treatments, which are now used to treat some cancers.

These modes of cancer treatment can be used individually or in combination.



#### How cancer spreads

### Appendix 2: Suggested websites and books

The following websites also have information on prostate cancer and support:

Cancer Council Australia: www.cancer.org.au

Cancer Research United Kingdom: cancerresearchuk.org/about-cancer/ prostate-cancer/about

Continence NZ: www.continence.org.nz

Ministry of Health - Manatū Hauora prostate website www.kupe.net.nz

Macmillan Cancer Support: www.macmillan.org.uk

Mental Health Foundation of New Zealand: www.mentalhealth.org.nz

Prostate Cancer Foundation of New Zealand: www.prostate.org.nz 0800 477 678 or 0800 4 PROSTATE

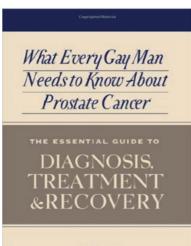
Prostate Cancer Foundation of Australia: www.prostate.org.au

Prostate Cancer United Kingdom: www.prostatecanceruk.org

The suggested websites are not maintained by the Cancer Society. We only suggest sites we believe offer credible and responsible information, but we cannot guarantee that the information on such websites is correct, up-to-date or evidence-based medical information.

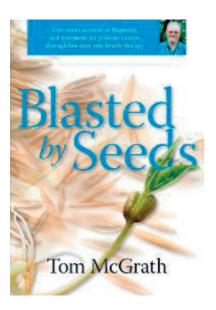
We suggest you discuss any information you find with your cancer treatment team.

#### Further reading:



EDITED BY GERALD PERLMAN, Ph.D.

<u>About Prostate Cancer</u> by Gerald Perlman (2013). Magnus Books, NY



#### **Blasted by Seeds**

by Tom McGrath (2015). This is Tom's story about his experience with prostate cancer – the tests, biopsies and diagnosis, and the difficult process of choosing a treatment.

## Appendix 3: Glossary (what this word means)

**adjuvant treatment** - a treatment that is done along with the main treatment or after it

**anaesthetic (local or general)** - a medication given to stop a person feeling pain. A local anaesthetic numbs part of the body; a general anaesthetic causes temporary loss of consciousness

**benign prostatic hyperplasia** (BPH) - a non-cancerous enlargement of the prostate gland

**benign tumour** - a tumour that is not malignant, not cancerous and won't spread to other parts of the body

**biopsy** - the removal of a small sample of tissue from the body for examination under a microscope to help in diagnosing a disease

bladder - a hollow organ in the body that stores urine

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

**diagnosis** - the act of identifying a disease from its signs and symptoms

diarrhoea - loose, watery bowel movements

**ejaculation** - the discharge of semen from the male reproductive tract (the penis)

**gland** - an organ that produces and releases substances directly into the bloodstream (such as hormones) that perform specific functions in the body, such as endocrine **glands** 

**Gleason score** - a system for grading prostate cancer tumours according to size and appearance

**grading** - refers to the differentiation of cancer cells when examined under a microscope

**hormones** - special chemical messengers in the body created in the endocrine glands, which control most major body functions

immune system - the body's natural defence system

infertility - inability to have children

**inflammation** - where a part of the body becomes red, swollen, hot and often painful, often as a reaction to injury or infection

**lymphatic system/lymph nodes/lymph vessels/lymph glands** - the lymphatic system is a network of very thin lymph vessels, which connects the major lymph glands in the abdomen, pelvis, groin, neck and armpits. The lymphatic system drains away fluid waste products and damaged cells, and contains cells that fight infection

**mestastases** - when cancer has spread from the original site to another part of the body. It can also be called secondary cancer.

**neo-adjuvant treatment** - a treatment that is done before the main treatment to enhance the other treatment

perineum - the area between the anus and the scrotum or vulva

**prostate-specific antigen (PSA)** - a protein normally produced by prostate cells. Tests of PSA levels are used in the diagnoses and monitoring of prostate cancer. This involves a simple blood test

**protein** - these are key parts of body tissue that can also serve as a nutrient source for the body.

**radiation treatment** - the use of particular forms of radiation, usually X-rays or gamma rays, to kill cancer cells

 ${\bf rectum}$  - the last 12-15 centimetres of the large bowel leading to the outside of the body

symptom - a warning sign or indicator of a disease

**testicles** - two egg-shaped glands that produce semen and sex hormones

**testosterone** - a male sex hormone produced by the testes, which stimulates male sexual activity and the growth of other sex organs including the prostate

**tumour** - a new or abnormal growth of tissue in or on the body, which may be benign or malignant

**ultrasound** - a scan that uses soundwaves to create a picture of the inside of a body

**urethra** - a tube that carries urine from the bladder and semen from the sex glands to the outside of the body via the penis

**urinary catheter** - an artificial tube inserted to drain urine from the bladder into a collecting bag

urinary incontinence - loss of bladder control, or urinary leaking

### Cancer Society of New Zealand Inc. Te Kāhui Matepukupuku o Aotearoa

# Cancer Society information and support services



The Cancer Information Helpline is a Cancer Society service where you can talk about your concerns and needs with cancer nurses on **0800 CANCER (226 237)**.



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

- volunteer support, including drivers providing transport to treatment
- accommodation while you are having treatment away from home
- support and education groups.

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

### National Office

PO Box 651, Wellington 6140 Telephone: 04 494 7270

### **Auckland Division**

PO Box 1724, Shortland Street, Auckland 1140 Telephone: 09 308 0160 Covering: Northland

#### Waikato/Bay of Plenty Division

PO Box 134, Waikato Mail Centre, Hamilton 3240 Telephone: 07 838 2027 Covering: Tauranga, Rotorua, Taupō, Thames and Waikato

### **Central Districts Division**

PO Box 5096, Terrace End, Palmerston North 4441 Telephone: 06 356 5355 Covering: Taranaki, Wanganui, Manawatū, Hawke's Bay and Gisborne/ East Coast

### Wellington Division

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

### **Canterbury/West Coast Division**

PO Box 13450, Armagh, Christchurch 8141 Telephone: 03 379 5835 Covering: South Canterbury, West Coast and Ashburton

#### **Otago/Southland Division**

PO Box 6258, Dunedin North, Dunedin 9059 Telephone: 03 477 7447 Covering: Urban and rural Otago and Southland

Cancer Information Helpline 0800 CANCER (226 237) www.cancernz.org.nz



Copies of Cancer Society booklets, brochures and information sheets are available from your local Cancer Society, by phoning the Cancer Information Helpline 0800 CANCER (226 237) or by downloading them from our website, www.cancernz.org.nz.

## Other titles from the Cancer Society

Our aim is to provide easy-to-understand and accurate information on cancer and its treatments. Our Living with Cancer information booklets are reviewed and updated by cancer doctors, specialist nurses and other relevant health professionals to ensure that the information is reliable, evidence based and up to date. The booklets are also reviewed by consumers to ensure they meet the needs of people with cancer and their carers. You can find information from us on:

Advanced Cancer/Matepukupuku Maukaha Advanced Melanoma of the Skin/Tonapuku Maukaha o te Kiri Bowel Cancer/Matepukupuku Puku Hamuti Breast Cancer/Te Matepukupuku o ng $\bar{a}$   $\bar{u}$ Chemotherapy, Immunotherapy and Targeted Treatments Early Stage Melanoma of the Skin/Wāhanga Tōmua Tonapuku ki te Kiri Eating Well during Cancer Treatment/Kia Pai te Kai te wā Maimoatanga Matepukupuku Getting on with Life after Treatment/Te Hoki Anō ki tō Toioranga Whai Muri i te Maimoatanga Living with Dry Mouth/Te Noho me te Waha Maroke Prostate Cancer/Matepukupuku Repeure Radiation Treatment/Haumanu Iraruke Secondary Breast Cancer/Matepukupuku ā-ū Tuarua Sex and Cancer/Hokakatanga me te Matepukupuku Brochures: Being Active When You Have Cancer Questions You May Wish to Ask.

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www.cancernz.org.nz

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

