









This presentation contains Aboriginal and Torres Strait Islander Men's/male business

Note to the presenter

Because what is known about prostate cancer and its treatment is constantly changing and being improved, the healthcare team can update you with information specific for your unique needs and situation.

This flipchart is written so it can be given as a stand-alone presentation. If you would like further information please contact PCFA (telephone: 02 9438 7000 or freecall 1800 22 00 99, email: enquiries@pcfa.org.au, website: www.pcfa.org.au).

Disclaimer

This flipchart series has been developed in consultation with Aboriginal and Torres Strait Islander communities and consultants to reach a culturally appropriate standard acceptable to Aboriginal and Torres Strait Islander people. PCFA develops materials based on the best available evidence and takes advice from recognised experts in the field when developing resources; however, PCFA cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

The 'Diagnosis, treatment options and challenges' presentation is part of a series of three flipcharts that aim to improve prostate cancer information and support for Aboriginal and Torres Strait Islander Communities.

Supporting men with prostate cancer through evidence-based resources and support is a Cancer Australia initiative, funded by the Australian Government.

Flipcharts in this set include:

- "Know about your prostate prevention and living well" (This presentation contains Aboriginal and Torres Strait Islander Men's/male business).
- "Diagnosis, treatment options and challenges prostate cancer" (This presentation contains Aboriginal and Torres Strait Islander Men's/male business).
- "Support and care what carers and partners of men with prostate cancer need to know".

Overview

The 'Diagnosis, treatment options and challenges – prostate cancer' presentation is part of a series of flipcharts that aim to improve prostate cancer information and support for Aboriginal and Torres Strait Islander communities.

This flipchart contains Aboriginal and Torres Strait Islander Men's/male business

It has been reported that Aboriginal and Torres Strait Islander men have lower prostate cancer relative survival rates when compared to non-Indigenous men, prostate cancer is an important issue for Aboriginal and Torres Strait Islander men. 'Diagnosis, treatment options and challenges – prostate cancer' is designed to provide Aboriginal and Torres Strait Islander men with an overview of prostate specific treatment issues in a culturally safe format.

Why flipcharts

Within the Aboriginal and Torres Strait Island communities news travels fast. Community presentations to spread health messages are good health practices. The project community consultations run by PFCA supported flipcharts as a preferred way of spreading the message.

Flipcharts are:

- applicable to a wide target audience
- an accepted communication method for Aboriginal and Torres
 Strait Islander health messages
- at an appropriate technology level for a variety of education settings
- more interactive than basic written materials
- delivered by a local male health professional who is able to include local context, language, terminology, clinical, health and cultural practices into the delivery.

These notes provide background information and references for male health professionals delivering the 'Diagnosis, treatment options and challenges' flipchart. The notes provide briefing information for the presenter. They do not follow exactly the flipchart pages as they are not a script and should not be read directly to the participants as part of the presentation. The notes support the flipchart presenter to enable discussion.

PCFA asks people delivering the 'Diagnosis, treatment options and challenges' resource to be particularly mindful of the language requirements, the local culture and appropriate introductions acknowledgements and relations with traditional land owners of the place where the presentation is being run.

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Website: www.pcfa.org.au Email: enquiries@pcfa.org.au Prostate Cancer Foundation of Australia (PCFA) respects and acknowledges the traditional custodians and the elders past and present of the land on which this meeting takes place.

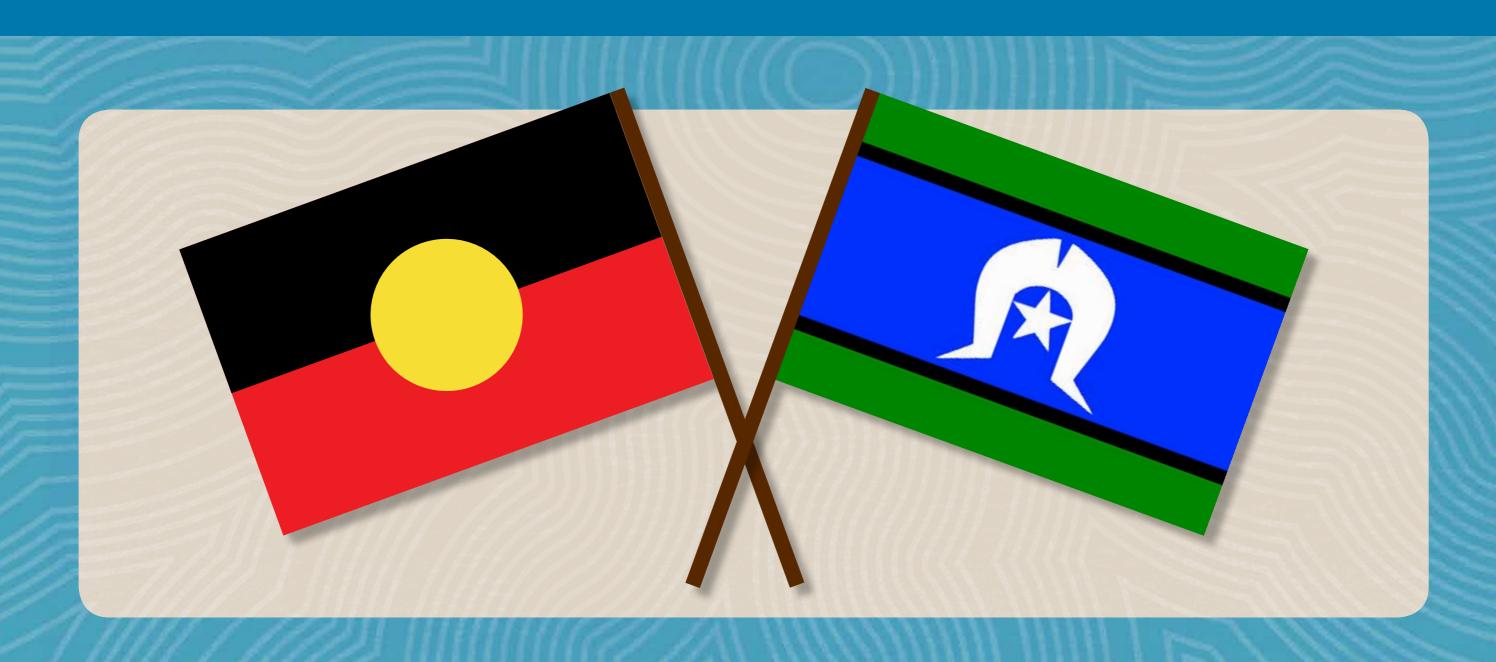
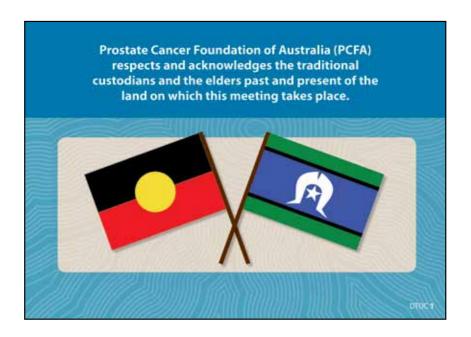






CHART 1 – ACKNOWLEDGEMENT OF COUNTRY

This presentation contains Aboriginal and Torres Strait Islander Men's/male business



Introduction

You should take a few minutes before the 'official' presentation to introduce yourself to your audience. Within Aboriginal and Torres Strait Islander communities relationships to people and 'where is your country' are important points in an introduction. This may be a good place to start.

If possible, get a person or traditional owner from the community to introduce you thereby creating the link.

Try to keep your introduction to 2-3 minutes.

It is important to acknowledge the traditional owners and elders past and present of the land where you are meeting. This needs to be done early in the presentation. The Acknowledgement of Country makes a good connecting point from introducing yourself to the presentation, it actively demonstrates respect for the people you are talking to.

An Acknowledgement of Country is a way of showing awareness of and respect for the traditional Aboriginal or Torres Strait Islander owners of the local area past and present. Incorporating welcoming and acknowledgement protocols into official meetings and events recognises Aboriginal and Torres Strait Islander peoples as the First Australians and custodians of their land. It promotes an awareness of the past and ongoing connection to place of Aboriginal and Torres Strait Islander Australians.

Prostate Cancer Foundation of Australia respects and acknowledges the traditional custodians and the elders past and present of the land on which this meeting takes place.

At a meeting, speech or formal occasion the speaker will begin their proceedings by offering an Acknowledgement of Country.

Acknowledgement of Country is recommended by Federal, State and Territory Government departments.

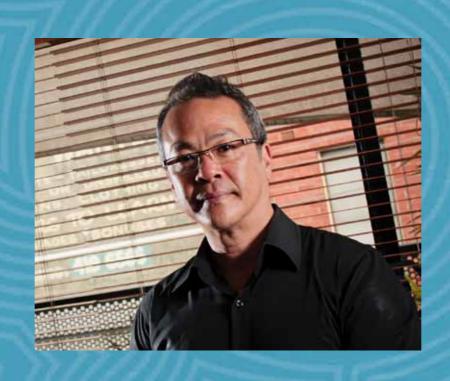
There are times speaking to a group when an elder or traditional owner may be present, in which case there may be a Welcome to Country given by this person as a more formal opening. This is particularly the case when the meeting involves people from outside the area other than locals.

Ask as part of your preparation if there will be a more formal Welcome to Country at the start of the event. When there has been a formal Welcome to Country, you should thank the elder or traditional land owner for the welcome, then start your Acknowledgement of Country. Always deliver the Acknowledgment of Country at the start of each presentation.

For more information about Welcome and Acknowledgement of country please refer to the Reconciliation Australia website. Information about traditional owners and elders is often available on the Aboriginal Land Council website covering the area where you are presenting.

Source:

 Reconciliation Australia. Welcome to and acknowledgement of country. Retrieved from www. reconciliation.org.au/wp-content/uploads/2013/12/QA-welcome-to-country.pdf



This artwork is designed and created by Marcus Lee.

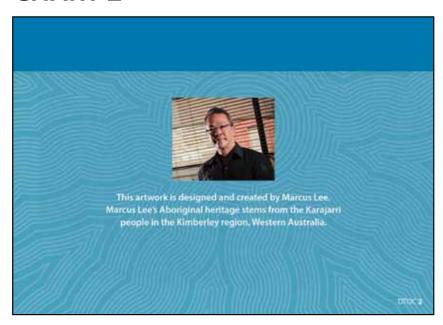
Marcus Lee's Aboriginal heritage stems from the Karajarri

people in the Kimberley region, Western Australia.





CHART 2



Marcus Lee

Marcus was born and raised in Darwin, pursued his design education in Adelaide, and works from Melbourne. Marcus's Indigenous heritage stems from the Karajarri people in the Kimberley region, Western Australia.

Marcus Lee Design is an Indigenous owned graphic design studio which has been successfully operating from Melbourne since 1996. Consisting of a small team of multi-talented graphic designers, illustrators and account service, the studio's combined skills offers a professional boutique design service. Managing and creative director Marcus Lee has been practising the art of graphic design for almost thirty years, through effective partnering in tandem with clients marketing strategies and objectives. This acquired experience has forged an exceptional understanding within the visual communication arena, which has enabled Marcus to efficiently lead and manage his own design business.

Marcus is of Aboriginal heritage and it was inevitable that those roots would pull at his art strings and take him and his design team into the evolving realm of communicating cultural diversity. This also brings with it the scope to participate within the commercial community helping to improve the living standards of Aboriginal and Torres Strait Islanders.

Specialising in the visual design of Indigenous related communication projects, Marcus's extensive design experience adds a professional skill level and value to client's objectives, resulting in the creation of culturally relevant and ultimately unique contemporary solutions.

In 2010 the studio became a certified supplier of AIMSC (Australian Indigenous Minority Supplier Council) now Supply Nation.

This presentation contains Aboriginal and Torres Strait Islander Men's/male business

Acknowledgments

These resources were developed in consultation with Aboriginal and Torres Strait Islander communities throughout the development process.

PCFA gratefully acknowledges the input, advice and guidance of the Aboriginal and Torres Strait Islander people and health professionals who helped in the development of this flipchart by offering their advice and time to review its content.

- Dr Mick Adams (Aboriginal and Torres Strait Islander Health)
- Associate Professor Nick Brook (Urologist)
- Bawley Point NSW Men's Yarning Group (Community Consultation)
- Mr Les Bursill OAM (Cultural consultant)
- Mr Michael Camit (NSW Multicultural Health Communications Service)
- Mr Lachlan Circuitt (Prostate Cancer Specialist Nurse)
- Mr Tuguy Esgin (Aboriginal and Torres Strait Islander Health)
- Dr Gail Garvey (Aboriginal and Torres Strait Islander Health)
- Gold Coast/ Tweed Qld Men's Yarning Group (Community Consultation)
- Ms Susan Hanson (Cancer Australia)
- Dr Michael Izard (Radiation Oncologist)
- Professor Lisa Jackson Pulver (Aboriginal and Torres Strait Islander Health)
- Associate Professor Michael Jefford (Medical Oncologist)
- Ms Bilawara Lee (Elder Cultural consultant)
- Mr Wayne Lonesborough (Cultural consultant)
- Associate Professor Anthony Lowe (PCFA)
- Manangrida NT Community AHW (Community Consultation)
- Mr Stewart Manawara-Nethercott (Aboriginal and Torres Strait Islander Health)

- Dr David Malouf (Urologist)
- Mr Brett McCann (Impotence Australia)
- Dr Vivienne Milch (Cancer Australia)
- Ms Jenny Mothoneos (NSW Cancer Council)
- Ms Hannah Nancarrow (Cancer Australia)
- Northern Territory Cancer Council (Community consultation)
- Prof Ian Olver (Cancer Council Australia)
- Ms Rebecca Palmer (Aboriginal and Torres Strait Islander Health)
- Mr Des Rogers (Cultural consultant)
- Mr David Sandoe OAM (PCFA)
- Ms Ester-Rose Seaton (Aboriginal and Torres Strait Islander Health)
- Ms Sue Sinclair (Cancer Australia)
- Mr John Stubbs (Consumer)
- Mr Raj Supramanian (NSW Cancer Council)
- Ms Julie Sykes (PCFA)
- Mr Kym Thomas (Aboriginal and Torres Strait Islander Health)
- Professor Neil Thompson (HealthInfonet)
- Warrnambool Vic Men's Yarning Group (Community consultation)
- Associate Professor Mark Wenitong (Aboriginal and Torres Strait Islander Health)
- Ms. Alyssa White (Cancer Council Australia)
- Dr Tim Wong (PCFA)
- Associate Professor Henry Woo (Urologist)

What we'll cover today.

- Prostate what is it?
- When the prostate gets sick
- Prostate cancer checks
- Treatment types
- Decisions
- Looking after yourself
- How can PCFA help?







CHART 3



By the end of this presentation

Aboriginal and Torres Strait Islander men should know:

- that not all prostate cancer news is a doom and gloom
- about the prostate and symptoms if the prostate is not well
- what is involved with testing and deciding on treatments
- what are the treatment options and side effects
- where to get information and help.

All good presentations outline what topics will be covered and in what order they will be presented. This provides some direction and focus for the participants.

This is the opportunity to tell the participants that we will be developing a 'safe space' to discuss prostate cancer. People understand and participate well when they feel safe.

Tell participants that this material has been designed with Aboriginal and Torres Strait Islander consultation all the way through and that this flipchart will cover sensitive topics but in a culturally sensitive way. This presentation contains Aboriginal and Torres Strait Islander Men's/male business

Remember throughout the session if you are not sure of a response refer the person to their healthcare team or the PCFA 1800 22 00 99 phone line.

Ask people to think about "why they have come", "what they would like to know about prostate cancer" and "what do we all need to do to make this a safe space".

What is a safe space?

It will help people if you can discuss what is a 'safe space'. Make a list of what people say we can do to make people feel safe in this group. Then you can compare it to the activities shown in the next chart.

Creating a safe space.

Mibbinbah 'Proper Way'

REMEMBERING
Respect
Diversity
Respect
History

CELEBRATING

Questing Collaborating

Transferring

Mediating Leading
ANTICIPATING

Healing





CHART 4

This presentation contains Aboriginal and Torres Strait Islander Men's/male business



Mibbinbah Ltd (http://mibbinbah.org/) has developed the idea of creating safe places for men to discuss health and wellbeing. This process has become accepted within Aboriginal and Torres Strait Islander communities as good practice for developing safe spaces. Compare the points listed by the group in the previous chart with the components in the Creating Safe Space Chart.

For the purpose of this presentation the terms are all defined below in case you need to clarify any of the points.

Today we want to create a 'safe space' to discuss prostate cancer. Let's compare our 'safe space' list with the Mibbinbah 'Safe Space' diagram.

There are three main parts to having a 'safe space' - Celebrating, Remembering and Anticipating. We will describe here what happens in a 'safe space' so people will know what to expect.

CELEBRATING - good news -

Celebrating means we collaborate, we question and we give and teach our skills and knowledge.

<u>Collaboration</u> is actively working together, sharing knowledge, encouraging others to take action, helping when a man is ill. This way we value each others experience, knowledge, skills and help.

Questing is asking and answering questions, seeking and sharing information and resources together.

Transferring knowledge is:

Mentoring - helping others take responsibility for themselves and take action on their health, families and communities.

Yarning - sharing stories, informing and encouraging each other.

REMEMBERING -

Respect yourself first and then respect all others we meet.

Respect History – Experience

- 1. There are triumphs and strengths remember most men continue living with prostate cancer.
- 2. There are challenges and trauma 3300 men die from prostate cancer in Australia each year.

<u>Respect Diversity</u> – People are different. Respect the culture of the person and who is their 'mob'? Respect where they are from and what is their journey? Every cancer journey is different.

ANTICIPATING

Leading is to be willing to show the way, support and guide those who may need encouragement. We will honour good conduct, health behaviours, wellbeing and positive spirit.

<u>Mediating</u> – Name problems for what they are, violence and anger are not a solution. Help people avoid negative health outcomes. We want to do things that will help all of us not feel 'shame' in this space today.

Spirit Healing – Look ahead to good ways of living healthy positive lives. Helping each other to take action, keep up hope and positive spirit. Practice and find Dadirri – inner deep listening and quiet still awareness.

We hope today having discussed prostate cancer in a 'safe space' you will be able to take action.

ources:

- Bulman J., & Hayes R. (2011). Mibbinbah and spirit healing: fostering safe, friendly spaces for Indigenous males in Australia. International Journal of Men's Health, 10(1), 6-25
- Ungunmerr-Baumann M-R. (2002). Dadirri a reflection. Retrieved from www.liturgyplanning.com. au/documents/main.php?g2_view=core.DownloadItem&g2_itemId=4696

What is your prostate?

All men have a prostate gland. Your prostate makes fluid that is part of your semen.

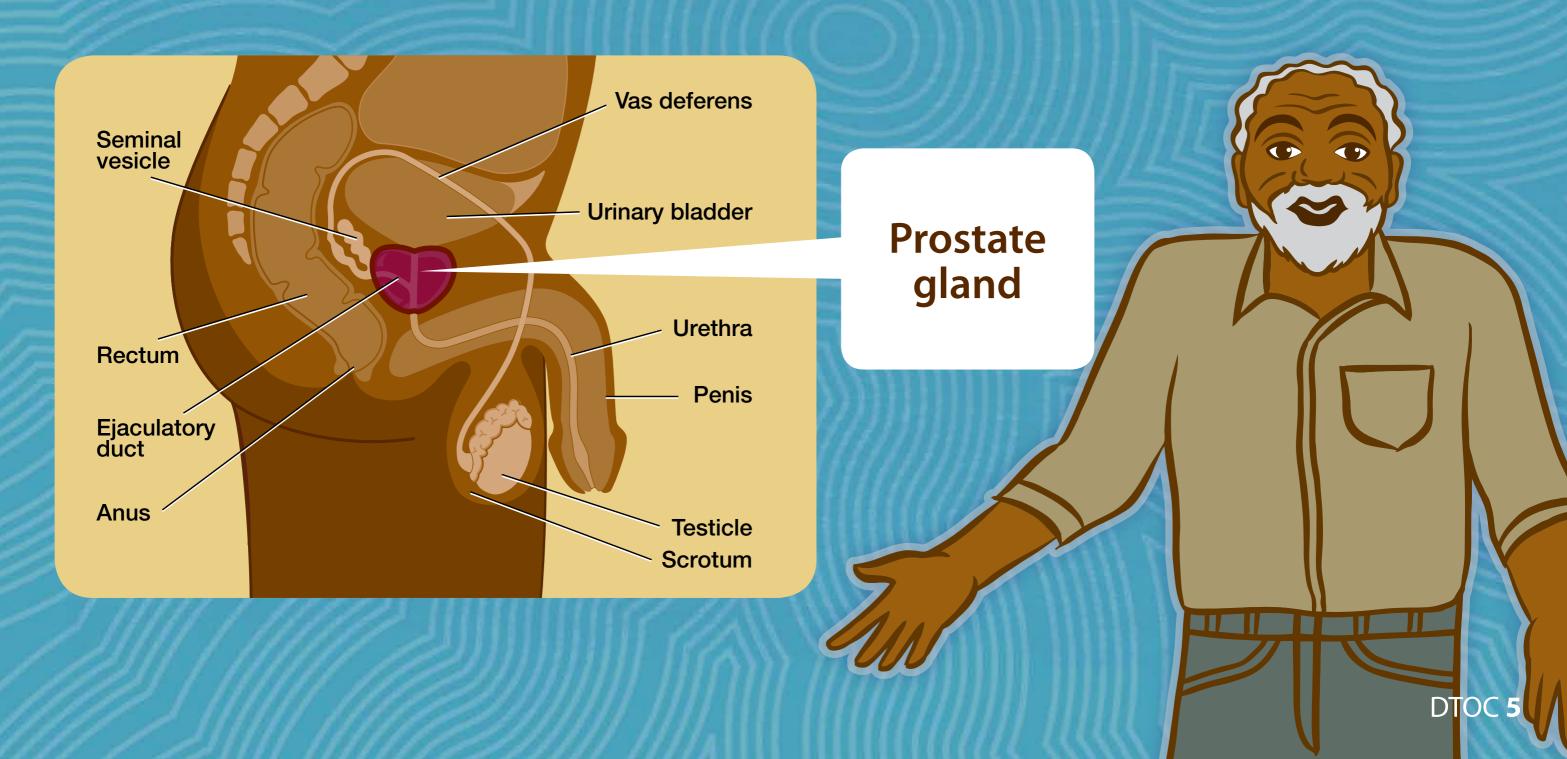
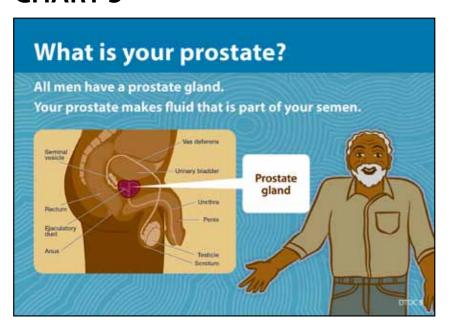






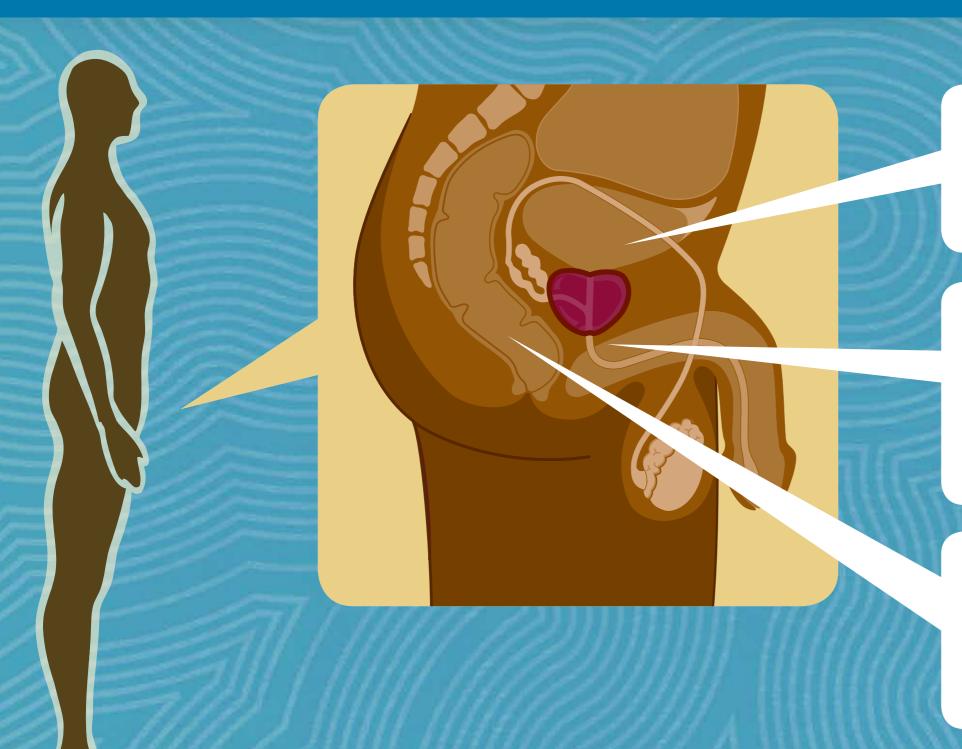
CHART 5



The prostate is a male sex organ. It provides some of the fluid that makes up semen. All men have a prostate.

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Where is your prostate?



Prostate sits under your bladder.

It wraps around the pee tube (urethra) that goes out through the penis.

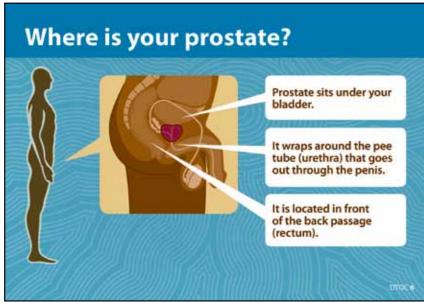
It is located in front of the back passage (rectum).





CHART 6





The prostate is located inside the body, immediately below the bladder and just in front of the end part of the bowel called the rectum.

The prostate produces fluid which protects and enriches sperm. The fluid is milky or white in appearance and usually makes up 1/3 of the volume of the semen.

A healthy human prostate is said to be slightly larger than a walnut. The average weight of the "normal" prostate in men is about 11 grams, usually ranging between 7 and 16 grams.

It is shaped like a doughnut and it surrounds the beginning of the urethra (pee tube). Urine passes through the pee tube (urethra) on its way from the bladder (storage bag) to the outside through the penis.

Testosterone (male hormone) makes the prostate grow. If the prostate grows too large, it can slow or stop the flow of pee (urine) down the pee tube.

The nerves that control hard penis (erections) surround the prostate and can be affected by prostate cancer treatment.

The prostate is located near the exit of the back passage (the rectum). The doctor can check the growth and size of the prostate by feeling the prostate through the rectum wall with a gloved finger. This check is called a Digital Rectal Examination. There are other ways to check the prostate size and growth but they are more involved in time and expense.

[•] Prostate Cancer Foundation of Australia www.pcfa.org.au

When your prostate gets sick.

Prostatitis is an infected or inflamed prostate.

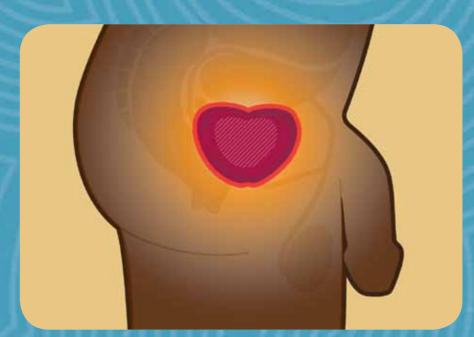
Benign Prostatic Enlargement (BPE) is a swollen prostate. Prostate cancer happens when prostate cells grow out of control and form a malignant tumour.

This is not cancer.

This is not cancer.

This is prostate cancer.







Some prostate cancer causes no or few problems.

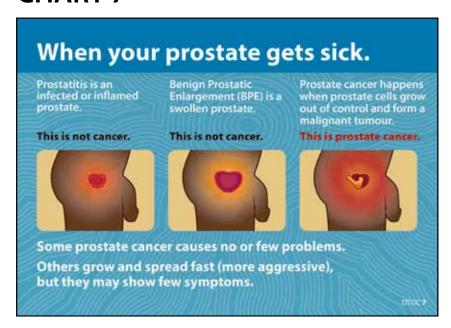
Others grow and spread fast (more aggressive), but they may show few symptoms.





CHART 7

This presentation contains Aboriginal and Torres Strait Islander Men's/male business



Prostatitis

Prostatitis is an infection in the prostate and sometimes the area around it. There are several types of prostatitis, each with a range of symptoms.

Some men with this disease will experience severe pain and some will not feel much at all. Most will feel some level of discomfort down low in their body. The symptoms can affect the way a man feels, thinks and behaves.

Prostatitis can affect men at any age and it is thought that 1 in every 6 men may experience this illness at some stage during their lives.

Sources

• Blandy J.(1998). Urology (5th Ed.) Oxford: Blackwell Science.

Benign Prostatic Enlargement (BPE) or Benign Prostatic Hyperplasia (BPH)

Benign Prostatic Enlargement (BPE) is not cancer, it is when the prostate gland grows too big and becomes large enough to cause problems.

As men get older, the prostate gland grows in size, and may press on the urethra (pee tube) which goes through the centre of the prostate. This can slow or stop the flow of urine (pee) from the bladder through the urethra to the outside. It can cause urine to back up in the bladder and lead to the need to go to the toilet more often during the day and night. Other common symptoms include a slow flow of urine (pee), the need to urinate urgently and difficulty starting the urinary stream. More serious problems include urinary tract infections and complete blockage of the urethra (retention), which may be a medical emergency and can damage the kidneys. These symptoms are called Lower Urinary Tract Symptoms or LUTS.

Sources:

- Urological Society of Australia and New Zealand www.usanz.org.au/benign-prostatic-hyperplasiabph/
- Garraway W., Collins G., & Lee R. (1991). High prevalence of benign prostatic hypertrophy in the community. The Lancet, 338(8765), 469–471.
- Napalkov P., Maisonneuve P., & Boyle P. (1995). Worldwide patterns of prevalence and mortality from benign prostatic hyperplasia. Urology, 46(3) Supp 1, 41–46.

Lower Urinary Tract Symptoms (LUTS)

Lower urinary tract symptoms are common and can significantly reduce men's quality and enjoyment of life. Having these symptoms does not mean men are more likely to have prostate cancer. Lower urinary tract symptoms do not only occur in cancer. Lower urinary tract symptoms are common in older men. It has been reported that 9 out of 10 men aged 50 to 80 years suffer from lower urinary tract symptoms. If you have any problems passing pee or pain you should go to the doctor or clinic.

Sources:

- NICE Clinical Guideline (2010). The management of lower urinary tract symptoms in men. Retrieved from www.nice.org.uk/nicemedia/live/12984/48554/48554.pdf
- Abrams P. (1994). New words for old: lower urinary tract symptoms for "prostatism". BMJ, 308(6934), 929-30.
- Boyle P., Robertson C., Mazzetta .C, et al. (2003). The prevalence of lower urinary tract symptoms in men and women in four centres. The UrEpik study. BJU Int, 92(4), 409-14.

Prostate cancer

Prostate cancer is out of control growth of cells in the prostate that form a lump (tumour).

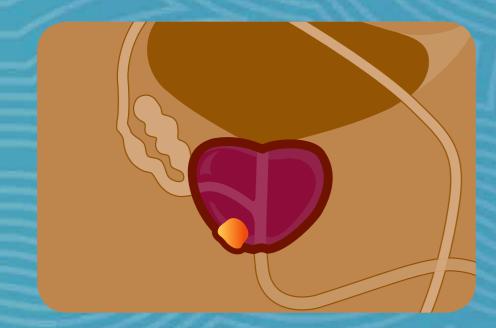
Most prostate cancers grow slower than other types of cancer.

Sources:

 Cancer Council NSW. (2013). Understanding prostate cancer – a guide for men with cancer, their families and friends.

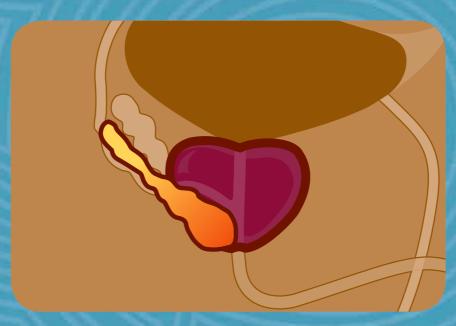
What is prostate cancer?

Localised



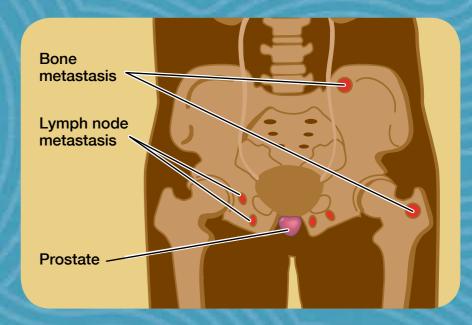
The prostate cancer is found only in the prostate gland.

Locally advanced



The cancer has extended beyond the prostate or to other surrounding organs such as the seminal vesicles, bladder or rectum.

Metastatic



The cancer has spread to distant parts of the body such as bone.

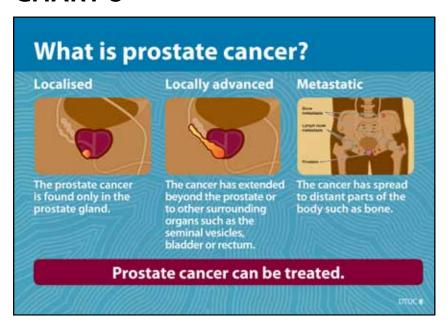
Prostate cancer can be treated.



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CHART 8



Prostate cancer occurs when abnormal cells develop in the prostate, forming a malignant tumour (cancerous growth). These cells have the potential to multiply in an uncontrolled way, and possibly spread outside the prostate into nearby or distant parts of the body.

Prostate cancer is generally a slow-growing disease, and the majority of men with prostate cancer live for many years or decades without painful symptoms, and without it spreading and becoming life-threatening.

Localised prostate cancer or early prostate cancer is when the cancer is found only in the prostate gland.

For some men, their prostate cancer grows slowly and is not aggressive. But in other men the type of cancer grows more quickly and spreads to other parts of the body – this is called advanced prostate cancer.

There are different stages of advanced prostate cancer.

- Locally advanced the cancer has extended beyond the prostate and may include seminal vesicles or other surrounding organs such as the bladder or rectum.
- Metastatic the cancer has spread to distant parts of the body such as bone.

Sources

• Cancer Council NSW (2013). Understanding prostate cancer – a guide for men with cancer, their families and friends.

Who can get prostate cancer?

All men are born with a prostate.

Any man can get prostate cancer.







CHART 9



Prostate cancer is an issue for Aboriginal and Torres Strait Islander men, their families and communities.

Any man can get prostate cancer.

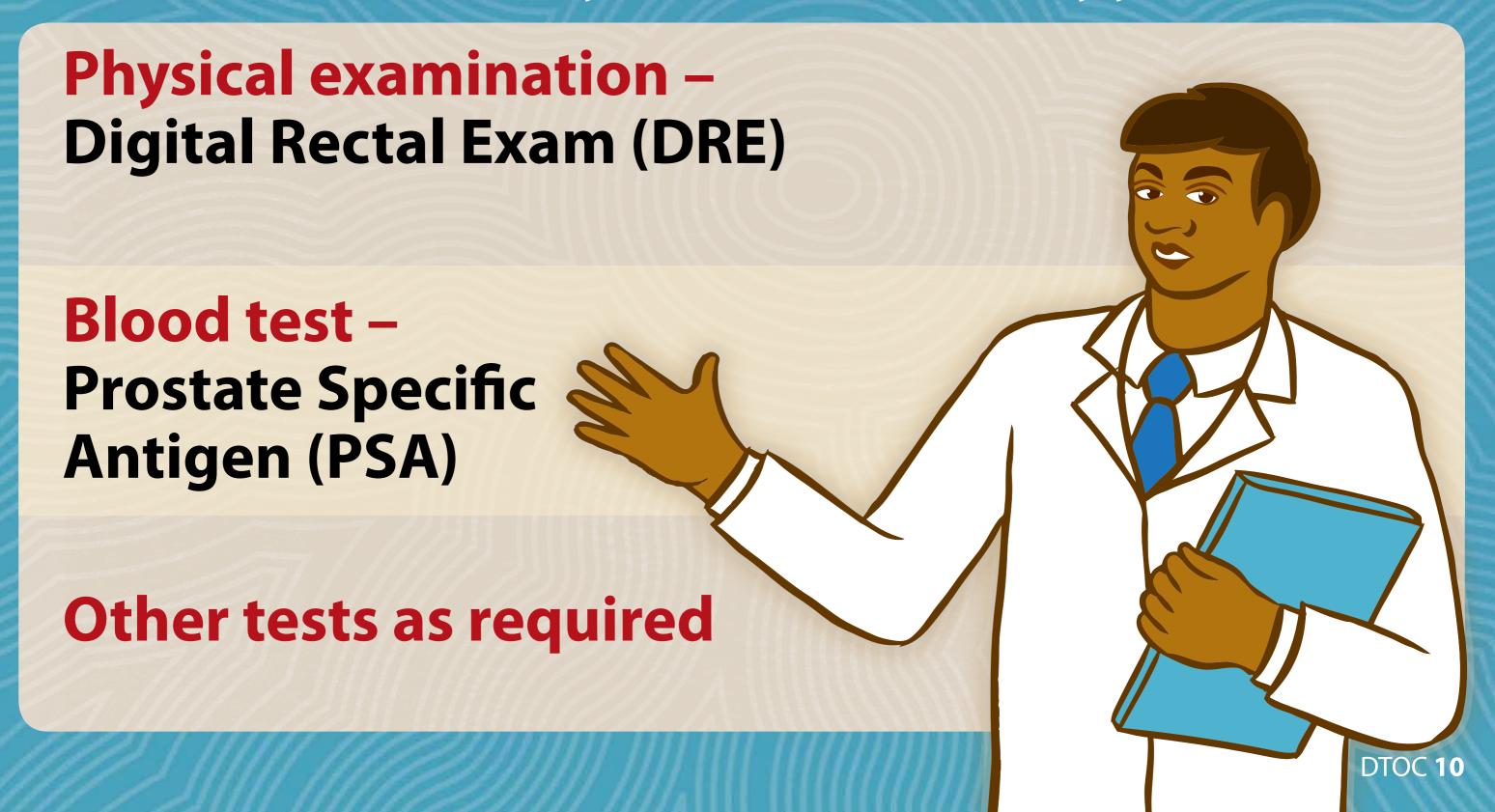
Source

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[•] Cancer Council Australia (2010). Localised prostate cancer – a guide for men and their families.

What are the tests for diagnosing prostate cancer?

These tests are done at your health clinic or by your doctor.

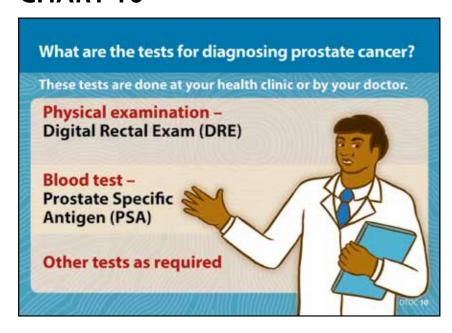




This presentation contains Aboriginal and Torres Strait Islander Men's/male business



CHART 10



A blood test and/or a physical examination are usually what a doctor will initially do to check the health of the prostate and for possible prostate cancer.

- **Blood test** (Prostate Specific Antigen PSA) PSA is a protein produced in the prostate and can be measured by a blood test. This test identifies whether there has been an increase in this specific protein in your blood.
- Digital Rectal Examination (DRE) This allows your doctor to feel the size of the prostate and check if there are any abnormalities. Occasionally a cancer can be felt this way, but not always. A normal DRE exam does not rule out prostate cancer.

As a result of these tests, your doctor may request repeat tests and refer you to a urologist, a doctor who specialises in the urinary and reproductive area.

• Biopsy: This is the only way a diagnosis of prostate cancer can be made. Your urologist removes small samples of tissue from your prostate using a very thin, hollow needle, guided by an ultrasound. The prostate is either accessed through the rectum (transrectal) or the perineum (transperineal), which is the area between the anus and scrotum. A biopsy is usually done as an out-patient procedure and your doctor will likely advise a course of antibiotics afterwards to reduce the chance of infection. The tissue is sent to a pathologist to identify whether the cells are malignant (i.e. cancerous) or benign (i.e. non-cancerous).

If you're taking medications, let your treating doctor know what they are before the biopsy to reduce the chance of problems.

After the procedure, you may:

- feel some soreness
- have light bleeding from your rectum
- have blood in your urine or stools for a few days
- notice blood or a rust-coloured tint in your semen (this can last for several weeks after the biopsy but depends on how often you ejaculate).

If you're concerned about any of these symptoms, tell your treating doctor.

Other tests that your doctor may suggest include:

 Free PSA test: If you have a moderately raised PSA score and your doctor is not sure whether you need a biopsy, you may have another test to measure the free PSA in your blood – that is, the PSA molecules that are not attached to other blood proteins. A decreased level of free PSA can indicate prostate cancer.

- Prostate Health Index (PHI): A combination of three blood tests that measure different forms of PSA protein. When reviewed together they provide a personalised risk assessment for prostate cancer.
- **PCA3:** A urine test which measures the level of the PCA3 gene and which, when looked at in conjunction with the PSA test, can help your doctor decide whether you need a biopsy.

The results of these tests are looked at together, giving an overall picture of the prostate cancer. It is only then that the correct treatment options can be discussed with you.

Medicare covers some of the costs of procedures and tests used to diagnose prostate cancer, but there may be some 'out-of-pocket' costs. The doctor or a member of the healthcare team can answer questions about why certain procedures and tests are needed, and the financial outlay.

Talk to a member of the healthcare team (e.g. social worker) about what financial and practical support services are available. Talk to the local Medicare office about the 'Pharmaceutical Benefits Scheme Safety Net' and the 'Medicare Safety Net' on costs of medications and medical bills (www.humanservices.gov.au/customer/services/medicare/pbs-safety-net and www.humanservices.gov.au/customer/services/medicare/medicare-safety-net).

Source:

• Cancer Council Australia (2010). Localised prostate cancer – a guide for men and their families.

What might happen next?

Abnormal digital rectal exam (DRE) or PSA

Referral to urologist.

No cancer Get advice. Cancer Found
Watch for problems or treat.

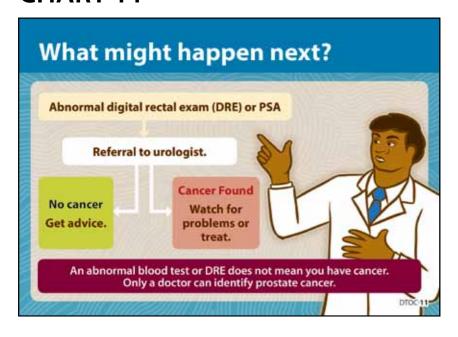


An abnormal blood test or DRE does not mean you have cancer.
Only a doctor can identify prostate cancer.





CHART 11



If your digital rectal examination (DRE) and/or PSA test are abnormal, you may be referred to a urologist. Urology is a medical speciality that focuses on the urinary tract illnesses of males and females, and the sexual reproductive system problems in males.

The urologist may want to do a biopsy – a biopsy is when small samples of prostate tissue are taken using a needle. The samples are then examined under a microscope by a pathologist to see if cancer cells are present.

If it is cancer, the biopsy test will give information about the type of cancer cells present.

When cancer is detected further tests will be made to find out how far the cancer has spread. These may include different types of scans such as: bone scans, Magnetic Resonance Imaging (MRI) or Computerised Tomography (CT) scans.

Source

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[·] Cancer Council NSW. Prostate cancer treatment. Retrieved from www.cancercouncil.com.au/prostate-cancer/treatment

What if it is cancer?

- Talk to your doctor and health care team.
- Talk to your family and community.
- Find out about your type of cancer.
- Visit the PCFA website for information.

Work out your treatment path.





This presentation contains Aboriginal and Torres Strait Islander Men's/male business



CHART 12



If it is cancer, there will be a number of different directions you can take. These directions depend on: the type, stage and grade of prostate cancer diagnosed. Your doctor will have this information. You can also choose not to do anything.

Cancer grade - The grade is a test score that gives an idea of how quickly the cancer may develop.

The Gleason system is used to grade prostate cancer. Low-grade prostate cancers are usually slow-growing and less likely to spread. High-grade tumours are likely to grow more quickly and are more likely to spread.

Cancer stage – Stage is a term used to describe

- cancer size
- whether it has spread beyond the prostate.
- There are different stages numbered from T1 T4.

T1 and T2 tumours are classified as localised prostate cancers.

T3 tumours mean that the cancer has spread beyond the prostate gland into the surrounding tissues. They are known as locally-advanced prostate cancer.

T4 tumours mean that the cancer has spread beyond the prostate gland into other surrounding organs such as the bladder.

If the cancer has spread to other parts of the body this is known as metastatic cancer.

Sources:

[•] Cancer Council Australia (2010). Localised prostate cancer – a guide for men and their families.

Management and treatment options.

If the cancer has not spread (localised)

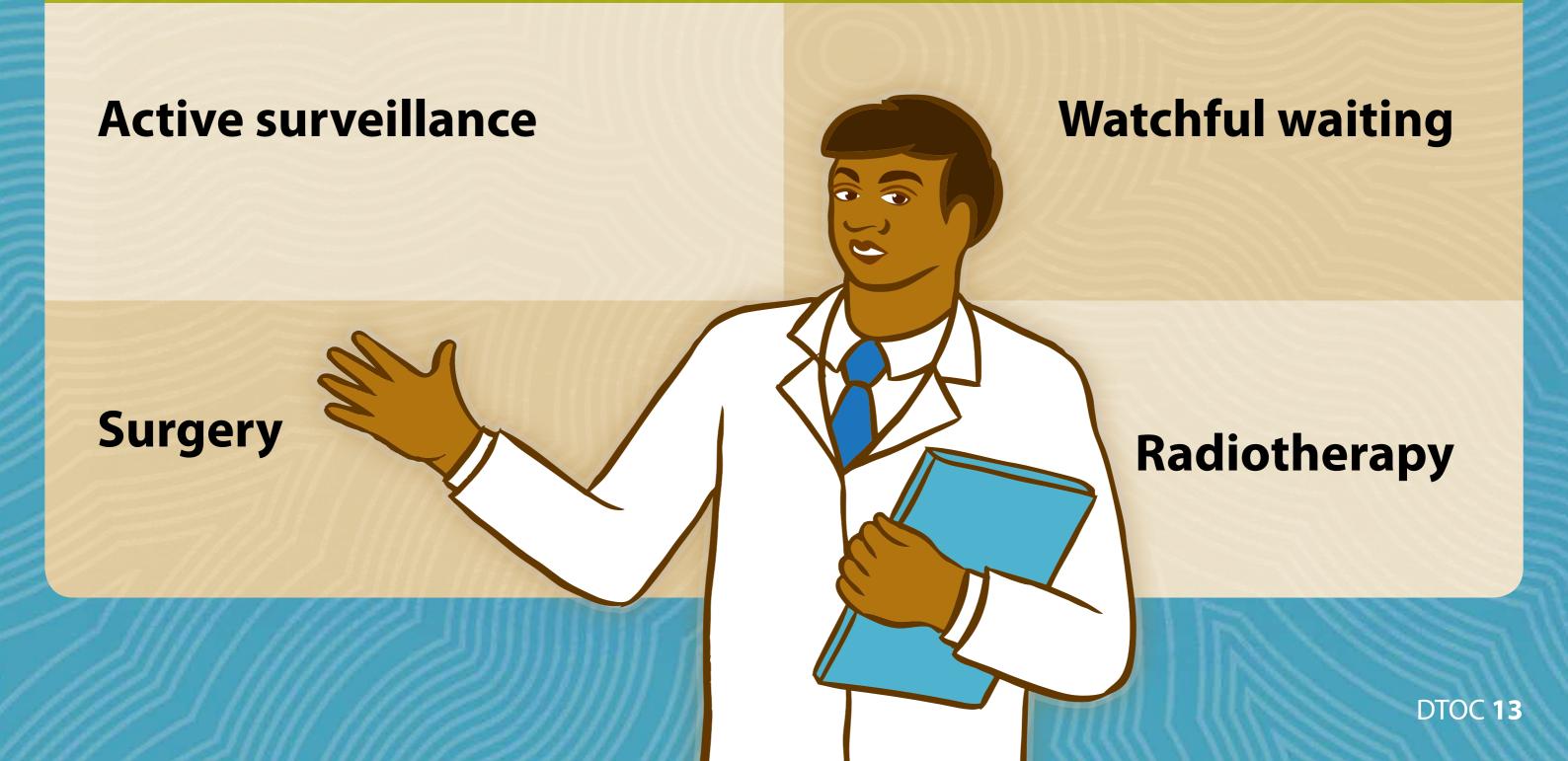
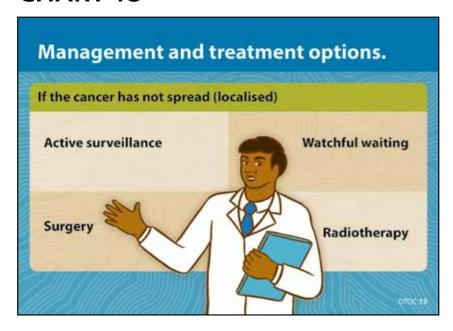






CHART 13



If the cancer has not spread

Active surveillance and watchful waiting

These terms were often used interchangeably in the past and this causes confusion as they are different approaches used for different reasons.

Active surveillance

For men who have low-risk localised prostate cancer, active surveillance is an option. Men are regularly monitored by the prostate specific antigen (PSA) test, digital rectal examination (DRE) and occasional further biopsies. The results from these tests and procedures will show if the cancer had changed. If the disease progresses, they are offered treatment, usually by surgery or radiotherapy. The thinking behind this strategy is that because treatments have side effects that affect quality of life, it can be better to delay treatment for as long as possible. Men on active surveillance may remain well without treatment.

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Watchful waiting

This approach is 'waiting to see what happens'. It generally involves:

- no extensive monitoring of the disease
- if symptoms do occur they are managed rather than treatment given to 'cure' the cancer.

This option is often chosen when there is:

- low risk of the disease developing or spreading
- the person is elderly and not at risk of dying specifically from prostate cancer
- other medical conditions such as heart disease, lung disease, kidney problems or stroke.

Surgery

Cutting out the whole prostate is called radical prostatectomy. Other tissue around the prostate might also be removed and checked for cancer (e.g. the lymph nodes). After the prostate and seminal vesicles are removed the bladder is re-attached to the urethra. Nerves that men need to get an erection (hard penis) are also next to the prostate gland – and these can be damaged during surgery. There can be problems with leaking and controlling your pee.

Radiotherapy

There are different types of radiation therapy available for prostate cancer

- External beam radiation: radiation from a machine is used to target the prostate gland. Treatment usually lasts for a few minutes each day for 6-8 weeks.
- Brachytherapy (or seed radiation): uses multiple needles to insert small radioactive 'seeds' into the cancer in the prostate gland and release radiation slowly over time.

There are several side effects associated with radiation therapy including problems with:

- leaking and controlling your pee
- controlling your bowels diarrhoea
- side effects affecting your ability to have a hard penis
- other issues such as tiredness, dry skin, unable to make babies.

Sources:

- Macmillan Cancer Support. Active surveillance for early (localised) prostate cancer. Retrieved from www.macmillan.org.uk/Cancerinformation/Cancertypes/ Prostate/Treatmentforearlyprostatecancer/Activesurveillance.aspx
- Cancer Council NSW. (2012). Understanding radiotherapy a guide for people with cancer, their families and friends.

Management and treatment options.

If the cancer has spread (locally advanced or metastatic cancer)

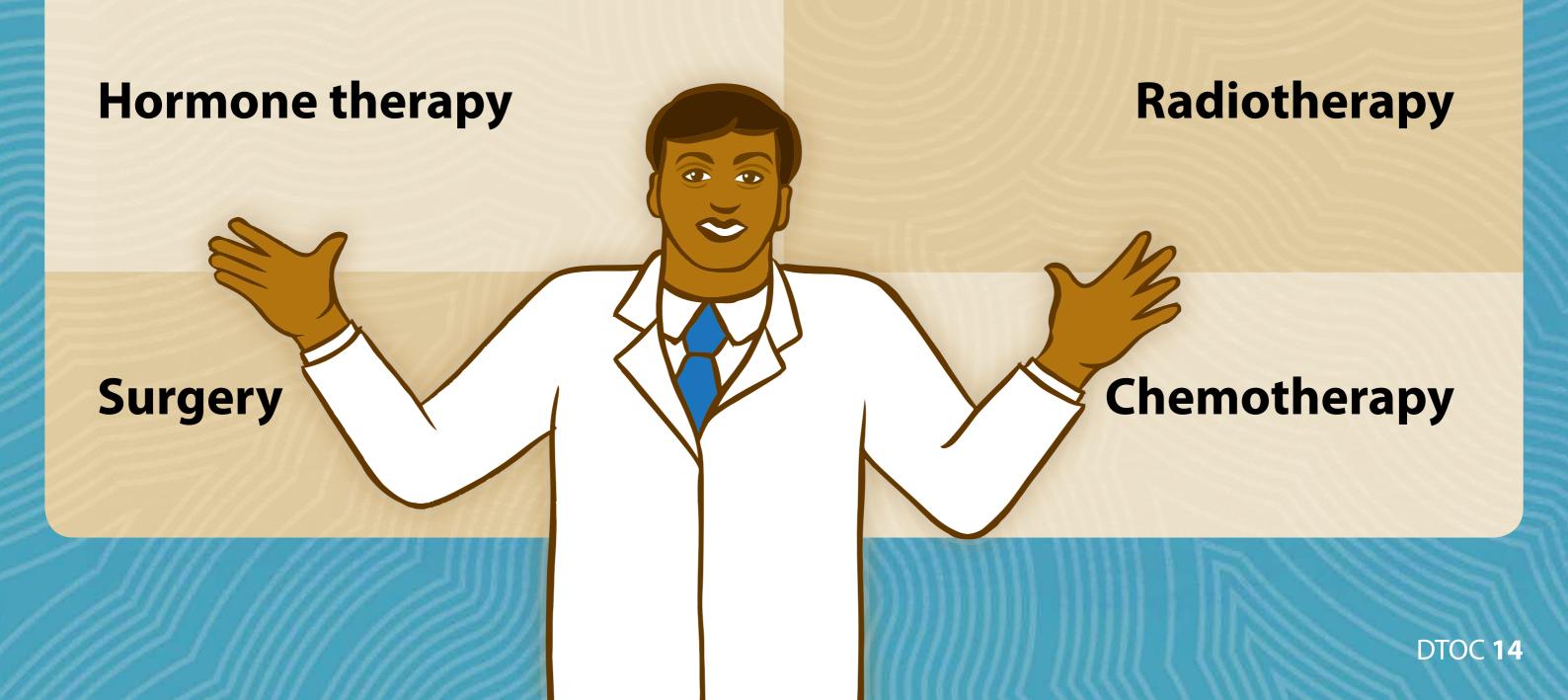
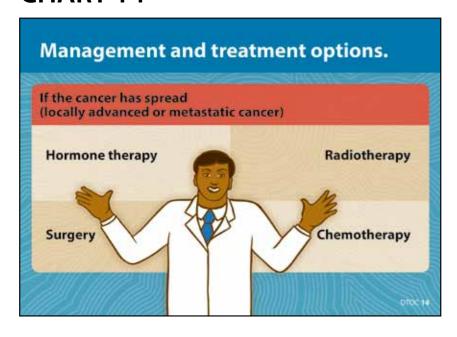






CHART 14

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If the cancer has spread

Hormone therapy/ Androgen Deprivation Therapy (ADT)

Prostate cancer is driven by hormones. So by reducing hormones, it is possible to slow the growth of the cancer. This is known as hormone therapy, also known as androgen deprivation therapy (ADT), and is the standard first treatment when prostate cancer has spread (metastatic prostate cancer).

Testosterone is a male sex hormone (or androgen), which is produced by the testicles. It is vital in reproductive and sexual function. Hormone therapy reduces testosterone levels, and can often keep the cancer under control for several years by shrinking it, delaying its growth and reducing symptoms. How well hormone therapy controls the cancer is different from one man to another. It depends on how aggressive the cancer is, and how far the cancer has spread when you start hormone therapy.

Your doctor will speak with you about the different types of hormone therapy available and what is best for you, depending on your specific needs and situation.

There are three main types of hormone therapy for advanced prostate cancer.

Injections to stop the production of testosterone

Injections block the messages from the brain to make testosterone, or block its action in the tissues. The drug (luteinizing hormone releasing hormone (LHRH) agonist) can be injected under the skin or into the muscle monthly or every 3, 4 or 6 months.

Tablets to block the effects of testosterone (anti-androgens)

Anti-androgen drugs stop testosterone from getting to the prostate cancer cells so they are not able to grow. They are taken as tablets and may be used in combination with injections (see above) or orchidectomy (see below) to completely stop the action of testosterone in the body because they are not as effective on their own.

Orchidectomy

This form of hormone therapy involves the surgical removal of the testicles. Even though it involves surgery, its main effect is as a form of hormone therapy. Unlike other types of hormone therapy, orchidectomy cannot be reversed. It is important for you to talk with members of your healthcare team to make sure this is the most appropriate option for you.

Sources:

- Macmillan Cancer Support. Hormonal therapy for locally-advanced prostate cancer.
 Retrieved from www.macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/
 Treatmentforlocallyadvancedprostatecancer/Hormonaltherapy.aspx
- Macmillan Cancer Support. Hormonal therapy for advanced prostate cancer. Retrieved from www. macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Treatmentforadvancedprostatecancer/ Hormonaltherapy.aspx

Chemotherapy

- Chemotherapy is the use of drugs to kill or slow the growth of cancer cells.
- Most chemotherapy drugs are given through a needle they enter the bloodstream and travel throughout the body to reach cancer cells. Chemotherapy drugs target and injure rapidly dividing cells. Both cancer cells and some normal cells are affected. When normal cells are damaged, this can cause other problems we call side effects. With side effects, you may feel very tired, lose appetite, feel sick and be vomiting, have toilet and bowel problems, lose memory and concentration.

Sources:

 Macmillan Cancer Support. Chemotherapy for advanced prostate cancer. Retrieved from www.macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Treatmentforadvancedprostatecancer/ Chemotherapy.aspx

Surgery

Some men require surgery for treatment of symptoms in locally advanced and advanced prostate cancer. The most common types of surgery is Transurethral resection of the prostate (TURP). This is an operation to clear a blocked pee tube (urethra).

Sources:

 Macmillan Cancer Support. Surgery for advanced prostate cancer. Retrieved from www.macmillan. org.uk/Cancerinformation/Cancertypes/Prostate/Treatmentforadvancedprostatecancer/Surgery.aspx

Radiotherapy

You may be offered radiotherapy if the cancer causes symptoms, such as pain in the prostate area, or if it has spread to other parts of the body such as the bones. This is called palliative radiotherapy, it does not cure the cancer but relieves the symptoms.

Sources:

 Macmillan Cancer Support. Radiotherapy for advanced prostate cancer. Retrieved from www. macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Treatmentforadvancedprostatecancer/ Radiotherapy.aspx

Possible treatment side effects.

	Problems getting an erection	Problems controlling pee	Problems with diarrhoea	Flushes, mood swings	Loss of energy
Surgery					
Radiotherapy					
Hormone therapy					

Side effects vary from person to person.

You should speak to your healthcare team about ways to manage any possible side effects <u>before</u> you decide or if they occur <u>during</u> your treatments.





CHART 15

	Problems getting an erection	Problems controlling pee	Problems with diarrhoea	Flushes, mood swings	Loss of energy
Surgery		•			
Radiotherapy	•				•
Hormone therapy	•			•	•
	eak to your	healthcare te	n. eam about way or if they occu		

All treatments have side effects but some treatments are more likely to cause some side effects than others. Talk to the healthcare team about side effects before you finally decide on the treatments you will have.

Erectile dysfunction (ED) also known as Impotence

ED means not being able to keep a hard penis (erection) during sex. There are several possible ways to treat ED. These may include: tablets, injections, penis rings, vacuum pumps, and penis implants. It is important to discuss ED with your healthcare team, there is help available.

Urinary problems

This refers to leaking or dribbling pee (urine), or not being able to hold your pee at all sometimes. It is called incontinence and can be improved/controlled with pelvic floor exercises. There are a range of incontinence pads that can be worn to help men manage leaks.

Bowel problems

These may include soft or watery poo (stools), feeling of urgent pressure to go to the toilet, burning, tenderness/soreness, or pain, gas, bleeding. After treatment these problems may stop naturally on their own. You should speak to your healthcare team about ways to manage any bowel issues.

Surgical treatments are also available to manage many of the incontinence (urinary and bowel) issues after prostate cancer treatment.

Flushes and mood swings

Changes in your hormone levels can trigger sudden intense hot sensations in your upper body and/or mood swings. Some medications can help with hot flushes. Some complementary therapies can help with hot flushes (e.g. acupuncture).

Practise 'Daddirri', deep breathing and relaxation techniques.

Loss of energy (fatigue)

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You can feel tired because the treatments affect your whole body. Fatigue can also be caused by the cancer itself and everything extra you have to do to manage it.

Make sure you get plenty of rest by having regular breaks during the day.

Do what you have to do when you have the most energy.

Plan ahead and prioritise activities so you only do those that are necessary.

Ask for help so you don't feel you have to do everything.

Do some light exercise (e.g. short, easy walks).

ources:

- Continence Foundation of Australia. (2010). The prostate and pee problems lets yarn about men's business. Retrieved from www.bladderbowel.gov.au/assets/doc/atsi/018_The%20Prostate%20 And%20Pee%20Problems.html
- Continence Foundation of Australia. (2012). Men and strong pelvic floor muscles let's yarn about men's business. Retrieved from www.bladderbowel.gov.au/assets/doc/atsi/015_Men%20And%20 Strong%20Pelvic%20Floor%20Muscles.html
- Adams, M.J., Collins, V.R., Dunne, M.P., de Kretser D.M., & Holden, C.A. (2013). Male reproductive health disorders among Aboriginal and Torres Strait Islander men: a hidden problem? Med J Aust, 198(1), 33-38.
- Cancer Council NSW. Aboriginal and Torres Strait Islander Resources. Retrieved from www. cancercouncil.com.au/1904/cc-publications/aboriginal-torres-strait-islander-resources/aboriginal-and-torres-strait-islander-cancer-resources/living-with-cancer-3/

Decision making.

What questions and information should I be giving my healthcare team?

What is the best treatment for me?

What side effects can I live with?

This is a shared process between you, your family/kin, the health care team and doctor. You are in control.

What does my family think is important?

How will these decisions affect my life?

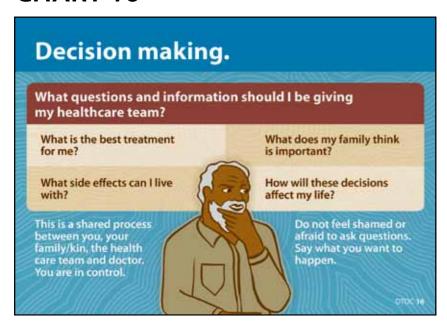
Do not feel shamed or afraid to ask questions. Say what you want to happen.



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CHART 16



Deciding on treatment pathways should *involve a discussion between you, your kin/family, your healthcare team and your doctor.* If you are feeling unsure about your choices, check with your doctor how soon your treatment should start, then take as much time as you can before making a decision. The decision is yours to make.

Make sure you understand all the options available to you and their possible side effects. You will need to decide what side effects you are and are not willing to live with. All of this information will help you make a decision you can live with. This decision will also take into account your values, responsibilities and the things that are important to you and your family. It is common to feel overwhelmed by information so it may help if you learn and talk about the options gradually.

- weigh up the advantages and disadvantages of different treatments, including the effect of any side effects
- if only one type of treatment is recommended, ask your doctor why other choices have not been offered
- if you have a wife/partner, you may want to discuss the treatment options together
- think if you want to have any more children
- you can also talk to family and friends to help you know all the issues.

You have the right to accept or refuse any treatment offered by your doctors and other health care professionals. Some people with advanced cancer choose treatment even if it only does a little good for a short period of time. Other people want to make sure the benefits outweigh the side effects so that they have the best possible quality of life. Some people choose options that focus on reducing symptoms and make them feel as well as possible. There are many paths you can take.

Getting *a second opinion from another doctor may be a valuable* part of your decision making process. It can confirm or clarify your doctor's recommendations and reassure you that you have explored all of your possible choices. Your doctor is able to arrange a second opinion and many are happy to do so. Many men find this helps their decision making.

Some people feel uncomfortable asking their doctor for a second opinion, but doctors are used to people doing this.

Do not feel shamed or afraid to ask questions, say what you want to happen.

Sources

• Cancer Council Australia (2009). Advanced prostate cancer – a guide for men and their families.

Treatment takes teamwork and support.

Your healthcare team will:

- talk to you about all possible treatment types and options for your situation
- talk to each other and work together for your care
- plan your cancer journey with you
- work together to improve your treatment and support.

This will improve your health and wellbeing







CHART 17



It is normal to feel confused, frightened or scared when working out your treatment or going to hospital. The healthcare team including Aboriginal Liaison Officers, Aboriginal Health Workers and interpreters are there to help you understand and feel comfortable.

- Your doctor will talk about tests and treatments with you. You get to decide on what tests and treatments you have.
- If you need to hear it in language or explained again for family, you can ask for an Aboriginal Health Worker or interpreter to talk with you
- Most importantly, it is okay for you to ask questions. Don't be afraid to ask.
- You can give permission for the healthcare team to give information to family, kin or carers if they ask questions. *You are in control*.

Ask your health clinic how to get help. There is a member of the healthcare team who will be your main contact person. This person might change during your cancer journey. If you're unsure who this person is, ask one of the health professionals you're seeing. Your contact person can talk with other health professionals for you and can make sure all your health care needs are met.

When working with your healthcare team, there are many people you may have to see. Always remember to ask your main contact person if you are confused about anything. Each person will explain to you who they are, their role on the team and what they are going to do.

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What else do I need to think about?

- Preparing to go to hospital and transport
- Being away from work
- Interpreters
- Family support while away
- Remote issues
- Culture and caring for country.







CHART 18



Going to Hospital

If you have to travel to Hospital for cancer tests or treatment -

Take with you:

- photo ID
- health Card
- medicare card
- all forms and papers for the doctors
- money
- shoes and warm clothes
- contact details for family

It is very important that you always ask for an interpreter if necessary. You may need help to understand what is being said.

Ask your doctor how long they think you will have to stay away.

You can ask to speak to an Aboriginal Liaison Officer or an Aboriginal Health Worker at the hospital for advice and assistance.

Travel and Accommodation

Assistance Travel Scheme Office can organise travel and accommodation. Inquire through your doctor or local Health Service.

Talk with your doctor if you would like a family member to go with you to help and ask questions when you go to hospital. When applying for assistance, be clear on the funding conditions needed for your family to travel with you.

Away from work

If self-employed you will have to check your own health insurances.

Employers usually have sick leave arrangements for their staff and you will need to check your sick leave conditions.

Other benefits and allowances can be checked through Centrelink. Community social workers and Aboriginal Liaison Officers at Centrelink can assist you with this information.

Support

- It is normal to feel frightened or worried when going to hospital. There are Aboriginal Liaison Officers, Aboriginal Health Workers and interpreters there to help you feel comfortable.
- Your doctor will talk about tests and treatments with you before they happen. You get to decide on what tests and treatment you have, you need to give permission before they happen.

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- tell your doctor if you have taken any other traditional or bush medicines for your illness.
- if you need to hear it in your language or have it explained again for family, you can ask for an Aboriginal Health Worker or interpreter to be with you.
- most importantly, it is okay for a patient, family member or friend to ask questions.
 Don't be afraid to ask, it is not a shame job
 Health staff want to know what you are thinking about your cancer.
- there are many people available to help you cope with cancer even after you return home to country. Ask your health clinic how to get this help.

Follow up care

Doctors can never be certain that the cancer will not grow back. Cancer can return:

- When you get home it is important to go to the community health clinic and tell them you are back so your health team can get the information on what type of treatment you had and your results.
- You will need to keep going back to the doctor or health clinic for check-ups. Your doctor will tell you how often they want to see you.
- If you or your family have any questions or need help, there are people and organisations who you can talk to or get help from. Ask your health clinic how to get this help.

Culture and Caring for Country.

It is important to note that your healthcare team cannot tell you exactly how long you may be away from home and they cannot promise what will happen in future. Severity of your illness, type of treatment and follow-up will affect what happens. Cancer treatment will affect your family, ceremony, even your return if you have the wet season at home. This is why it is important for you to ask questions, get as much information as you need and discuss these issues with your family and kin. Asking questions and learning about what will happen is not a 'shame'.

Sources:

- Healthcare Management Advisors (HMA). NT patient cancer care referral pathways. Prostate cancer. Retrieved from www.health.nt.gov.au/library/ scripts/objectifyMedia.aspx?file=pdf/53/89.pdf&siteID=1&str_title=Cancer
- Northern Territory Department of Health. A cancer journey. Retrieved from www.cancerlearning.gov.au/docs/indig_can_journey.pdf

AIMHI Grow Strong Tree

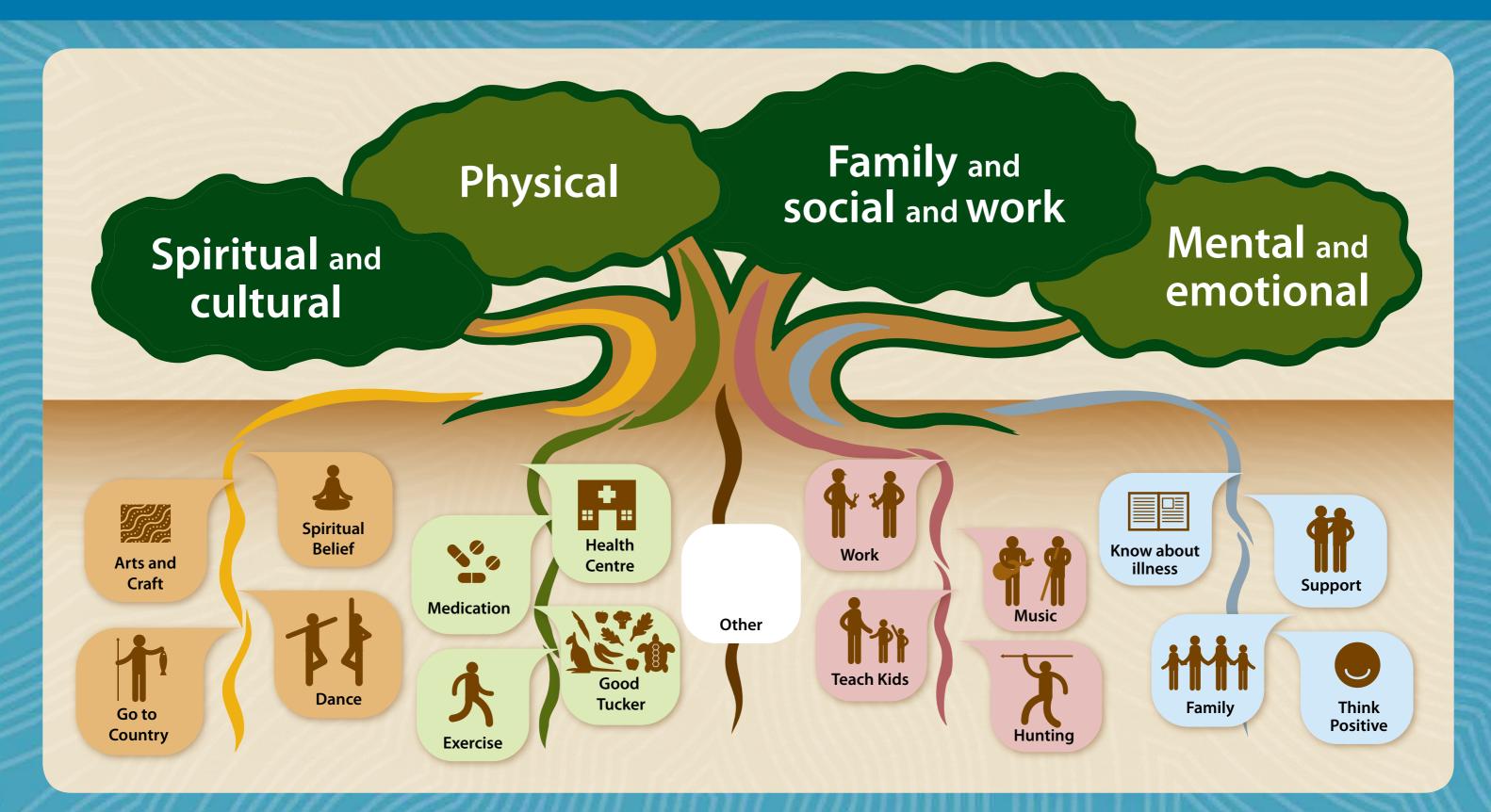






CHART 19

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Look after your mental and emotional wellbeing

Mental Health is part of wellbeing. Wellbeing involves the way we see ourselves, feel about ourselves and the world around us. It refers to our emotional, psychological, physical and spiritual being.

Feeling down - Depression and anxiety

The word 'depression' is often thought to mean sadness or a low mood. However, depression is more than just a low mood – it's a serious illness and effective treatments are available. Having a depressed mood can extend beyond the issue of cancer and into all areas of a person's life. Men with depression find it hard to carry out their normal daily activities.

Anxiety is more than just feeling stressed – it can be a serious illness. People with anxiety disorders find it hard to function every day. There are many types of anxiety disorders, each with a range of symptoms. Prostate cancer may contribute to the development of an anxiety disorder and is common in men with prostate cancer and their partners/carers. You should speak to your healthcare team about ways to deal with either of these issues.

Look after yourself

There are many things that contribute to your health and wellbeing. The Grow Strong Tree may assist when considering the many things that make up your life.

To manage worry and help cope, carers and men with prostate cancer need to:

- balance issues in their whole life including physical, family and social, mental and emotional, spiritual and cultural life
- prioritise and focus on health and wellbeing
- talk and communicate with family and kin
- accept help when needed
- keep in touch with the healthcare team
- follow through and complete the treatment.

The Grow Strong Tree developed by Menzies School of Health Research AIMHi program has a blank (other) space. Discuss what you could add to the tree in this space that would help you stay strong.

You can yarn with the participants about any points in this Grow Strong Tree. They can:

- add any points they would like to emphasise or
- name their own priorities for the things in this list that support their health and wellbeing.

How can we make sure we do not forget to do these things?

Source

- Beyondblue. Prostate cancer and the risk of depression/anxiety. Retrieved from www.prostate.org au/articleLive/attachments/1/BEY%20fact%20sheet%2034-4pp.pdf
- Australian Integrated Mental Health Initiative. (2008). Depression. Retrieved from www.menzies.edu au/icms_docs/161354_Depression.pdf
- Australian Integrated Mental Health Initiative. (2008). Anxiety. Retrieved from www.menzies.edu.au/ icms_docs/161595_Anxiety.pdf

Your health matters.

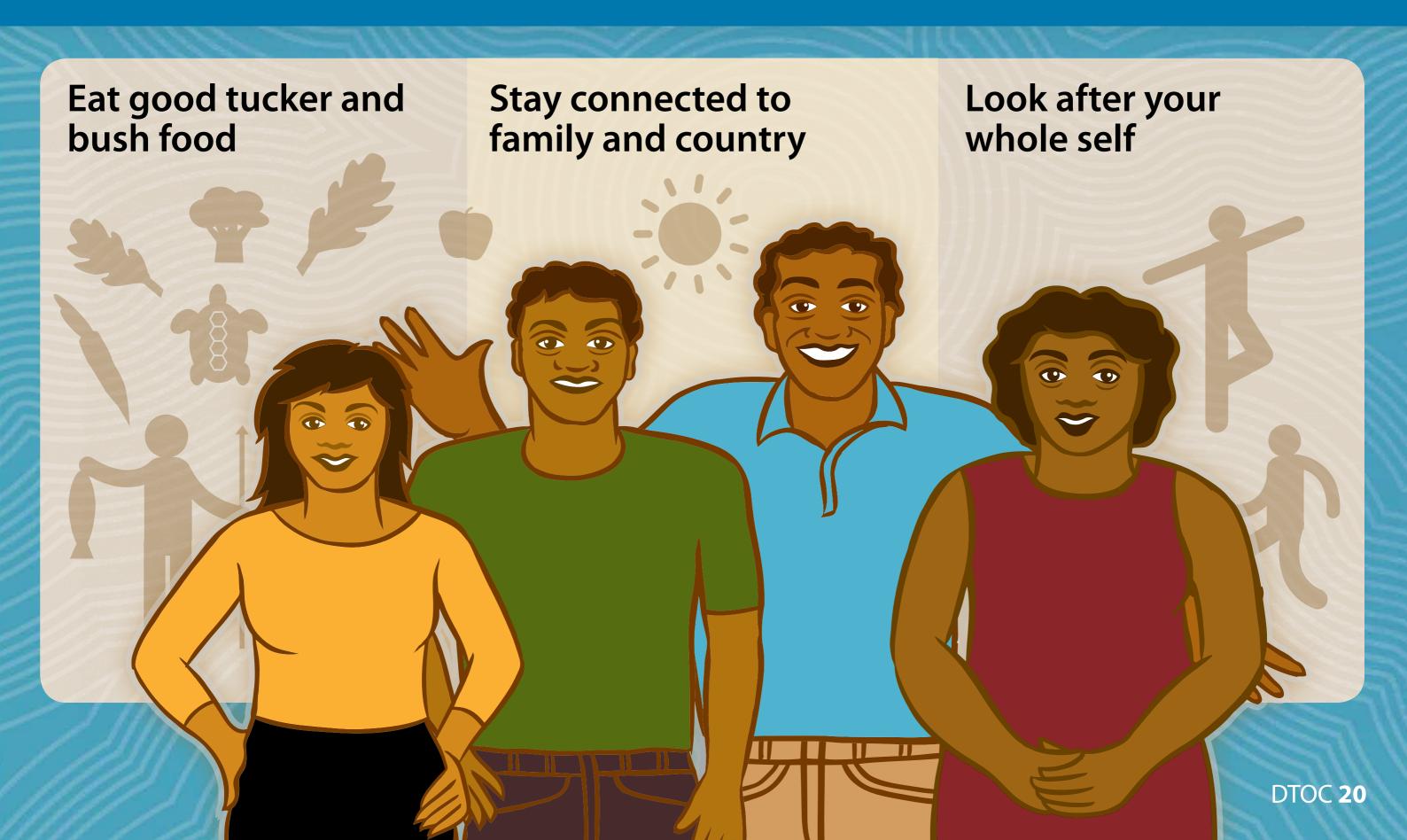






CHART 20

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There are existing materials and information packages you can use to support this section of the presentation. Health promotion materials are already available on HealthInfonet and through the National Aboriginal Community Controlled Health Organisations.

Eat a balanced diet

Having a balanced, adequate and varied diet is an important step towards a happy and healthy lifestyle. Vitamins and minerals in the diet are vital to boost immunity and healthy development. A healthy diet can protect the human body against certain types of diseases, in particular non-communicable diseases such as obesity, diabetes, cardiovascular diseases, some types of cancer and skeletal conditions. Healthy diets can also contribute to maintaining healthy body weight.

Enjoy a wide variety of nutritious foods

The Australian Dietary Guidelines (2013) suggest:

- eat plenty of vegetables, legumes/beans
- eat fruits
- eat plenty of grains (cereals) that are wholegrain and high fibre (including breads, cereals, rice, pasta, noodles, polenta. couscous, oats, quinoa, barley), preferably wholegrain
- include fish, lean meat and poultry, eggs, tofu, nuts, seeds, and legumes/beans
- include milks, yoghurts, cheeses and/or alternatives reduced fat varieties should be chosen, where possible
- drink plenty of water.

And limit

- saturated fat and moderate total fat intake
- the amount of salt you eat
- your alcohol intake if you choose to drink
- foods containing sugar
- high fat sources. Replace fats by using poly-unsaturated and monosaturated fats such as oils, spreads, nut butters/pastes and avocado.

Sources:

- World Health Organisation. Benefits of a balanced diet. Retrieved from www.euro.who.int/en/what-we-do/health-topics/disease-prevention/nutrition/a-healthy-lifestyle/benefits-of-a-balanced-diet
- National Health and Medical Research Council. Australian dietary guide. Retrieved from www.nhmrc.gov.au/guidelines/publications/n55

Limit alcohol consumption

National Health and Medical Research Council Guidelines for alcohol consumption have been developed to help reduce your risk of harm from alcohol.

The guidelines are based on the most current and best available scientific research and evidence.

- For healthy men and women, drinking no more than two standard drinks on any day reduces your risk of harm from alcohol-related disease or injury over a lifetime.
- Drinking no more than four standard drinks on a single occasion reduces the risk of alcohol-related injury arising from that occasion.
- The guidelines warn against the use of alcohol and medications together – always seek and comply with medical advice.

Sources:

 National Health and Medical Research Council (2009), Australian guidelines to reduce health risks from drinking alcohol. Retrieved from www.nhmrc.gov.au/_files_nhmrc/publications/attachments/ ds10-alcohol.pdf

Your health matters.







CHART 21

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Do some physical activity

The Australian Physical Activity Guidelines (Adult) refer to the minimum levels of physical activity required for good health. The guidelines are based on the most current and best available scientific research and evidence.

- think of movement as an opportunity, not an inconvenience
- be active every day in as many ways as you can
- put together at least 30-60 minutes of moderate intensity physical activity on most, preferably all, days
- try some regular, vigorous exercise for extra health and fitness.

Look after your mental and emotional wellbeing

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. It refers to our emotional, psychological, physical and spiritual being.

Sources

- Department of Health and Ageing (2005). An active way to better health. Retrieved from www. commcarelink.health.gov.au/internet/main/publishing.nsf/Content/DDBDA0E9445F726CCA257BF0 0020630E/\$File/adults_phys.pdf
- Rock, C.L., Doyle, C., Demark-Wahnefried, W., et al. (2012). Nutrition and physical activity guidelines for cancer survivors. CA Cancer J Clin, 62(4), 242-274.
- Cormie, P., Newton, R.U., Taaffe, D.R., Spry, N., & Galvao, D.A. (2013). Exercise therapy for sexual dysfunction after prostate cancer. Nature Reviews Urology, 10, 731-736.
- NT Department of Health. (2008). Keeping fit, keeping healthy, keeping strong. Retrieved from digitallibrary.health.nt.gov.au/prodjspui/bitstream/10137/132/1/keeping_fit_poster.pdf
- WHO, (1948).Preamble to the Constitution of the World Health Organization as adopted by the International Health Conference, New York. Retrieved from www.who.int/about/definition/en/print.

What you can do?

- Look after your health and spirit
- Talk to people healthcare team, family, kin and carers
- Have a plan
- Be willing to support prostate Men's Business
- Know where to go for help and information
- Become a PCFA Ambassador/Supporter.







CHART 22



Ask the group if they have any further comments or questions about prostate cancer. Refer people further to their health provider or PCFA 1800 22 00 99 if necessary.

How can PCFA help?

PCFA offers:

- Information
- Support materials
- Affiliated support groups acrossAustralia
- Prostate CancerSpecialist Nurses



For more information: Contact or call www.pcfa.org.au Freecall 1800 220 099





CHART 23



Information and materials

Prostate Cancer Foundation of Australia (PCFA) funds a research program to investigate prostate cancer issues. (www.pcfa.org.au)

PCFA has a range of information available. If you would like more information, please go to the website or call the Freecall number – 1800 22 00 99.

In addition, PCFA has a number of local support groups across Australia. These are held face-to-face or sometimes over the phone. The support groups are a great way to meet other people who are in a similar situation. Some groups have guest speakers on a range of different topics, some groups are social – most groups are a combination of these two things.

PCFA also supports Prostate Cancer Specialist Nurses - There are lots of nurses throughout Australia working in a variety of jobs helping those affected by prostate cancer. A Prostate Cancer Specialist Nurse is an experienced registered nurse who has received additional training to make them an expert nurse in prostate cancer care. Prostate Cancer Specialist Nurses will help men and their families travel along the prostate cancer journey, providing information and coordinating care.

Support groups – how to find them.

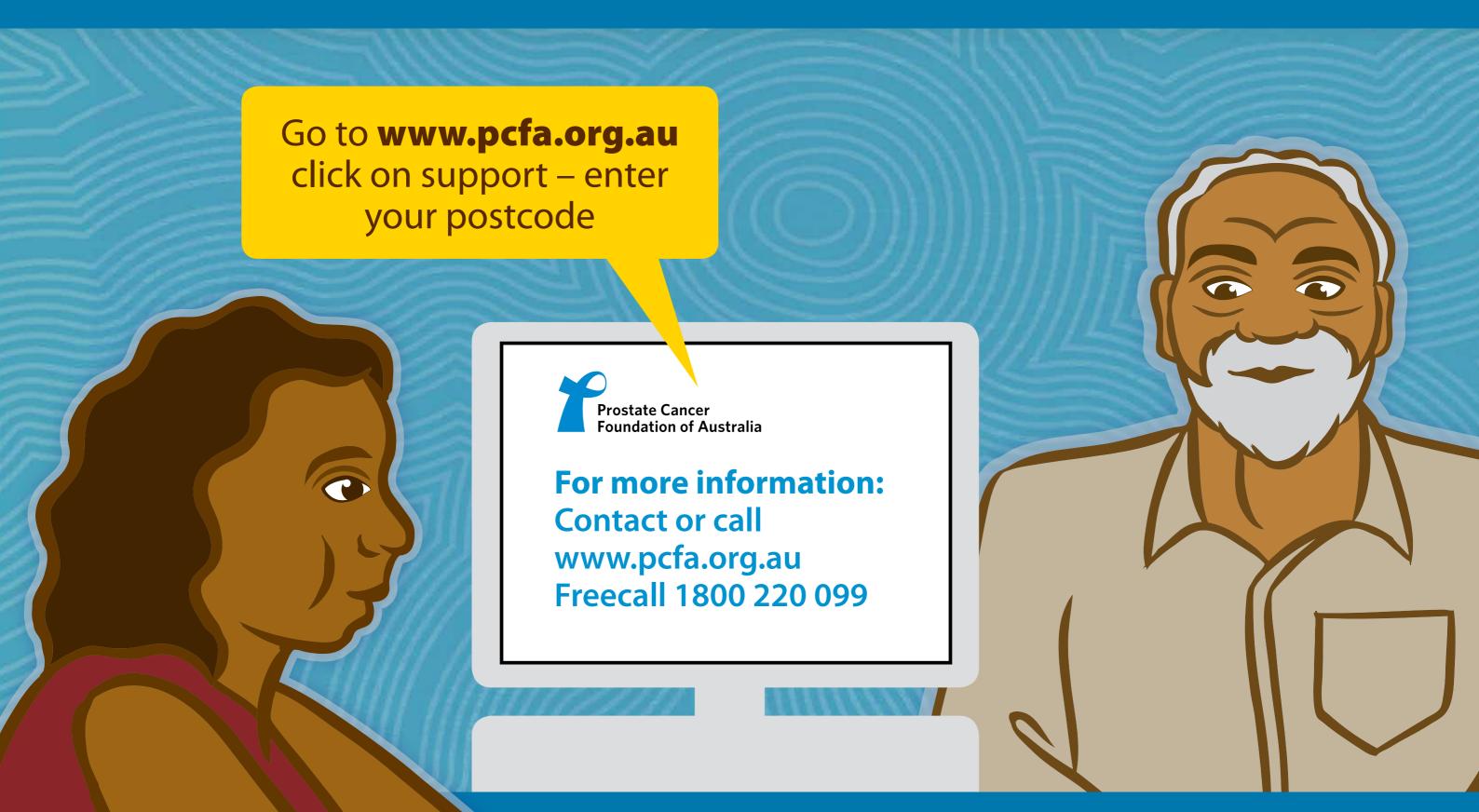






CHART 24



Find Support

Prostate Cancer Foundation of Australia Support Groups - www.prostate.org.au/articleLive/pages/Prostate-Cancer-Support-Groups.html

Online Chat Websites

Australian Healthinfonet – National Indigenous Cancer Network (NICaN) - Yarning places - www.yarning.org.au/group/15

Chatting online with other people can be informative, therapeutic and a valuable source of contact, especially when circumstances prevent a person from meeting face-to-face with friends or attending support groups. An internet search reveals that there are numerous online chat websites for cancer patients and carers. It is recommended to use those facilitated by reputable cancer organisations.

Contacts.

Prostate Cancer Foundation Australia

1800 22 00 99 (freecall) www.pcfa.org.au

Cancer Australia

www.canceraustralia.gov.au

Carers Australia

Carer and support services 1800 242 636 (freecall) www.carersaustralia.com.au

National Aboriginal Community Controlled Health Organisation (NACCHO)

02 6246 9300

www.naccho.org.au

Australian Indigenous Doctors' Association (AIDA)

02 6273 5013/1800 190 498 (freecall) www.aida.org.au

National Aboriginal and Torres Strait Islander Health Worker Association (NATSIHWA)

02 6221 9220/1800 200 800 (freecall)

www.natsihwa.org.au





CHART 25



Ask the group if they have any further comments or questions about prostate cancer. Refer people further to their health provider or PCFA 1800 22 00 99 if necessary.











GLOSSARY

Abdomen	The part of the body that includes the stomach, intestine, liver, bladder and kidneys. The abdomen is located between the ribs and hips.
Aboriginal	A person of Aboriginal descent who identifies as an Aboriginal and is accepted as such by the community in which he or she lives.
AIDA	Australian Indigenous Doctors Association
AIHW	Australian Institute of Health and Welfare
Androgen deprivation therapy	Treatment with drugs that minimises the effect of testosterone in the body. This is also referred to as ADT and is another term for hormone therapy.
Biopsy	The removal of a small amount of tissue from the body, for examination under a microscope, to help diagnose a disease.
Bladder	A sac with an elastic wall of muscle; found in the lower part of the abdomen. The bladder stores urine until it is passed from the body.
Brachytherapy	A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.
Cancer	A term for diseases in which abnormal cells divide without control.
Cancer journey	An individual's experience of cancer, from detection and screening, diagnosis and treatment, to relapse, recovery and/or palliative care.
Cancer survivor	In these resources, this term is used to mean anyone who has finished their active cancer treatment.
Carer	A person who helps someone through an illness or disability such as cancer.
Confined	Using prostate cancer as an example – the cancer if confined to or confined within the prostate gland. This means that the cancer cells have not spread from the prostate gland to other areas of the body.
CT (computerised tomography) scan	The technique for constructing pictures from cross-sections of the body, by x-raying the part of the body to be examined from many different angles.
Cultural engagement	Actively involve people with respect to their cultural needs.
Diagnosis	The identification and naming of a person's disease.
Diarrhoea	Opening the bowels very frequently. Motions may be watery.
Dietitian	A health professional who specialises in human nutrition.
Digital rectal examination (DRE)	An examination of the prostate gland through the wall of the rectum. Your doctor will insert a gloved finger into the rectum and is able to feel the shape of the prostate gland. Irregularities in the shape and size may be caused by cancer.

Dose	The amount of medication taken.
Erectile dysfunction	Inability to achieve or maintain an erection firm enough for penetration.
Erection	When the penis becomes enlarged and rigid.
External beam radiotherapy (EBRT)	Uses x-rays directed from an external machine to destroy cancer cells.
External radiotherapy	Radiotherapy administered by a machine, which targets radiation at the cancer.
Faeces	Bowel motions or stools (poo).
Fertility	Ability to have children.
General practitioner (GP)	General practitioners diagnose, refer and treat the health problems of individuals and families in the community. Also commonly referred to as family doctors.
Grade	A score that describes how quickly the tumour is likely to grow.
Health outcome	A health-related change due to a preventive or clinical intervention or service. The intervention may be single or multiple, and the outcome may relate to a person, group or population, or be partly or wholly due to the intervention.
Hormone	A substance that affects how your body works. Some hormones control growth, others control reproduction. They are distributed around the body through the bloodstream.
Hormone therapy/ treatment	A treatment that blocks the body's natural hormones, which help cancer grow.
Impotence	See erectile dysfunction.
Incidence	The number of new cases of a disease diagnosed each year.
Incontinence	Inability to hold or control the loss of urine or faeces.
Kin	A group of persons descended from a common ancestor or constituting a family, clan, tribe, or race.
Libido	Sex drive.
Localised prostate cancer	Prostate cancer that is at an early stage and is still contained within the prostate gland.
Locally advanced prostate cancer	Cancer which has spread beyond the prostate capsule and may include the seminal vesicles but still confined to the prostate region.





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Lymphoedema	Swelling caused by a build-up of lymph fluid. This happens when lymph nodes do not drain properly, usually after lymph glands are removed or damaged by radiotherapy.
Magnetic resonance imaging (MRI)	Similar to a CT scan, but this test uses magnetism instead of x-rays to build up cross-sectional pictures of the body.
Medical oncologist	A doctor who specialises in diagnosing and treating cancer using chemotherapy, hormonal therapy, and biological therapy. A medical oncologist often is the main health care provider for someone who has cancer. A medical oncologist also gives supportive care and may coordinate treatment given by other specialists.
Metastasis/ metastasise	The cancer has spread away from the place where it began.
Mortality	The death rate, or the number of deaths in a certain group of people in a certain period of time. Mortality may be reported for people who have a certain disease, live in one area of the country, or who are of a certain sex, age, or ethnic group.
MRI scan	See magnetic resonance imaging.
Multidisciplinary care	This is when medical, nursing and allied health professionals involved in a person's care work together with the person to consider all treatment options and develop a care plan that best meets the needs of that person.
NACCHO	National Aboriginal Community Controlled Health Organisation
Nausea	Feeling sick or wanting to be sick.
Neoadjuvant therapy or neoadjuvant treatment	Treatment given before the main treatment to increase the chances of a cure.
NGO	Non-Government Organisation
NHMRC	National Health and Medical Research Council
Nutrition	The process of eating and digesting the necessary food the body needs.
Oncologist	A doctor who specialises in the study and treatment of cancer.
Osteoporosis	A decrease in bone mass, causing bones to become fragile. This makes them brittle and liable to break.

Pathologist	A person who studies diseases to understand their nature and cause. Pathologists examine biopsies under a microscope to diagnose cancer and other diseases.
Patient-centred care	Patient-centred care considers patients' cultural traditions, their personal preferences and values, their family situations, and their lifestyles. It makes patients and their families an integral part of the care team who collaborate with health care professionals in making clinical decisions. Patient-centred care provides an opportunity for patients to decide important aspects of self-care and monitoring. Patient-centred care ensures that transitions between providers, departments, and health care settings are respectful, coordinated, and efficient. When care is patient centred, unneeded and unwanted services can be reduced.
PBS	Pharmaceutical Benefits Scheme
Pee	Urine a fluid stored in the bladder.
Pee tube	Urethra - The tube that carries urine and semen out through the penis and to the outside of the body.
Pelvic	The area located below the waist and surrounded by the hips and pubic bone.
Penis	The male reproductive organ consists of a body or shaft which starts deep inside the body and extends externally to the end of the penis at the glans (head).
PET scan	Positron Emission Tomography. A technique used to build up clear and detailed cross-section pictures of the body. The person is injected with a glucose solution containing a small amount of radioactive material. The PET scanner can 'see' the radioactive substance. Damaged or cancerous cells show up as areas where the glucose solution is being used.
Potency	The ability to have and maintain erections firm enough for penetration.
Primary cancer/ site	The original cancer. Cells from the primary cancer may break away and be carried to other parts of the body, where secondary cancers form. / The initial location of a cancer in the body when it is first diagnosed.
Prostate cancer	Cancer of the prostate, the male organ that sits next to the urinary bladder and contributes to semen (sperm fluid) production.
Prostate gland	The prostate gland is normally the size of a walnut. It is located between the bladder and the penis and sits in front of the rectum. It produces fluid that forms part of semen.





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Prostate specific antigen (PSA)	A protein produced by cells in the prostate gland, which is usually found in the blood in larger than normal amounts when prostate cancer is present.
Quality of life	An individual's overall appraisal of their situation and wellbeing. Quality of life encompasses symptoms of disease and side effects of treatment, functional capacity, social interactions and relationships, and occupational functioning.
Radiation oncologist	A doctor who specialises in treating cancer with radiotherapy.
Radiotherapy or radiation oncology	The use of radiation, usually x-rays or gamma rays, to kill tumour cells or injure them so they cannot grow or multiply.
Rectum	The last part of the bowel, leading to the anus, through which stool passes.
Recurrence	Cancer that has returned sometime after it was first treated.
Recurrent cancer	A cancer that grows from the cells of a primary cancer that have evaded treatment.
Risk factor	A substance or condition that increases an individual's chances of getting a particular type of cancer.
Secondary cancer	Also called a metastasis. A tumour that has spread from the original site to another part of the body.
Self-management	An awareness and active participation by people with cancer in their recovery, recuperation, and rehabilitation, to minimise the consequences of treatment, promote survival, health and well-being.
Shared decision making	Integration of a patient's values, goals and concerns with the best available evidence about benefits, risks and uncertainties of treatment, in order to achieve appropriate health care decisions. It involves clinicians and patients making decisions about the patient's management together.
Side effect	Unintended effects of a drug or treatment.
Stage	The extent of a cancer and whether the disease has spread from an original site to other parts of the body.
Support group	People on whom an individual can rely for the provision of emotional caring and concern, and reinforcement of a sense of personal worth and value. Other components of support may include provision of practical or material aid, information, guidance, feedback and validation of the individual's stressful experiences and coping choices.
Supportive care	Improving the comfort and quality of life for people with cancer.
Surgery	Treatment that involves an operation. This may involve removal of tissue, change in the organisation of the anatomy or placement of prostheses.

Testes/testicles	Organs which produce sperm and the male hormone testosterone. They are found in the scrotum.
Testosterone	The major male hormone which is produced by the testicles.
Therapy	Another word for treatment, and includes chemotherapy, radiotherapy, hormone therapy and surgery.
Tissue	A collection of cells that make up each piece (or organ) of the body.
TNM	Tumour Node Metastasis - a staging system used by clinicians to describe how advanced a particular cancer is - which then informs the type of treatment provided.
Torres Strait Islander	A person of Torres Strait Island descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he or she lives.
Tumour	An abnormal growth of tissue. It may be localised (benign) or invade adjacent tissues (malignant) or distant tissues (metastatic).
Ultrasound	The use of soundwaves to build up a picture of the internal parts of the body.
Urethra	The tube that carries urine and semen out through the penis and to the outside of the body. (pee tube)
Urine	Fluid stored in the bladder (pee)
Urologist	Urologists are surgeons who treat men, women and children with problems involving the kidney, bladder, prostate and male reproductive organs. These conditions include cancer, stones, infection, incontinence, sexual dysfunction and pelvic floor problems.
Vasectomy	a permanent form of contraception. It is an operation that cuts and blocks off the tubes in the groin (the vas) that carry sperm from the testicles to the penis.