Support and care –
what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

Australian Government
Cancer Australia

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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 'Support and care - what carers and partners of men with prostate cancer need to know' presentation is part of a series of 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

This resource provides Aboriginal and Torres Strait Islander people with an overview of prostate specific health issues for carers. The ***'Support and care - what carers and partners of men with prostate cancer need to know'*** presentation is part of a series of flipcharts developed by Prostate Cancer Foundation of Australia (PCFA) to improve prostate cancer information delivery and support for Aboriginal and Torres Strait Islander communities. The process has involved consultation with Aboriginal and Torres Strait Islander communities and health workers throughout.

The Support and Care presentation provides people with an overview of prostate specific health issues, and provides information pertaining to the caring role. It includes information for carers and/or partners on self-care and the importance of looking after yourself.

An introduction to the services of PCFA is outlined, directing people where to go for further information in the form of resources or supportive care services.

A general overview of health promotion strategies concludes the presentation, outlining diet, exercise, and alcohol intake recommendations as directed by the Australian Government.

'Support and care - what carers and partners of men with prostate cancer need to know' is designed to provide information 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:

- delivered by a health professional who is able to adapt local context, language, terminology, clinical health and cultural practices into the delivery
- 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.

These notes provide background information and references for health professionals delivering the 'Support and care - what carers and partners of men with prostate cancer need to know' package. The notes contain 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 that people running the 'Support and care - what carers and partners of men with prostate cancer need to know' resource be particularly mindful of the language requirements, the local culture and available health services. Please use appropriate introductions and acknowledge elders and traditional land owners of the place where the presentation is being run.

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.

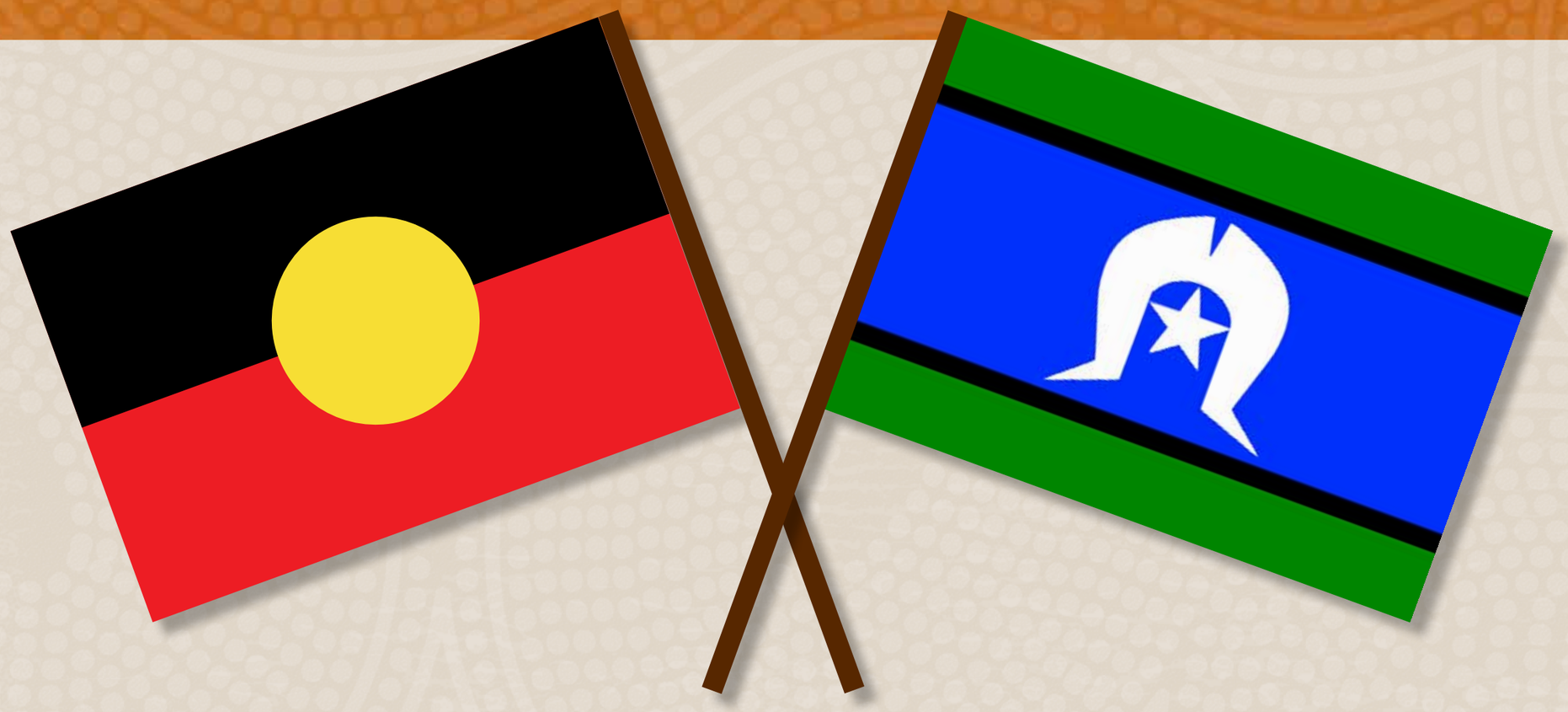

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CHART 1 – ACKNOWLEDGEMENT OF COUNTRY

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.

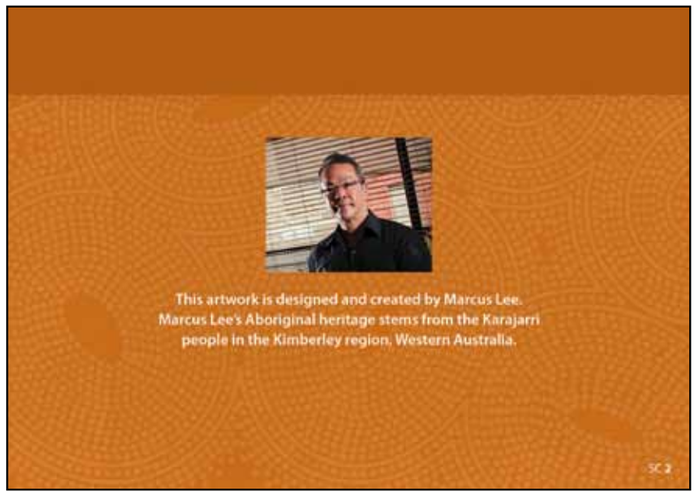
Source:

- 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.

Support and care – what carers and partners of men with prostate cancer need to know

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.

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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.

- The prostate
- Prostate cancer statistics
- Prostate cancer
- Treatment decisions and options
- Carers information
- How can PCFA help?
- Prostate related health promotion activities

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CHART 3

Prostate cancer is a men's disease. Knowing about prostate cancer and providing support and care is everyone's business.

By the end of this presentation

Aboriginal and Torres Strait Islander people should know:

- that not all prostate cancer news is doom and gloom
- about the prostate and symptoms if the prostate is not well
- what is involved with testing and deciding on treatments
- where to get information and help
- information for carers.

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.

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'

Image reproduced with the permission of Jack Bulman. Mibbinbah Limited.

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CHART 4

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 a Safe Space chart.

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

Collaboration 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.

Respect Diversity – 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.

Mediating – 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.

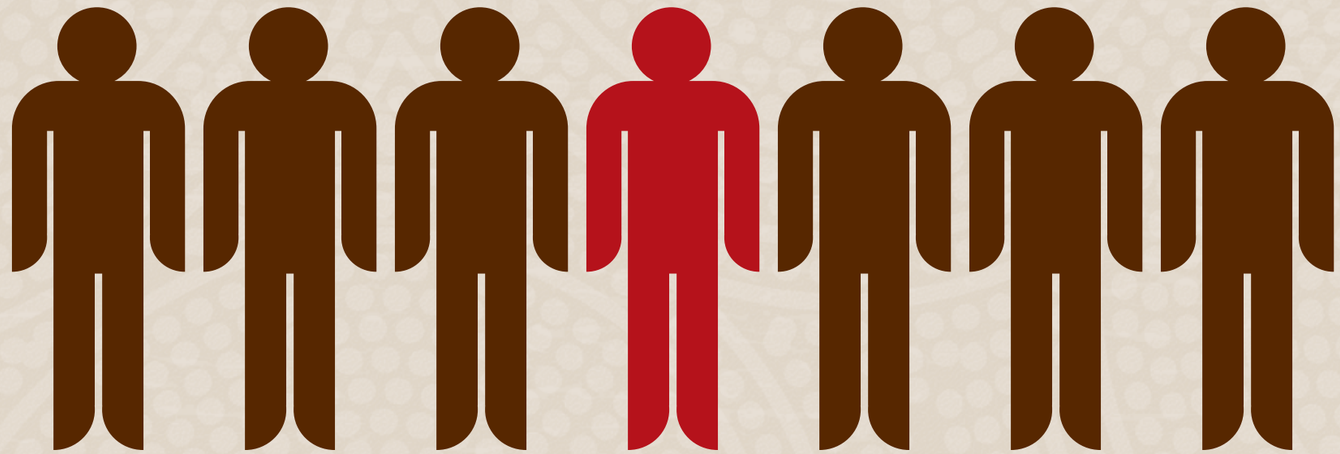
Sources:

- 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

Prostate cancer statistics.

1 in 7

Australian men will be diagnosed by age 75.



1 in 5

Australian men will be diagnosed by age 85.

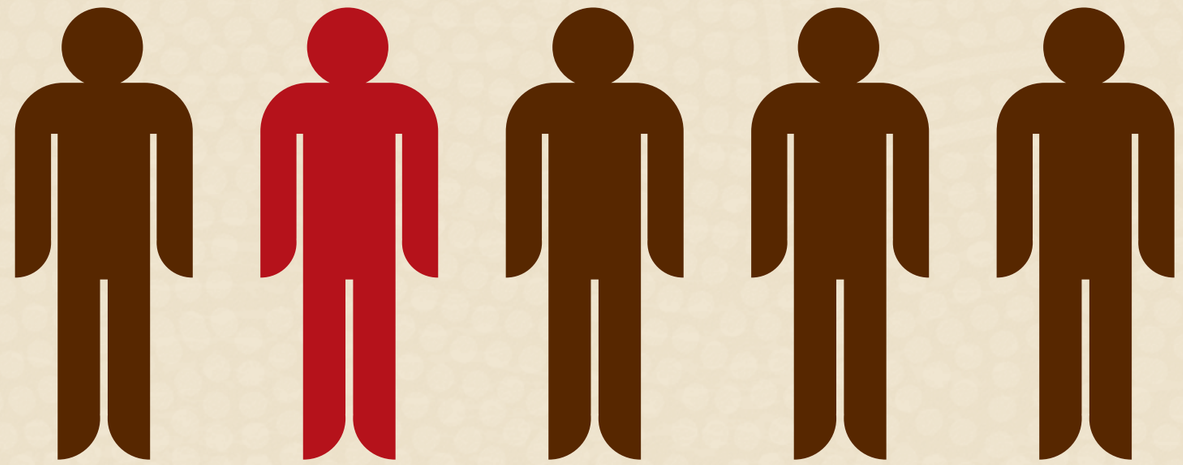


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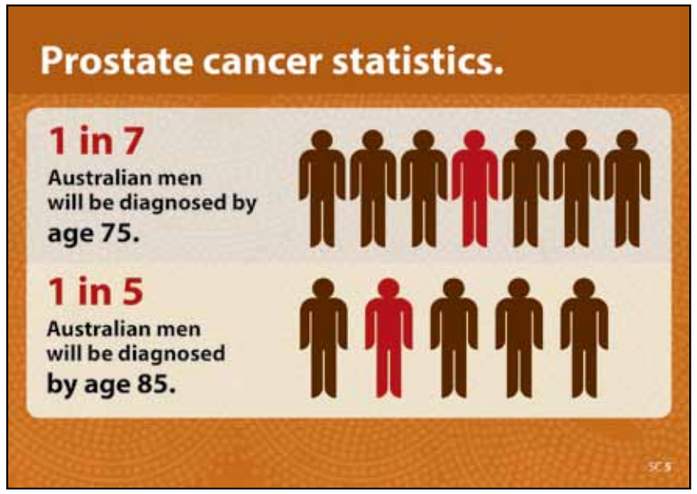
CHART 5



In Australia it was estimated that 1 in 7 men had prostate cancer by age 75, 1 in 5 men had prostate cancer by age 85.

Good news – Getting diagnosed in the early stages and having treatment may stop the cancer.

In Australia prostate cancer is the most common cancer in males. About 57 men are diagnosed each day (that's more than 20,000 each year).

In 2012 it was estimated that prostate cancer was the second most common cause of cancer deaths in Australian men.

In the decade 2002-2012 around 7.5 million PSA blood tests for prostate problems were performed in Australia (Medicare item # 66655).

Sources:

- Australian Institute of Health and Welfare. (2012). Cancer incidence projections: Australia, 2011 to 2020. Cancer Series no. 66. Cat. No. CAN 62. Canberra: AIHW.
- Australian Institute of Health and Welfare. (2012). Cancer in Australia: an overview, 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW.
- Department of Health Services. Medicare Item Reports. Requested Medicare items processed from July 2002 to June 2012. Retrieved from www.medicareaustralia.gov.au/statistics/mbs_item.shtml

Is prostate cancer a problem for Aboriginal and Torres Strait Islander men?

Prostate cancer is the second most common cancer in Aboriginal and Torres Strait Islander men.

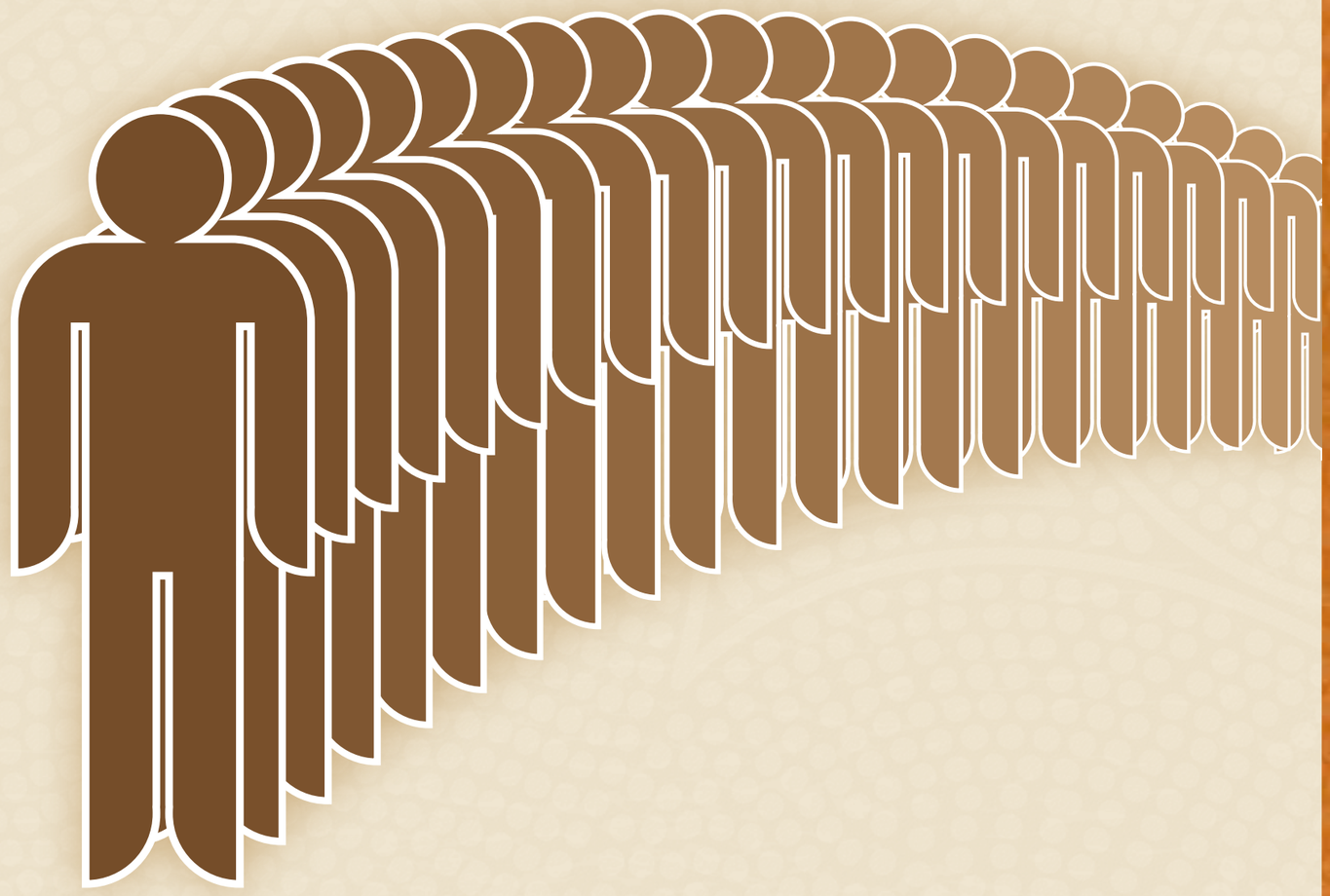


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CHART 6

Prostate cancer

Compared to non-indigenous Australians, Aboriginal and Torres Strait Islander men:

- were less likely to be diagnosed with prostate cancer
- were less likely to be hospitalised for prostate cancer
- had a lower chance of being alive 5 years after their cancer was first found.

Sources

- Rodger, J., Supramaniam, R., Gibberd, A., Saunders, V., & O'Connell, D. (2012, November). Treatment and survival outcomes for prostate cancer for Aboriginal men in New South Wales (NSW) Australia. Poster session presented at the COSA-IPOS Annual Scientific Meeting, Brisbane.
- Australian Institute of Health and Welfare & Cancer Australia. (2013). Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series no.78. Cat. no. CAN 75. Canberra: AIHW.
- Roder, D. (2005). Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory. Cancer Forum, 29(1), 7–9.
- Cunningham J., Rumbold A.R., Zhang X., & Condon J.R. (2008). Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. The lancet Oncology, 9(6), 585–95.
- Thomson, N., Midford, R., Debuyst, O., MacRae, A. (2010). Review of Indigenous male health. Retrieved from www.healthinfonet.ecu.edu.au/male_review

Is prostate cancer a problem for Aboriginal and Torres Strait Islander men?

6 out of 10 Aboriginal men with prostate cancer will be **alive 5 years** after their cancer was first found

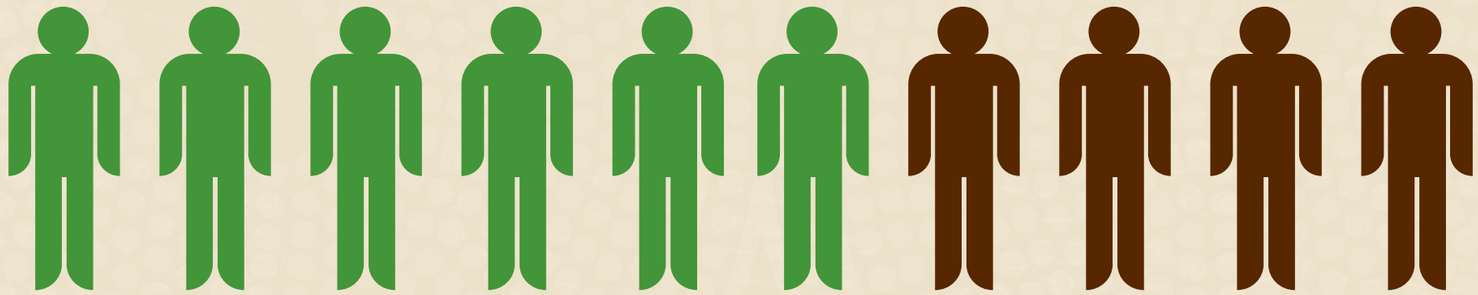

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CHART 7

Demographics

Aboriginal and Torres Strait Islander men are less likely to be diagnosed with prostate cancer and are less likely to go to hospital for treatment.

Aboriginal and Torres Strait Islander men living in remote areas had lower incidence and hospitalisation rates than non-Indigenous men or even Aboriginal and Torres Strait Islander men living in cities or regional areas.

These results could suggest that Aboriginal and Torres Strait Islander people living in remote and very remote areas have poorer access to healthcare services and are more likely to have cancers that are diagnosed at a later stage when the primary site is no longer apparent.

Sources

- Rodger, J., Supramaniam, R., Gibberd, A., Saunders, V., & O'Connell, D. (2012, November). Treatment and survival outcomes for prostate cancer for Aboriginal men in New South Wales (NSW) Australia. Poster session presented at the COSA-IPOS Annual Scientific Meeting, Brisbane.
- Australian Institute of Health and Welfare & Cancer Australia. (2013). Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series no.78. Cat. no. CAN 75. Canberra: AIHW.
- Roder, D. (2005). Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory. Cancer Forum, 29(1), 7–9.
- Cunningham J., Rumbold A.R., Zhang X., & Condon J.R. (2008). Incidence, aetiology, and outcomes of cancer in Indigenous peoples in Australia. The lancet Oncology, 9(6), 585–95.

Is prostate cancer a problem for Aboriginal and Torres Strait Islander men?

Improving a man's health and care for other diseases, identifying the prostate cancer early, getting and staying with treatment, can all improve a man's wellbeing.

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CHART 8

A comparison of Aboriginal and Torres Strait Islander and non-Indigenous men in NSW found that:

- Aboriginal and Torres Strait Islander men with the cancer staying within the prostate were less likely to have their prostate removed (the most common treatment)
- the risk of death from prostate cancer was higher for Aboriginal and Torres Strait Islander men compared with non-Indigenous men after allowing for age at diagnosis, time since diagnosis and spread of disease.

There is still research to be done to improve the lives of men who have prostate cancer.

Good News - treating other illnesses the man may have (comorbidities), helping with access to treatment and cost of the treatment may improve prostate cancer survival rates for Aboriginal and Torres Strait Islander men.

Sources

- Rodger, J., Supramaniam, R., Gibberd, A., Saunders, V., & O'Connell, D. (2012). Treatment and survival outcomes for prostate cancer for Aboriginal men in New South Wales (NSW) Australia. Poster session presented at the COSA-IPOS Annual Scientific Meeting, Brisbane.
- Australian Institute of Health and Welfare & Cancer Australia. (2013). Cancer in Aboriginal and Torres Strait Islander peoples of Australia: an overview. Cancer series no.78. Cat. no. CAN 75. Canberra: AIHW.

Some facts.

- Cancer doesn’t always cause death.
- Cancer is not punishment for something you did wrong.
- You can’t catch prostate cancer from someone who has the cancer.
- Treatment may help cancer go away.

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This resource contains Men's Business

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CHART 9

Good news - The majority of men with prostate cancer have learned to manage their prostate cancer, they are living active lives with the disease.
Prostate cancer is not infectious and cannot be given or caught. Prostate cancer is not an infection.
When action is taken early in the prostate cancer development, treatment can help the cancer to go away.

Ask participants what questions they would like to ask. Here are a set of statements that are commonly asked about prostate cancer, they may assist you to discuss points that arise during the presentation. There is no need to go through all of these points stay focused on the group discussion.
If there is a difficult question refer the person to the PCFA 1800 22 00 99 number.
Here are 11 statements about prostate cancer that may be useful in answering general questions.

Risk

Myth 1 - Prostate cancer is common, but few men actually die from it

Facts -

- Around 9 men die each day of prostate cancer in Australia.
- The good news is that if detected early, a man can have more choices about his treatment options.

Myth 2 - Prostate cancer is an old man's disease

Facts -

- While it is true that prostate cancer is more common in older men, it can be found in men of all ages.

Myth 3 - If prostate cancer doesn't run in my family, I won't get it

Facts -

While a family history of prostate cancer doubles a man's odds of being diagnosed, the fact remains that 1 out of 7 Australian men will be diagnosed with prostate cancer by age 75, and 1 in 5 by age 85.

Myth 4 - Vasectomies cause prostate cancer

Facts -

- A vasectomy is 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.
- Having a vasectomy was once thought to increase a man's risk of prostate cancer, but recent research suggests that this is NOT the case.
- Vasectomy may however lead to a man getting his prostate checked more often and prostate cancer is subsequently detected more often in men who have had vasectomies.

Myth 5 - Sexual activity increases the risk of developing prostate cancer

Facts -

- High levels of sexual activity or frequent ejaculation were once thought to increase prostate cancer risk.
- In fact, some studies show that men who reported more frequent ejaculations had a lower risk of developing prostate cancer.
- Ejaculation itself has not been linked to prostate cancer.

Myth 6 - You can pass your prostate cancer on to others

Facts -

- Prostate cancer is not infectious.
- This means that there is no way for you to "pass it on" to someone else.

Symptoms

Myth 7 - If you don't have any symptoms, then you don't have prostate cancer

Facts -

- Today, because of the availability of the blood test (Prostate Specific Antigen or PSA test), and Digital Rectal Examination many men are diagnosed with prostate issues, some of which are cancer, before they have had any physical symptoms.
- Urinary symptoms like hesitancy, frequency, or dribbling are important and could mean a problem with your prostate. However, not having these symptoms does not rule out prostate cancer.

Myth 8 - The Prostate Specific Antigen (PSA) blood test is a cancer test

Facts -

- The PSA test measures levels of prostate-specific antigen in the bloodstream.
- PSA is increased in the bloodstream in response to a number of problems which could be present in the prostate including an inflammation or infection (prostatitis), enlargement of the prostate gland (also known as benign prostatic hyperplasia) or, possibly, cancer.

Myth 9 - A high PSA level means that you have prostate cancer and a low PSA means you don't

Facts -

- Although prostate cancer is a cause of elevated PSA levels, some men with prostate cancer may have low levels of PSA.
- Factors such as being overweight can impact on PSA levels.
- Again, high levels can be an indication of other medical conditions.

Treatment

Myth 10 - All prostate cancers need to be aggressively treated

Facts -

- Many low grade cancers are not likely to progress to clinical symptoms, and pose limited risk of death if left untreated.
- Some men with prostate cancer may need careful monitoring but no treatment straight away.

Myth 11 - Treatment for prostate cancer always causes impotence or incontinence

Facts -

- While erectile dysfunction (ED) and urinary incontinence are possibilities following surgery or radiation therapy for prostate cancer, it is not true that all men experience complications.
- These side effects can also be highly dependent on age and physical condition. Numerous therapies and aids can improve erectile function and limit incontinence following treatment. Nerve sparing surgical procedures have improved outcomes for patients.

Sources:

- Australian Institute of Health and Welfare. (2012). Cancer in Australia: an overview, 2012. Cancer series no. 74. Cat. no. CAN 70. Canberra: AIHW.
- Prostate Cancer Foundation. 10 Myths and misconceptions about prostate cancer. Retrieved from www.pcf.org/site/c.leJRIROrEpH/b.7425707/k.7A02/10_Myths_and_Misconceptions_About_Prostate_Cancer.htm
- About.com Health. Prostate cancer. The top ten prostate cancer myths. Retrieved from http://prostatecancer.about.com/od/prostatecancer101/a/toptenmyths.htm

What is the prostate?

All men have a prostate gland.

The prostate makes fluid that is part of a man's semen.

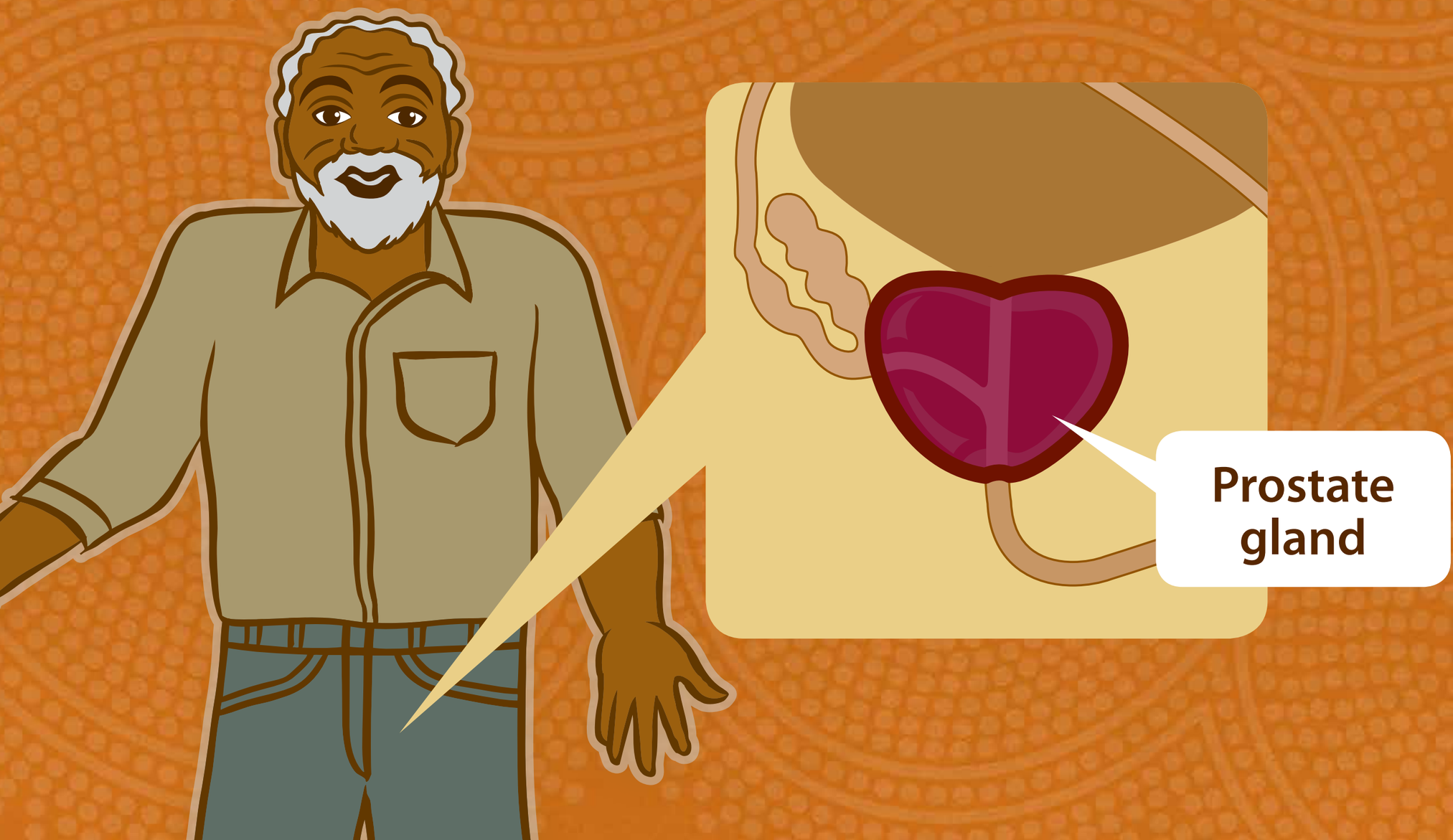

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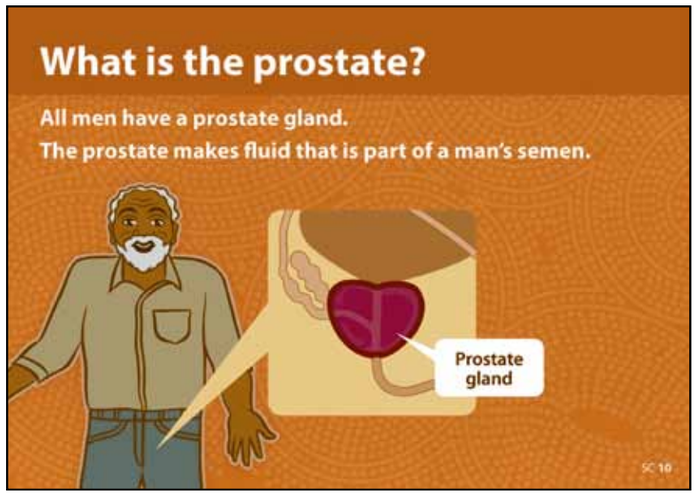
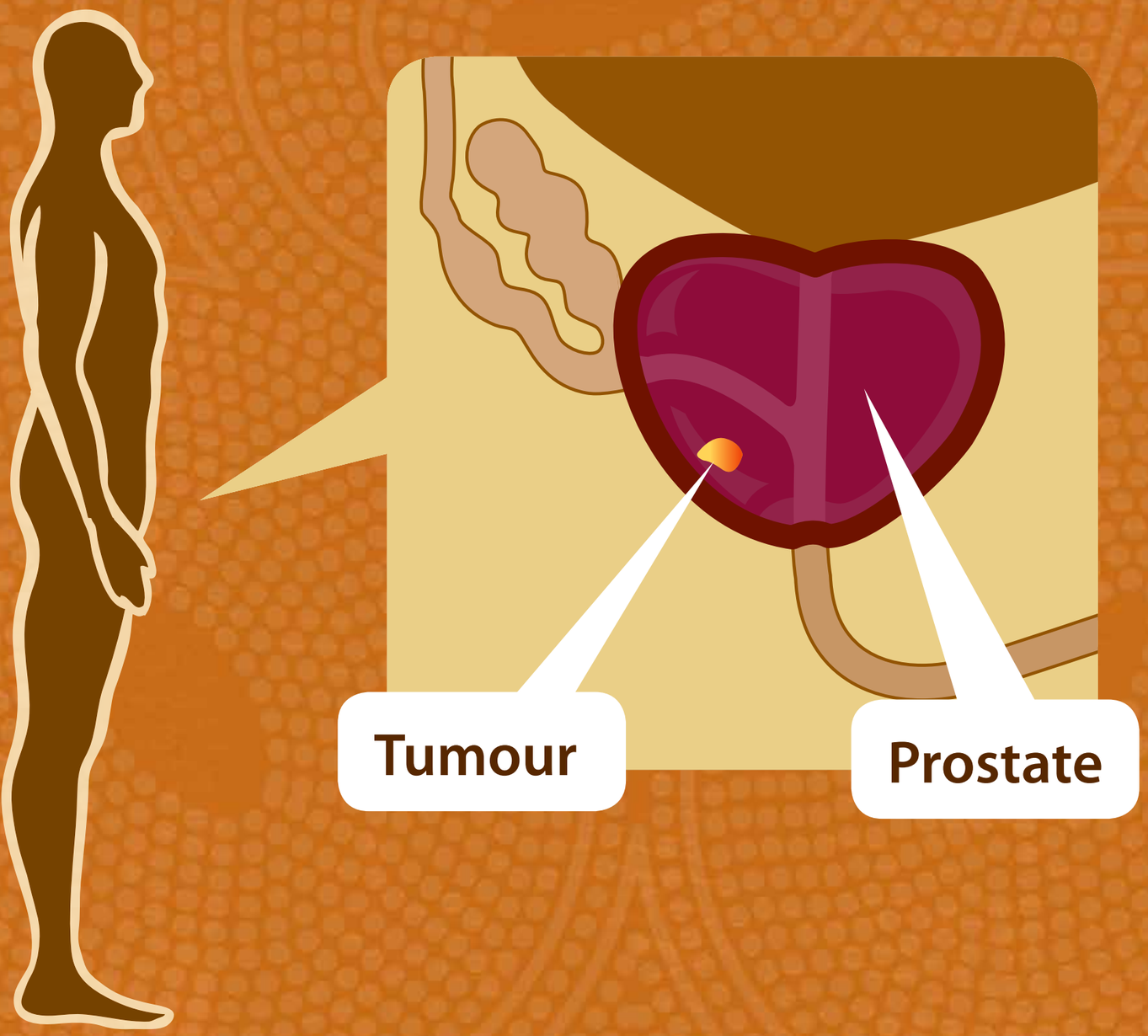
CHART 10



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

Where is the prostate?



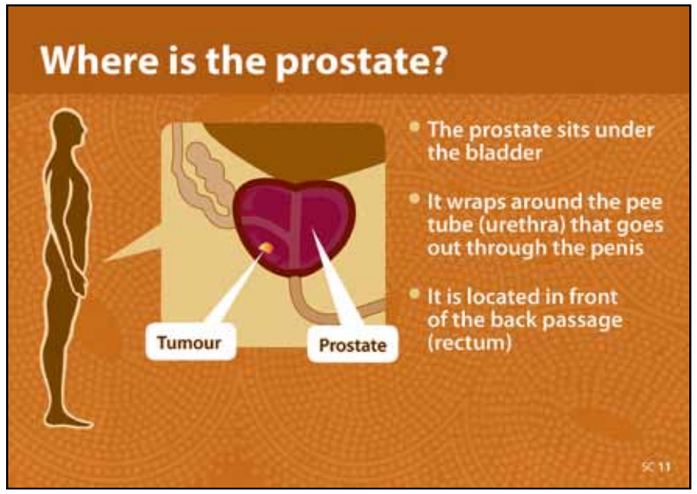
- The prostate sits under the bladder
- It wraps around the pee tube (urethra) that goes out through the penis
- It is located in front of the back passage (rectum)

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

Australian Government
Cancer Australia

CHART 11



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 a 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.

Source:

- Prostate Cancer Foundation of Australia www.pcfa.org.au

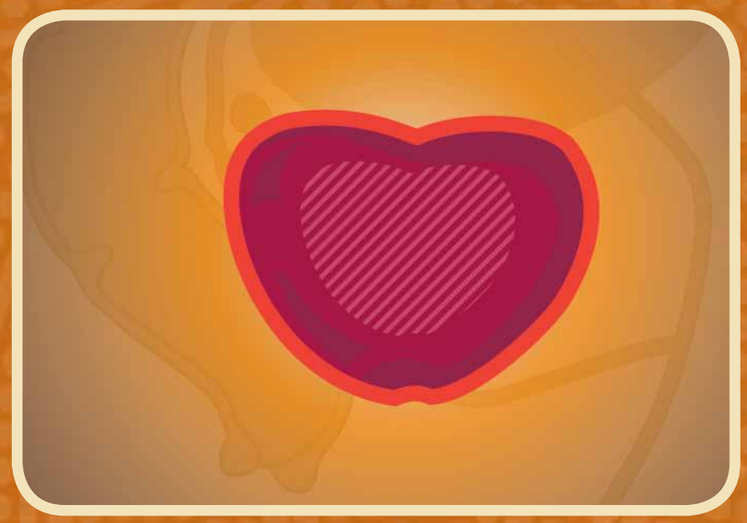
When the prostate gets sick.

Prostatitis is an infected or inflamed prostate.

This is not cancer.

Benign Prostatic Enlargement (BPE) is a swollen prostate.

This is not cancer.



Prostate cancer happens when prostate cells grow out of control and form a malignant tumour.

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.

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

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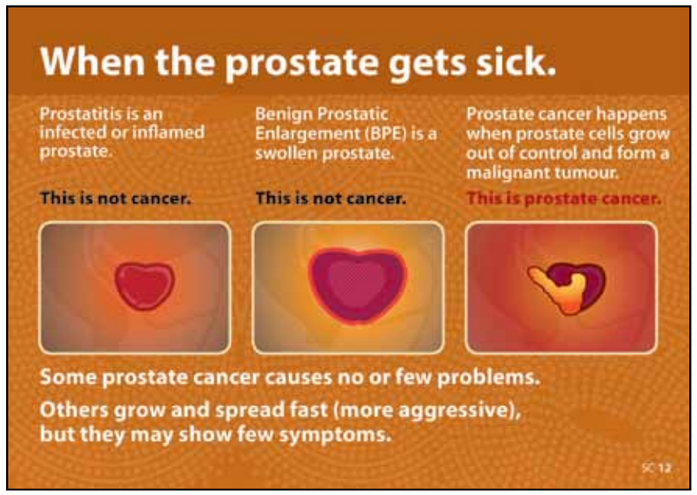
CHART 12



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-hyperplasia-bph/
- 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 he has any problems passing pee or pain he 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).

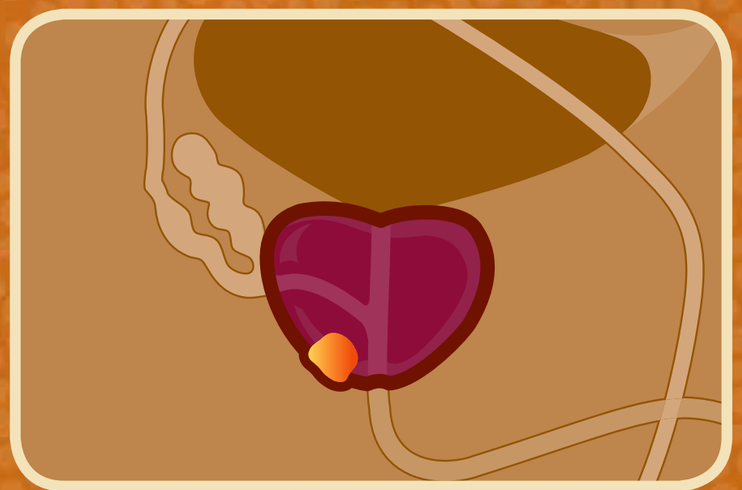
Most prostate cancers grow slower than other types of cancer.

Sources:

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

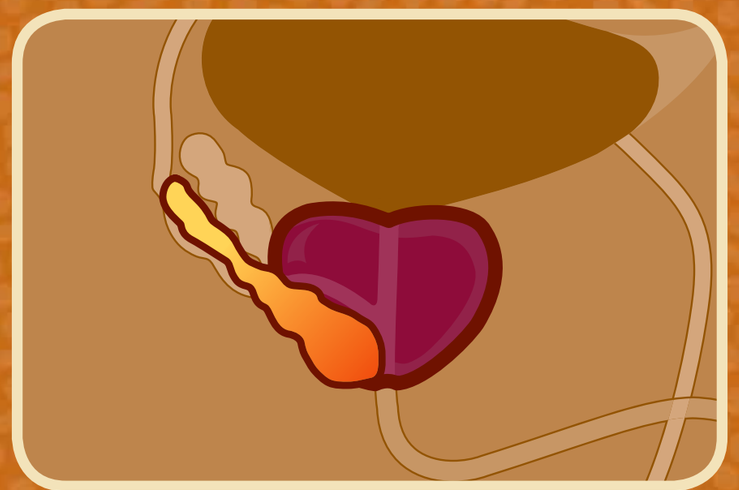
What is prostate cancer?

Localised



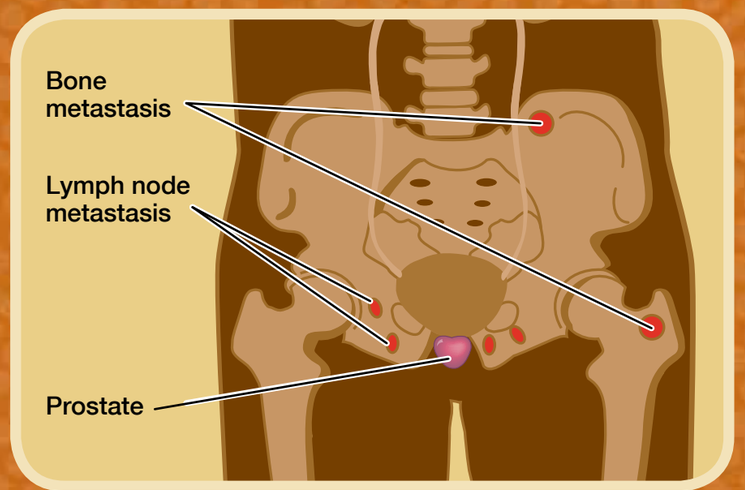
The prostate cancer is found only in the prostate gland.

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.

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

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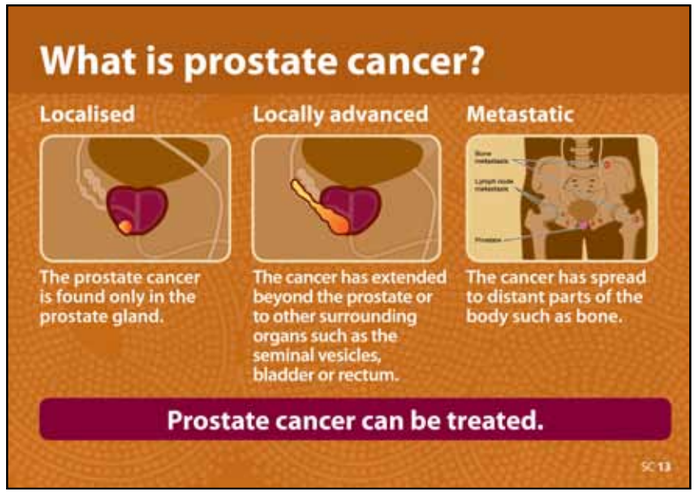
CHART 13



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.

How would a man know?

Possible symptoms:

- feeling the frequent or sudden need to urinate
- finding it difficult to urinate (for example, trouble starting, or not being able to urinate when the feeling is there, poor urine flow)
- discomfort when urinating
- finding blood in urine or semen.

Some men may have <u>no</u> symptoms.

Support and care – what carers and partners of men with prostate cancer need to know

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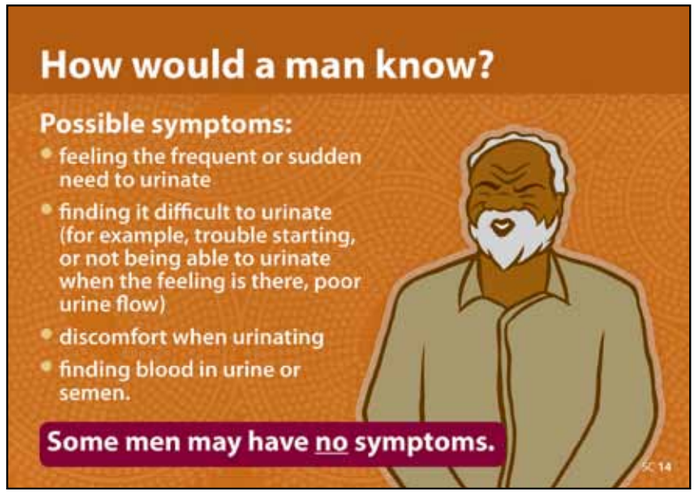
CHART 14



In the early stage of prostate cancer, there are usually no symptoms.
Later stage prostate cancer may cause symptoms that include:

- feeling the frequent or sudden need to urinate
- finding it difficult to urinate (for example, trouble starting, or not being able to urinate when the feeling is there, poor urine flow)
- discomfort when urinating
- finding blood in urine or semen.

These symptoms are not necessarily caused by prostate cancer. However, it is very important that he speaks with a doctor if he has any of these symptoms.

Source:

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

Who can get prostate cancer?

All men are born with a prostate.

Any man can get prostate cancer.

Support and care – what carers and partners of men with prostate cancer need to know

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Cancer Australia

CHART 15

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

Any man can get prostate cancer.

Source

- 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 the health clinic or by a doctor.

Physical examination –
Digital Rectal Exam (DRE)

Blood test –
Prostate Specific Antigen (PSA)

Other tests as required

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

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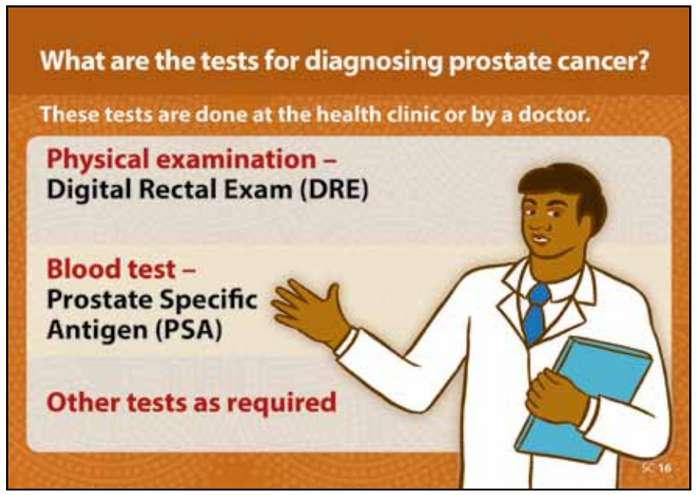
CHART 16



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 the blood.
- **Digital Rectal Examination** (DRE) – This allows the 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, the doctor may request repeat tests and refer him 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. The urologist removes small samples of tissue from the 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 the 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 the person you are caring for is taking medications, he should let the treating doctor know what they are before the biopsy to reduce the chance of problems.

  After the procedure, there may be:

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

  If there is concern about any of these symptoms, tell the treating doctor.

Other tests that the doctor may suggest include:

- **Free PSA test:** If there is a moderately raised PSA score and the doctor is not sure whether a biopsy is needed, he may have another test to measure the free PSA in the 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 the doctor decide whether a biopsy is needed.

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 and care options can be discussed.

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

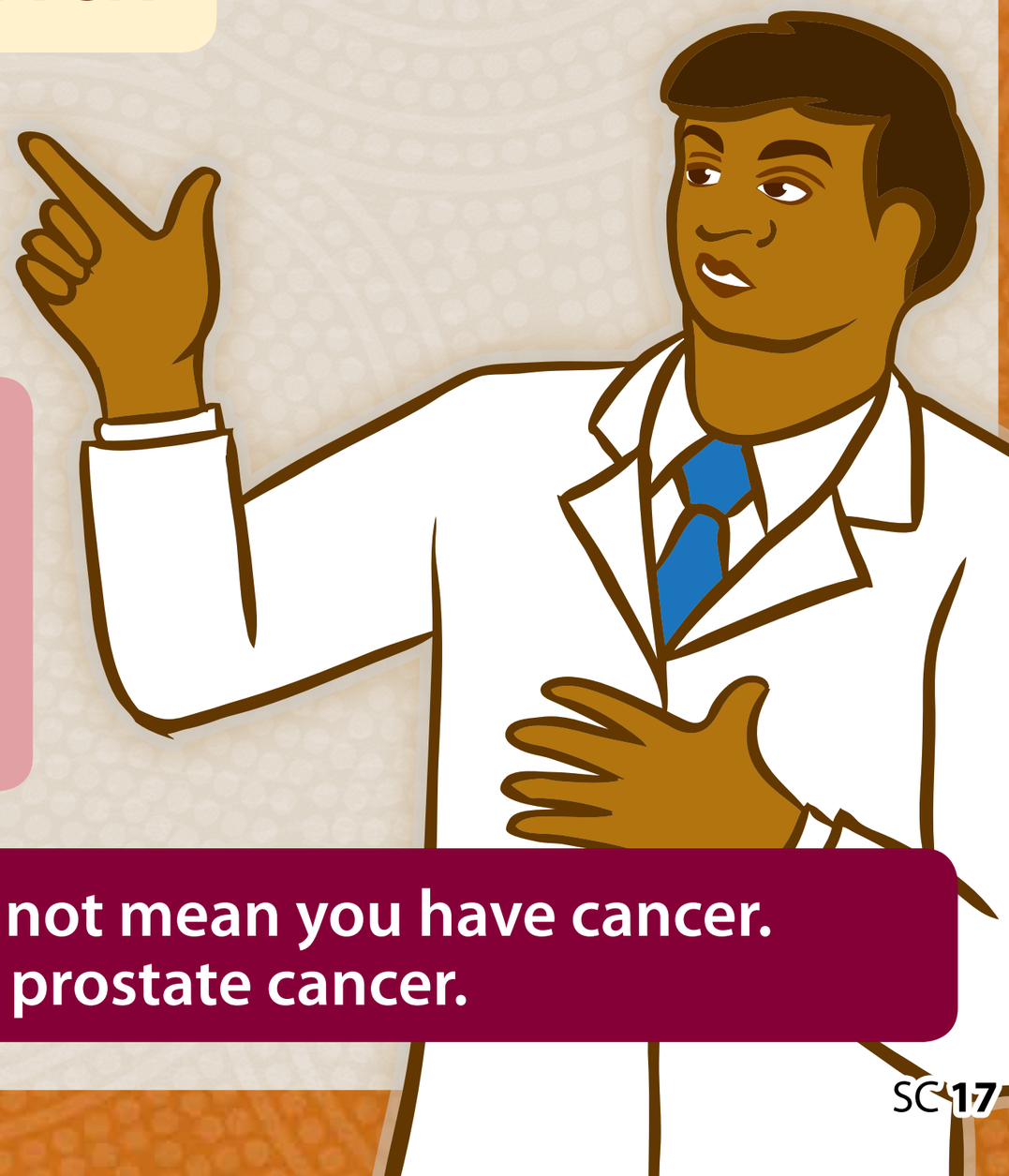
Referral to urologist.

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.

Support and care – what carers and partners of men with prostate cancer need to know

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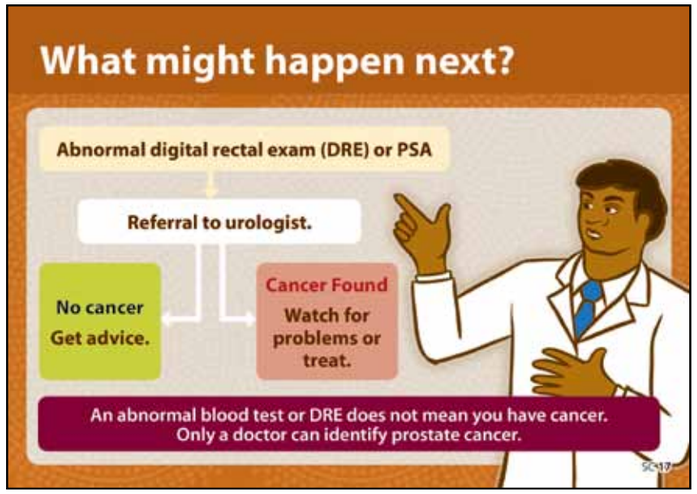
CHART 17



If the digital rectal examination (DRE) and/or PSA test are abnormal, he 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:

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

What if it is cancer?

- Talk to the doctor and health care team.
- Talk to the person you are caring for about your care role and how to talk to family and community.
- Find out about the type of cancer.
- Visit the PCFA website for information.

Work out your care plan.

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

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CHART 18

If it is cancer there are a number of directions that can be taken. These directions depend on: the type, stage and grade of the prostate cancer diagnosed. The doctor will have this information. The patient can 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)

Active surveillance

Watchful waiting

Surgery

Radiotherapy

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

Australian Government
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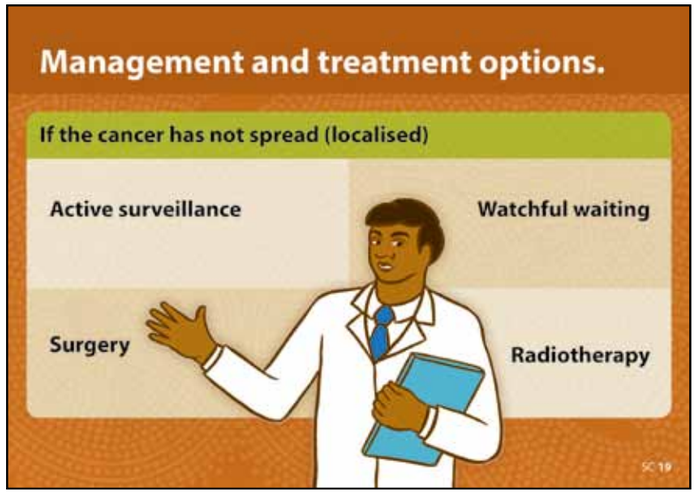
CHART 19



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.

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. He can have problems with leaking and controlling his 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 pee
- Bowel control - diarrhoea
- side effects affecting his ability to have a hard penis
- other issues such as tiredness, dry skin, unable to make babies.

Sources:

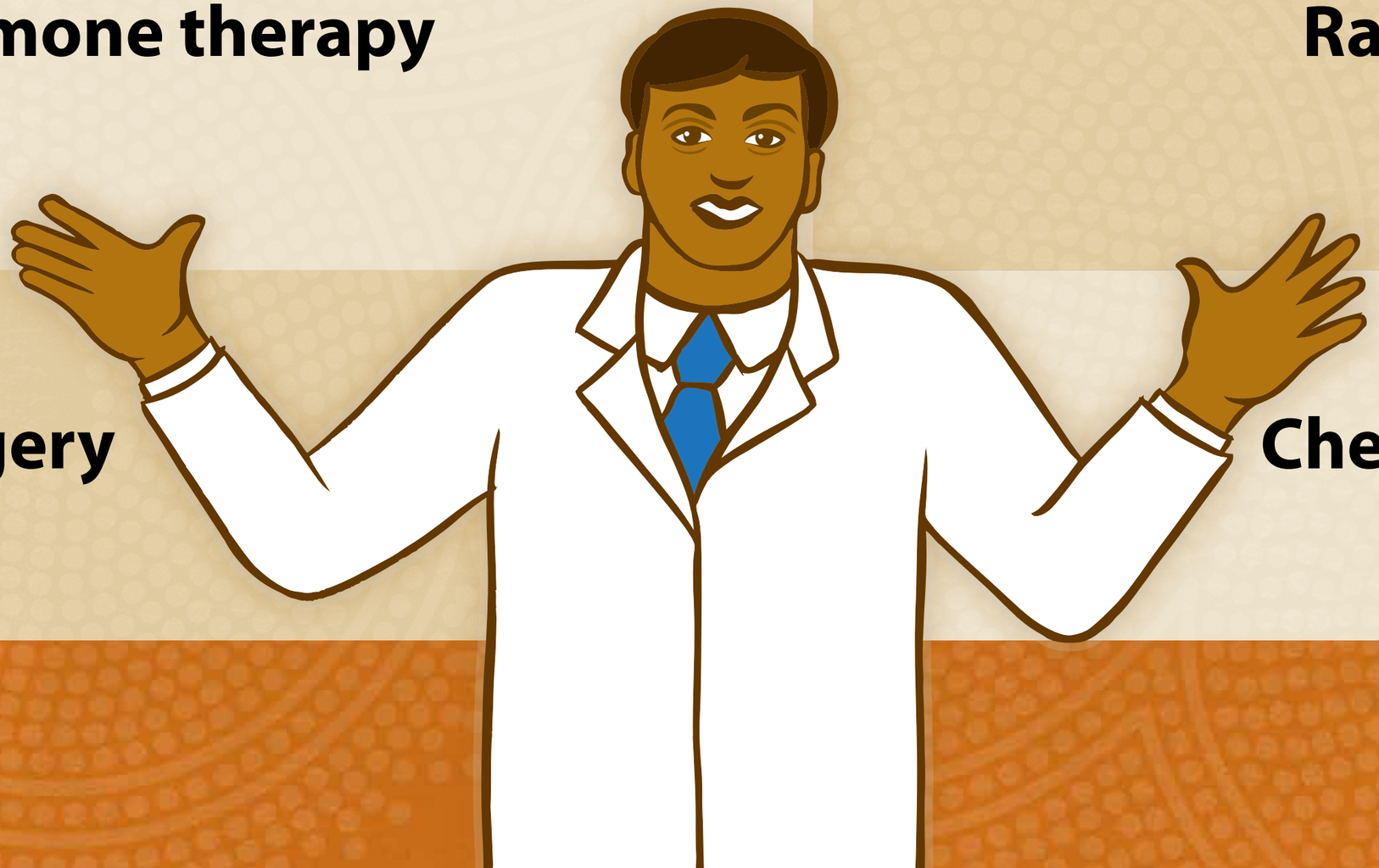
- Macmillan Cancer Support. Active surveillance for early (localised) prostate cancer. Retrieved from www.macmillan.org.uk/Cancerinformation/Cancertypes/Prostate/Treatmentforearlyprostatecancer/Activesurveillance.aspx
- Cancer Council NSW. (2012). Understanding radiotherapy – a guide for people with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

Management and treatment options.

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

Hormone therapy

Surgery



Radiotherapy

Chemotherapy

Support and care – what carers and partners of men with prostate cancer need to know

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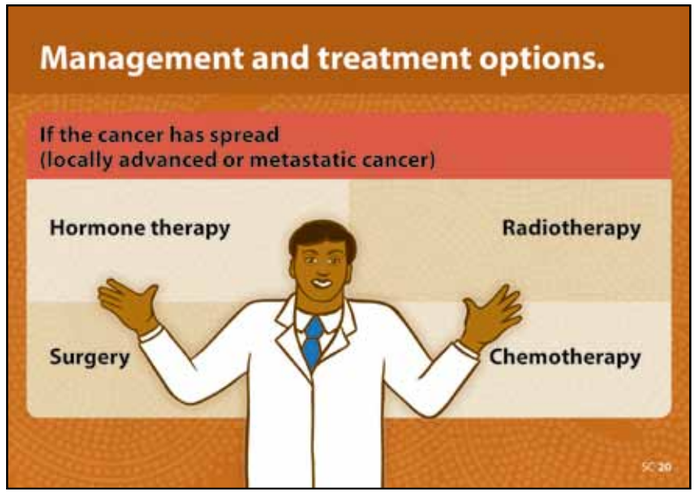
CHART 20



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 he starts hormone therapy.

The doctor will discuss the different types of hormone therapy available and what is the best option with the man you are caring for, depending on his 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 the man you are caring for to talk with members of the healthcare team to make sure this is the most appropriate option.

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, he 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

Radiotherapy maybe offered 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.

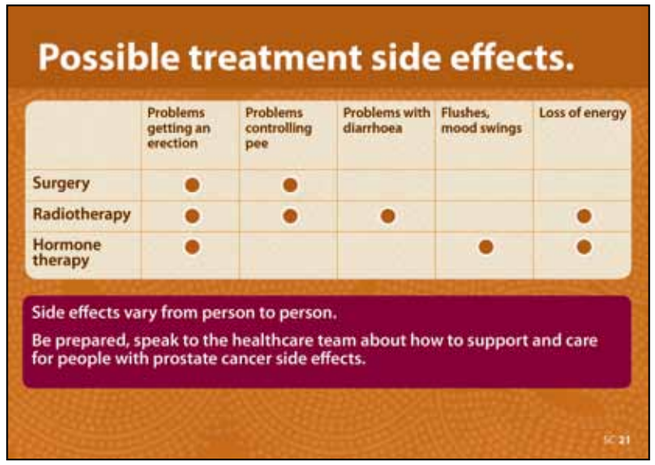
	Problems getting an erection	Problems controlling pee	Problems with diarrhoea	Flushes, mood swings	Loss of energy
Surgery	●	●			
Radiotherapy	●	●	●		●
Hormone therapy	●			●	●

Side effects vary from person to person.

Be prepared, speak to the healthcare team about how to support and care for people with prostate cancer side effects.

Support and care – what carers and partners of men with prostate cancer need to know

CHART 21



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, care and support before the treatment decision is made.

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 the healthcare team, there is help available.

Urinary problems

This refers to leaking or dribbling pee (urine), or not being able to hold the 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 the 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 hormone levels can trigger sudden intense hot sensations in the 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)

Men can feel tired because the treatments affect the whole body. Fatigue can also be caused by the cancer itself and everything extra that is needed to manage it.

Carers also report fatigue as a problem. While caring 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).

Sources:

- 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%20And%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%20Strong%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/

Who is a carer?

A carer can be anyone and any age

- Male or female.
- Relative, wife, de-facto, same-sex partner or friend.
- In Aboriginal and Torres Strait Islander Communities they can also be a skin relative, or an ‘uncle’ or an ‘aunt’.
- Anyone who supports a person who is ill, frail or disabled in any way.

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A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner (spouse, de-facto, same-sex) or friend who is ill, frail, disabled or has mental health or substance misuse problems.

Anyone can become a carer, carers come from all walks of life, all cultures and can be of any age. Many carers feel they are doing what anyone else would do in the same situation. They are looking after their father, son, uncle or best friend and just getting on with it.

Carers don't always plan to become carers, it just happens and they have to get on with it. If they did not do it, who would help and what would happen to the person they care for?

Caring is rewarding, but not always easy.

Most carers in Australia will say that caring for someone is very rewarding and something they want to do. However, caring is not always easy. 35% of primary carers provide care for 40 or more hours a week and can go on for many years. 31% of primary carers have been caring for more than 10 years, and 6% have been caring for more than 25 years.

Caring comes at a cost. Carers often have poorer health and wellbeing than non-carers. Caring responsibilities can upset family finances because of the costs involved in caring and because of the carer's reduced ability to do outside work and save.

Caring can contribute to relationship breakdown, depression and anxiety.

Who can help you? Carers Australia, government departments and other support organisations can assist carers who need help. They can make the lives of carers easier.

Carers are Valuable - Some quick statistics on Australia's carers

Australian Bureau of Statistics surveys and other information sources shed some light on carers in Australia. By understanding characteristics and who carers are, we are better able to provide advice to support them.

Some quick statistics:

2.6 million unpaid carers in Australia

31,600 Indigenous carers are over the age of 15

In Australia the estimated annual value of care provided in 2012 was over $40.9 billion

It is estimated that Australian carers provided 1.32 billion hours of unpaid care in 2010

On average carers spend approximately 40 hours per week providing care.

Sources:

- Carers Australia. Some quick stats on Australia's carers. Retrieved from www.carersaustralia.com.au/about-carers/statistics
- Australian Bureau of Statistics (2009). Survey of Disability, Ageing and Carers
- Australian Bureau of Statistics (2008). Summary of Findings: ABS Census of Population and Housing, Health and Welfare of Australia's Aboriginal and Torres Strait Islander People.
- Access Economics (2010). The Economic Value of Informal Care in 2010, Report for Carers Australia. Retrieved from www.carersaustralia.com.au
- Mental Health Council of Australia (2000). Carers of People with Mental Illness.

Challenges for carers.

- *No* time
- Depression
- Anxiety to get it right
- Reduced wellbeing
- Chronic illness
- Cost

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No Time – Partners and carers may have other work commitments as well as other family and social responsibilities. The extra organisation needed to care for someone who is ill can be exhausting, though most partners and carers do this willingly.

Depression - Research shows that partners/carers of cancer patients are often more depressed/ anxious than the patient themselves. This may be due to the fact that services and health care professionals focus their attention on the patient. It also relates to the length of time people may be in a caring role with or without enough support or a break.

Reduced wellbeing – Generally when we know someone is ill, all our attention and time can become focussed on the person and their illness. This means the partner/carer may not take time to do the things they used to. They stop the things which may benefit their own physical, psychological, mental, emotional and spiritual health.

Chronic pain – stress, anxiety, and exhaustion can all produce physical pain. Sometimes when people are unable to talk about or express how they are feeling to others this can be experienced as physical pain in the body (somatisation).

Keeping silent - carers often feel as though their needs are less important - after all, they are not the ones with such a serious illness or even dying. Carers often do not speak up for themselves.

Group exercise:

What challenges have you experienced? How did you deal with them?

Sources

- Carers Australia. www.carersaustralia.com.au
- Voss C. (2011). Hope, empowerment, resilience and outcomes for carers. Oral session presented at the NSW Biennial Conference, Sydney.
- Cummins, R., Hughes, J., Tomyn, A., et al. (2007). Wellbeing of Australians – carer health and wellbeing. Geelong: Deakin University.
- Olson, R.E. (2009). Carers of cancer patients: understanding their support service needs. A report to Cancer Australia. Retrieved from www.actcancer.org/downloads/File/Carers_of_cancer_patients.pdf

Caregiving: a balancing act.

Resources

- Being strong
- Getting help
- Focus on solutions

Stressors

- Care giving can be tiring
- Life worries
- Missing life events

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Resources

Being strong – this is often based on our life experience, our personal style, ways we have been brought up.

Getting Help

- Family members, friends
- Therapist / counsellor/doctor
- Services - Respite care, clinic, Carers Australia, Dept. of Human Services (carers allowance) and other agencies

Main caregiving and patient care can be tiring and include:

- Keeping spirits up and enabling family/cultural roles
- Being organised and a support to help with big decisions
- Physical help depends on patients treatment options, but could include:
  - Wound cleaning
  - Pain management
  - Meal Preparation
  - Showering assistance

Life worries: spill over effects

- Financial hardship: the extra costs of caring can be enormous. Caring families often have to find money for extra expenses like heating and laundry, medicines, health care and transport.
- Personal health & wellbeing: carers often ignore their own health and are 40% more likely to suffer from a chronic health condition. Some health problems, like back problems, anxiety and depression, can be directly linked to caring.
- Social isolation and relationships: many carers feel isolated, missing the social opportunities associated with work, recreation and leisure activities.
- Carers often have to deal with strong emotions, like anger, guilt, grief and distress that can spill into other relationships and cause conflict and frustration.

Missing life events

- Many carers miss out on important life events and opportunities such as paid work, a career, education and obligations to family and country.
- Caring can take the freedom and spontaneity out of life.

Sources:

- Deakin University (2010). What makes us happy – ten years of the Australian Unity Wellbeing index. www.aoa.gov

Ways you can help as a carer.

- Learn all you can about prostate cancer care and how to get information
- Stay healthy
- Know the daily routine and how you are going to help
- Help keep records, results, actions, dates such as PSA levels, medication implant dates. All are important for clinic visits

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Learn all you can about prostate cancer care – knowledge helps you in your role.

Know the routine – sometimes people need assistance from others to keep track of doctors, nurses, allied health professionals appointments. What do they need to bring to the clinic?

Remind the person to stay in touch with people and the health team. They can feel alone.

Have regular breaks, don't let yourself get overtired. It will help you both get through the day.

Exercise and healthy eating helps everyone – exercise can lessen some of the health effects of chronic illness. It also assists to reduce anxiety and depression.

Be on the lookout for depression and anxiety. Depression and anxiety are common especially in carers – be aware. If you notice changes seek help. You can refer to Beyondblue website for information on how to identify when you or someone close to you is anxious or depressed.

Seek and accept support and help from friends and family. Speaking with someone outside the family such as a trained health worker and clinician can assist. They will know what is available and link people to other supports available in the local community.

Sources:

- Cancer Council, Aboriginal Health and Medical Research Council of NSW. Looking after someone with cancer. www.cancercouncil.com.au/wp-content/uploads/2010/10/looking_after_someone_can3234.pdf

Looking after yourself.

Lead a healthy lifestyle:

- eat good food
- get enough sleep
- be active – move more
- practice Dadirri use methods for relaxing and reducing stress levels
- don't leave it too late – ask for help.

Carer Line for information, referrals, support groups, counselling
1800 242 636 Monday – Friday, 9am – 5pm

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Lead a healthy lifestyle. Looking after your own health is the best way carers can make sure that they are able to look after others.

Relaxation & Reducing Stress:

Exercise – including walks, yoga, Tai Chi, social time with friends, meditation, gardening or other enjoyable hobbies.

Practice Dadirri - inner deep listening and quiet still awareness. Dadirri recognises the deep spring that is inside us. It is something like contemplation.

Support can include

Getting someone to help with the shopping, cleaning or pet care

Attending support groups

Time out – through linking the person you are caring for to other social events with people in similar situations

Respite care – is a chance for you and the person you care for to take a break. This can be:

- in the care recipient's home with care ranging from a few hours a week to overnight care
- in a Day Centre which provides full or half day care
- in a community respite cottage for overnight or weekend care
- in a residential aged care home for one to six weeks
- emergency respite.

Respite care is provided by community care services, such as those provided by the Home and Community Care Program (HACC), the National Respite for Carers Program (NRCP) and by residential care homes.

A local doctor, Aged Care Assessment Team or Commonwealth Respite and Carelink Centre can advise on respite care.

Talk therapy – with a trusted friend. Sometimes more professional support is needed. Make sure the person is professionally qualified and talk with your doctor about whether you can access free sessions through Medicare to see a trained social worker, psychologist, dietician, exercise physiologist

CentreLink benefits: Australian Government, Department of Human Services. See the Carer Payment / Carer Allowance booklet available online at www.humanservices.gov.au/customer/forms/ci002

Sources

- NHMRC. Australian guide to healthy eating. www.eatforhealth.gov.au/guidelines/australian-guide-healthy-eating
- Department of health and Aging. An active way to better health. www.health.gov.au/internet/main/publishing.nsf/Content/DDBDA0E9445F726CCA257BF00020630E/$File/adults_phys.pdf
- Ungunmerr-Baumann M-R. Dadirri - A Reflection. www.liturgyplanning.com.au/documents/main.php?g2_view=core.DownloadItem&g2_itemId=4696
- Olson R., (2009). A Report to Cancer Australia,: Carers of cancer patients: Understanding their support service needs – information for carers. www.actcancer.org/patients-family-friends/information-for-carers.aspx?
- Commonwealth Department of Health. Respite Care. www.health.gov.au/internet/main/publishing.nsf/Content/ageing-carers-respite.htm

AIMHI Grow Strong Tree

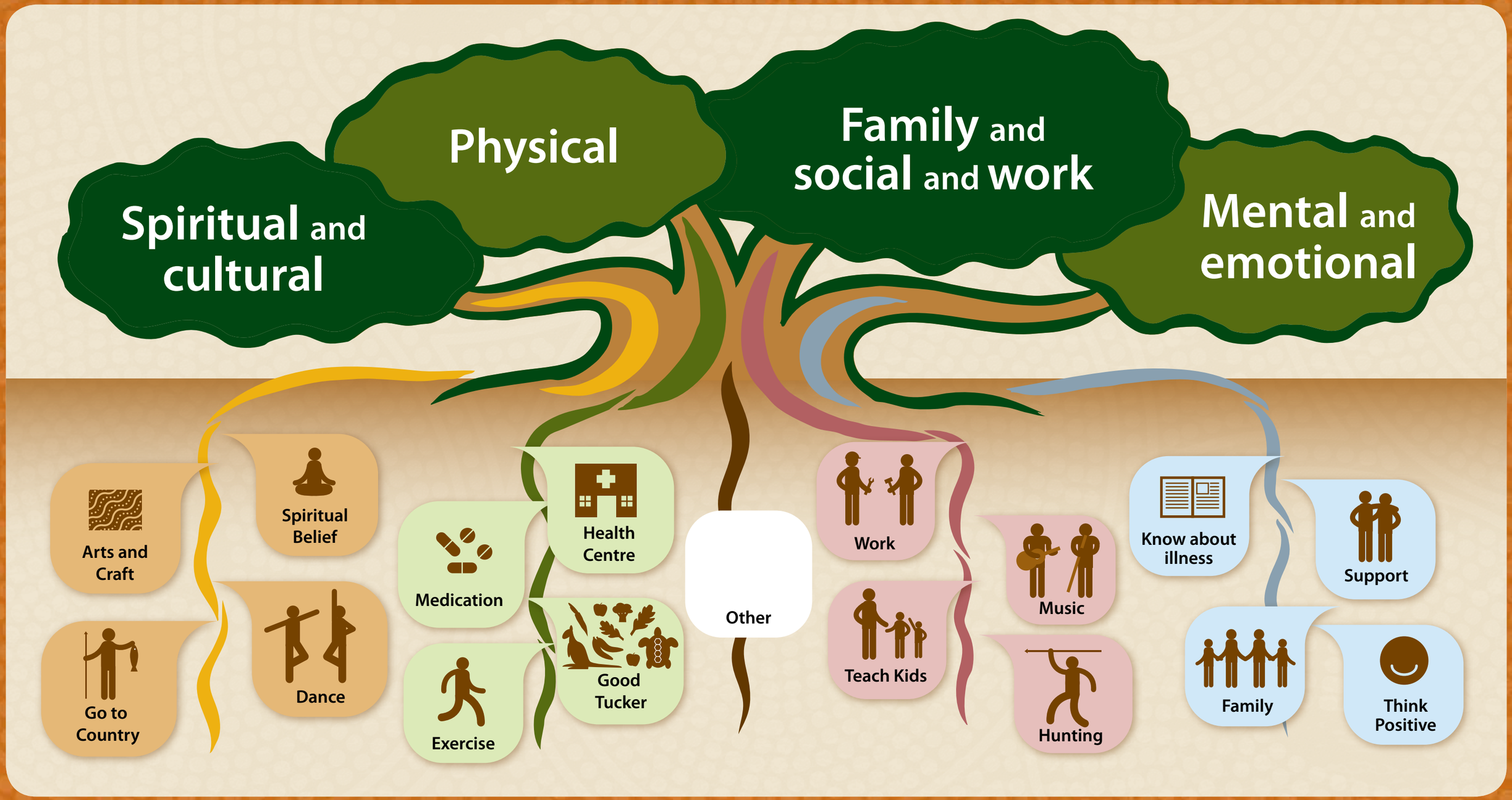

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CHART 27

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. Speak to the healthcare team about ways to deal with either of these issues.

Look after yourself

There are many things that contribute to 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

Being close - intimacy.

Depending on the patient's treatment, loving, sharing and intimate concerns may become an issue for both of you - including:

- performance problems or concerns
- loss of interest.

Talk – don't keep it to yourself. There are health professionals who can also help and advise.

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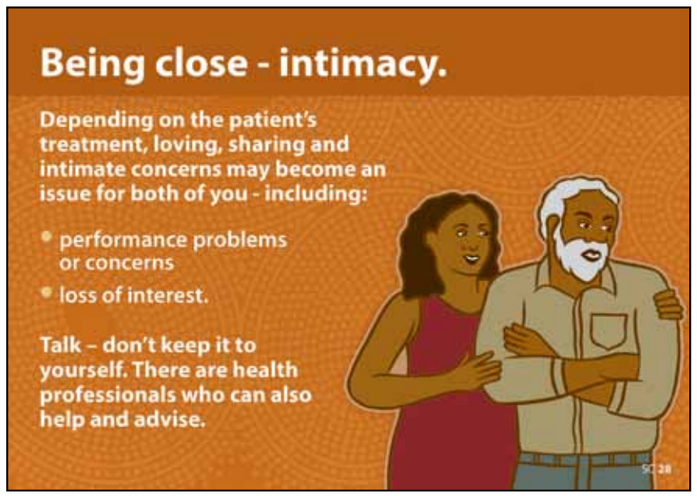


Intimacy is 'connecting emotionally'.

Make time to enjoy each other's company and relax together.

Treatment for prostate cancer can affect a man's love making and ability to have children.

There may be loss of the ability to have or maintain an erection (erectile dysfunction), loss of desire for sex (libido). This may be temporary or permanent depending on the treatment.

The man may also lose his ability to make a baby so family planning may be very important for a couple to talk about. Have honest conversations about what the doctor has said before the treatment is started.

Moving forward:

Men may have important things to think and talk about with the way their bodies are changing. This can affect relationships. Counselling and support can help people with relationship problems.

Communication is important.

Talk to a doctor, counsellor or therapist if you have any questions or worries in these matters. Your GP may be able to assist or refer you for counselling sessions.

Contact can also be made with organisations such as Impotence Australia (www.impotenceaustralia.com.au/site/) or the Society of Australian Sexologists in your state (http://assertnational.org.au/contacts/)

Sources

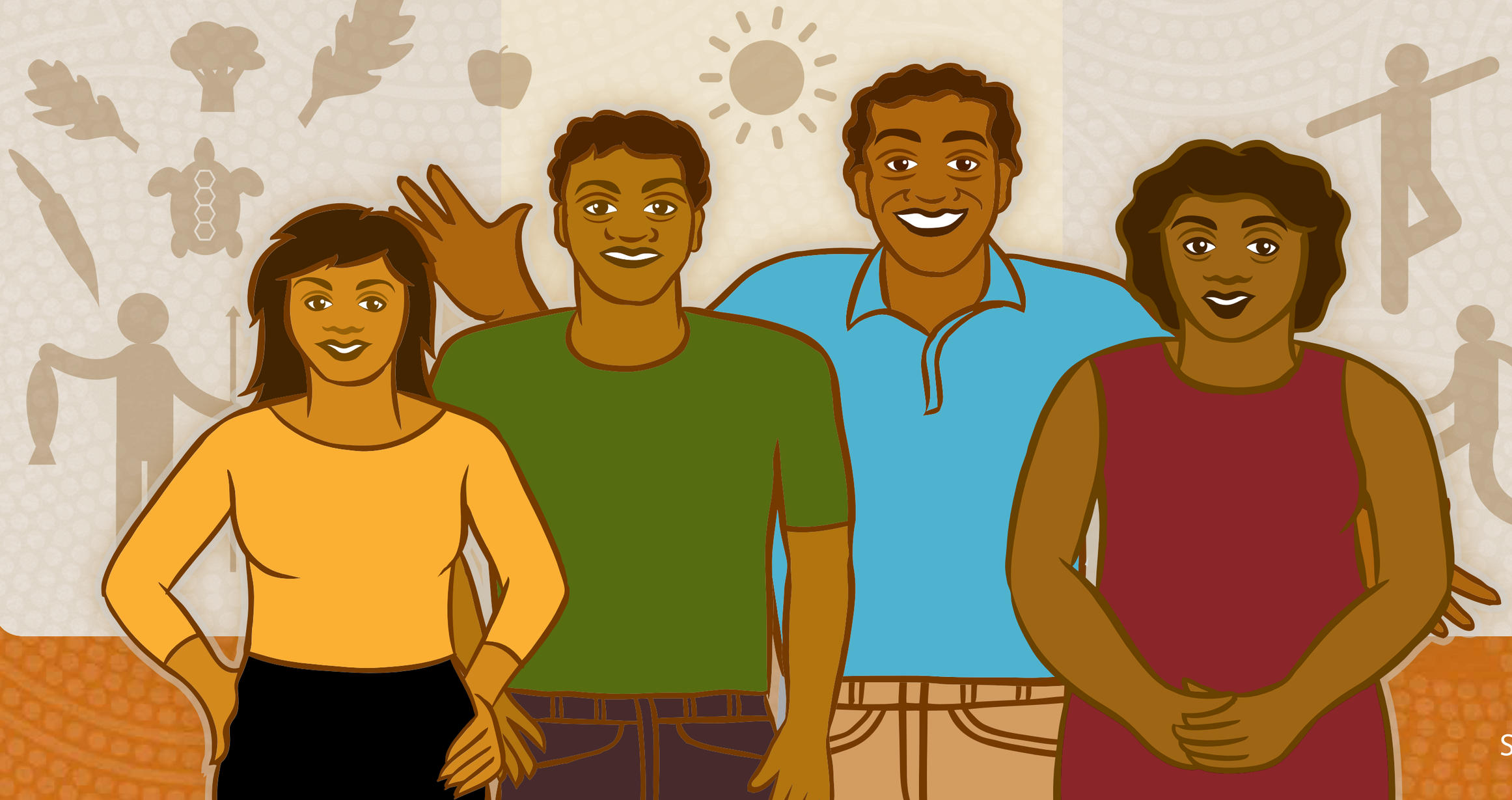
- Rodriguez D., (2011). Intimacy After Prostate Cancer Treatment. Retrieved from www.everydayhealth.com/prostate-cancer/intimacy.aspx
- Ness S., (2010).Intimacy and sex after prostate cancer, www.mayoclinic.com/health/prostate-cancer/MY01444

Your health matters.

Eat good tucker and bush food

Stay connected to family and country

Look after your whole self



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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 the 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 the 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.

Get up, get moving

Don’t drink much grog

Don’t smoke

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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/DDBDA0E9445F726CCA257BF00020630E/$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.html

Treatment takes teamwork and support.

Your healthcare team will:

- talk to you about the support necessary for all possible treatment types and options for your situation
- talk to each other and work together to develop a care plan with you
- advise on resources and managing costs your treatment and support.

Working together will improve your ability to provide support and care. This will improve health and wellbeing.

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It is normal to feel confused, frightened or scared when caring or supporting someone with cancer. There are many new situations and unknowns. The healthcare team including Aboriginal Liaison Officers, Aboriginal Health Workers and interpreters are there to help you understand and feel comfortable.

- The doctor will talk about tests and treatments with you. ***You need to check if there is any special support or care needed for the tests and treatments.***
- If you need to hear it in language or explained again, ***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.***
- The person you care for will have to give permission for the healthcare team to give information to family, kin or carers if they ask questions. The patient is in control of who gets told what.

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

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

Sources

- NT Government Department of Health and families. A cancer Journey. Retrieved from www.cancerlearning.gov.au/docs/indig_can_journey.pdf

Know where to get help and information.

- Aboriginal Health Workers
- PCFA support groups
- Regional Cancer Centres
- Prostate Cancer Specialist Nurses
- Carers Australia
- Cancer Australia

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Contact the local health centre, Doctor or Aboriginal Community Controlled Health Organisation for assistance.

Online –

Carers Australia – providing specialist services across Australia for carers including counselling and information.

www.carersaustralia.com.au

Carers Australia – Resources for Aboriginal and Torres Strait Islander Carers (by State/Territory).

http://carersaustralia.com.au/about-carers/aboriginalandtorresstraitislandercarers/resources-for-aboriginal-and-torres-strait-islander-carers2/

Australian Indigenous Cancerinfonet site - Yarning places, quality information and resources about how to prevent and/or minimise the harm associated with cancer among Indigenous peoples.

www.healthinfonet.ecu.edu.au/chronic-conditions/cancer

HealthInfonet - Aboriginal and Torres Strait Islander health information.

www.healthinfonet.ecu.edu.au

Tomorrow counts – stories online of people with prostate cancer and carers.

www.tomorrowcounts.com.au

Incontinence Australia – is the national peak body promoting bladder and bowel health. Our vision is to have a community free of the stigma and restrictions of incontinence.

National Continence Helpline Freecall – 1800 33 00 66

www.continence.org.au/pages/aboriginal-torres-strait-islander.html

Cancer Australia - providing national leadership in cancer control and improving outcomes for Australians affected by cancer.

www.canceraustralia.gov.au

How can PCFA help?

PCFA offers:

- Information
- Support materials
- Affiliated support groups across Australia
- Prostate Cancer Specialist Nurses

Prostate Cancer Foundation of Australia

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

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Information and materials

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

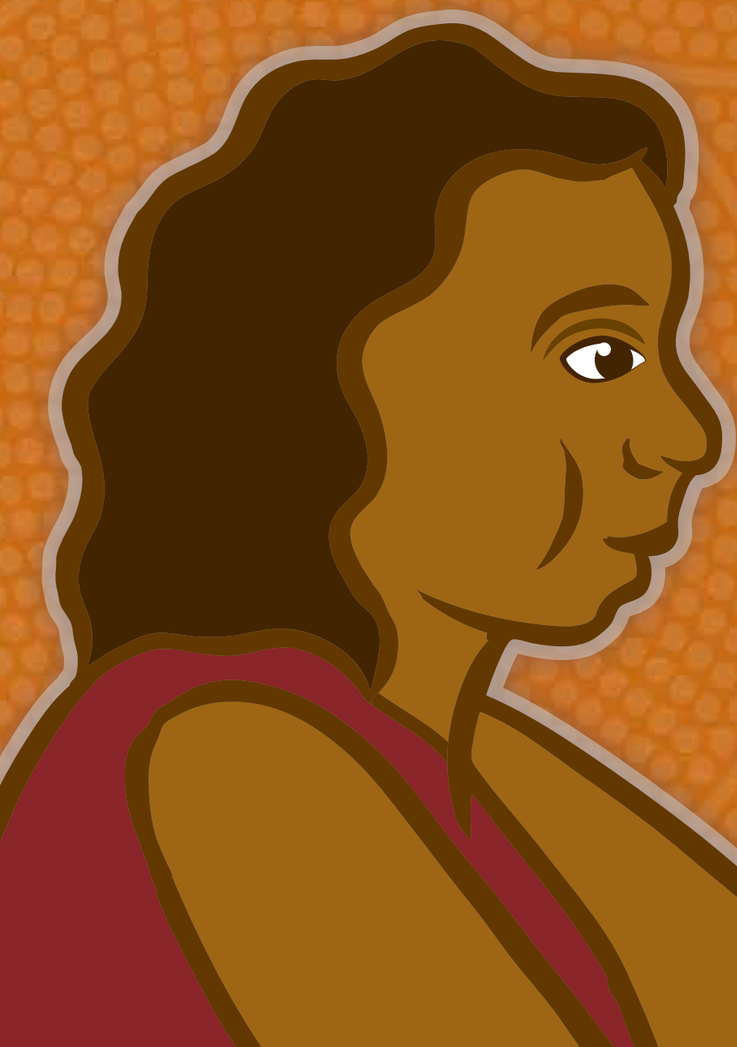
PCFA has a range of information available. If you would like more information, please go to the website or call the Freecall number – 1800 22 00 99

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. The nearest Prostate Specialist Nurse can be located through the PCFA website or calling by 1800 22 00 99.

Support groups – how to find them.

Go to **www.pcfa.org.au**
click on support – enter
your postcode



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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 carer 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.

Carers Australia

www.carersaustralia.com.au

Carers Australia – Resources for Aboriginal and Torres Strait Islander Carers (by State/ Territory)

http://carersaustralia.com.au/about-carers/aboriginalandtorresstraitislandercarers/resources-for-aboriginal-and-torres-strait-islander-carers2/

Australian Indigenous Cancerinfonet site –

www.healthinfonet.ecu.edu.au/chronic-conditions/cancer

HealthInfonet

www.healthinfonet.ecu.edu.au

Tomorrow counts – stories online of people with prostate cancer and carers.

https://tomorrowcounts.com.au/

Incontinence Australia – is the national peak body promoting bladder and bowel health. Our vision is to have a community free of the stigma and restrictions of incontinence.

National Continence Helpline Freecall – 1800 33 00 66

www.continence.org.au/pages/aboriginal-torres-strait-islander.html

Cancer Australia - providing national leadership in cancer control and improving outcomes for Australians affected by cancer.

www.canceraustralia.gov.au

Support and care – what carers and partners of men with prostate cancer need to know

Prostate Cancer Foundation of Australia

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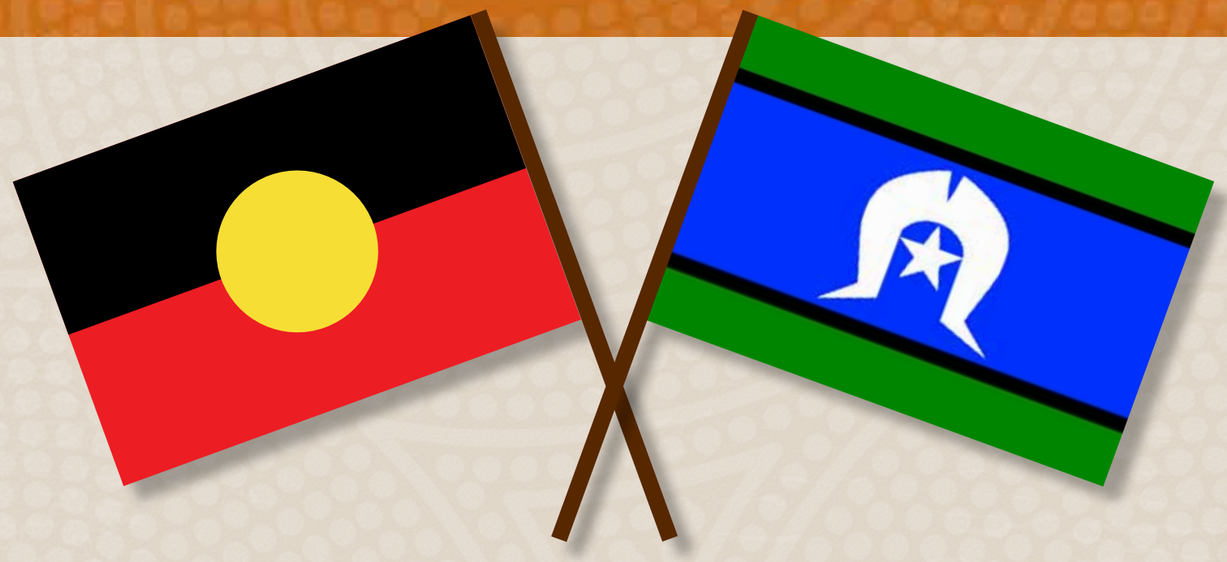
CHART 35

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.



Thank you.

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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.
Orchidectomy	The surgical removal of the testicles.
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.