UNDERSTANDING URINARY PROBLEMS FOLLOWING PROSTATE CANCER TREATMENT
This book is for men who have made a decision to have a specific treatment or have already received treatment for prostate cancer. It contains information about important issues to help men who need to know about treatment, urine symptom management issues and incontinence.

PCFA provides a range of resources to support men, partners and their families with prostate cancer. For further information, please see www.pcfa.org.au.

NOTE TO READER
Because what is known about prostate cancer and its treatment is constantly changing and being updated, your treating health professionals will give you information that is specific to your unique needs and situation.

If you would like further information please contact PCFA (telephone: (02) 9438 7000 or freecall 1800 220 099 email: enquiries@pcfa.org.au website: www.pcfa.org.au).

DISCLAIMER
PCFA develops materials based on the best available evidence and advice from recognised experts; however, it cannot guarantee and assumes no legal responsibility for the currency or completeness of the information.

PERIODIC UPDATES
It is planned that PCFA will review this booklet after a period of, but not exceeding, four years.

© Prostate Cancer Foundation of Australia 2014
This work is copyright. Apart from any use as permitted under the Copyright Act 1968 no part may be reproduced by any process without prior written permission from the Prostate Cancer Foundation of Australia. Requests and enquiries concerning reproduction and rights should be addressed to the Chief Executive Officer, Prostate Cancer Foundation of Australia, PO Box 499, St Leonards, NSW 1590 Australia. Website: www.pcfa.org.au Email: enquiries@pcfa.org.au

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

ACKNOWLEDGEMENTS
This resource was developed by a multidisciplinary Expert Advisory Group.
PCFA gratefully acknowledges the input, advice and guidance of the men with prostate cancer and health professionals who helped in the development of this booklet by offering their time to review its content.

— Associate Professor Nick Brook (Urologist)
— Professor Suzanne Chambers (Psychologist)
— Associate Professor Pauline Chiarelli (Physiotherapist)
— Associate Professor Eric Chung (Urologist)
— Mr Nigel Cook (Consumer)
— Professor Jon Emery (Primary care physician)
— Ms Susan Hanson (Cancer Australia)
— Dr Amy Hayden (Radiation Oncologist)
— Mr Ian Henderson (Prostate Cancer Specialist Nurse)
— Ms Sharron Hickey (Clinical Nurse)
— Associate Professor Michael Izard (Radiation Oncologist)
— Associate Professor Michael Jefford (Medical Oncologist)
— Ms Jocelyn Klug (Sexual Rehabilitation Specialist)
— Associate Professor Anthony Lowe (PCFA)
— Dr David Malouf (Urologist)
— Dr Vivienne Milch (Cancer Australia)
— Professor Ian Olver (Cancer Council Australia)
— Ms Carolyn Russell (Radiation Oncology Nurse Specialist)
— Ms David Sandoe OAM (PCFA)
— Ms Jennifer Siemsen (Prostate Cancer Specialist Nurse)
— Ms Sue Sinclair (Cancer Australia)
— Mr Alex Sloss (Consumer)
— Mr John Stubbs (CanSpeak)
— Ms Julie Sykes (PCFA)
— Ms Kyla Tilbury (Urology Nurse)
— Ms Glenice Wilson (Continence Advisor)
— Dr Tim Wong (PCFA)
— Associate Professor Henry Woo (Urologist)

Editor:
Ms Helen Signy

Medical Illustration:
Mr Marcus Cremonese
Welcome. We hope you find the following content informative and clear.

## Contents

1. Introduction .................................................. 2
2. Your prostate and bladder: the connection ......................... 3
3. How is urine function controlled? ................................ 4
4. What is urinary incontinence? .................................... 5
5. What causes urinary problems? .................................... 5
6. Common reactions to urinary side effects from treatment ............ 6
7. Urinary side effects following treatment .......................... 6
   — Surgery
   — Radiotherapy
8. Where can I find help? .......................................... 9
9. Looking after yourself ............................................ 12
10. Glossary ...................................................... 14
This book is for men who have made a decision to have a specific treatment or have already received treatment for prostate cancer. It contains information to help you understand important issues about urinary problems following prostate cancer treatment. It may also be helpful for significant people in your life (e.g. your partner, family and friends) to read this booklet. Urinary problems are common after treatment for prostate cancer. However, with the right advice (and understanding), side effects can be managed and in many cases, resolved.

Your cancer journey
After being diagnosed with prostate cancer, it’s common for you to see a number of health professionals with different expertise who work together as a team, called a multidisciplinary team (also known as a healthcare team). Best practice treatment and supportive care for people with cancer involves a team of different health professionals. Each team member brings different skills that are important in managing care and in making decisions around your individual needs. The team includes health professionals who are involved in diagnosing your cancer, treating your cancer, managing symptoms and side effects and assisting you with your feelings or concerns during your cancer experience.

The cancer journey is your personal experience of cancer. It’s not the same for everybody, even with the same type of cancer. Depending on your stage of prostate cancer and other underlying conditions, your experience may be quite different. As the diagram Your cancer journey shows, it can be useful to think of the journey in stages that may include detection, diagnosis, treatment, follow-up care and survivorship. For some, it may include end of life care. Take each stage as it comes so you can break down what feels like an overwhelming situation into smaller, more manageable steps.

For some men, the impact of treatment may be minimal or quickly resolved. For others, this impact can be more difficult, requiring further support and help. The aim of this booklet is to provide you with information that you can then use as a guide to further discussions with your doctor and healthcare team about your situation. Being informed enables you to participate in decisions about your care and leads to improved experiences and better care.

This booklet contains information on:
— possible urinary side effects of some treatments for prostate cancer
— why urinary problems can occur following treatment
— helpful strategies for managing these problems
— people and resources that can help.
To understand your urinary problems, it is important to know how the prostate and bladder are connected, and how your prostate cancer treatment affects them both.

— The prostate gland is normally the size of a walnut but may enlarge as you age. It is located between the bladder and the penis and sits in front of the rectum.

— The main function of the prostate gland is to produce fluid that nourishes and protects sperm. During ejaculation, the prostate squeezes this fluid into the urethra (urine tube) and it is expelled with the sperm as semen.

— The urethra is the thin tube that runs through the centre of the prostate from the bladder to the penis. It is the passage used for urine and semen.

I needed more information on dedicated physiotherapy interventions to control incontinence.
Urination is controlled by two urinary sphincters, which are muscles acting like valves. The internal sphincter is located where the bladder and urethra join, called the bladder neck. The external sphincter sits below the prostate near the pelvic floor.

These two sphincter muscles act together, and control urine by opening and closing around the bladder neck and urethra. When they get permission from the brain, the sphincters relax to allow the bladder to empty. At the same time, the bladder muscles contract and squeeze urine out of the bladder. When you have finished urinating, the sphincter muscles contract and close while the bladder relaxes.

**INTERNAL AND EXTERNAL URINARY SPHINCTERS**

A) Full bladder

The pelvic floor muscles also play a part in bladder control. The floor of the pelvis is made up of muscle layers and tissues. The layers stretch like a hammock from the tailbone at the back to the pubic bone in front. Your pelvic floor muscles support your bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.
UNDERSTANDING URINARY PROBLEMS FOLLOWING PROSTATE CANCER TREATMENT

What is urinary incontinence?

Urinary incontinence is the accidental leaking of urine and a possible side effect in men who have had surgery or radiotherapy for treating their prostate cancer. The amount of leakage can vary from a drop to total emptying of the bladder.

For some men, urinary problems may not occur or are quickly resolved. For other men, they can be more problematic, requiring further support and help from members of their healthcare team who specialise in prostate cancer and urinary problems. It is important to talk to your healthcare team about any urinary problems you are experiencing because they understand your individual situation, and are able to give you the most relevant advice.

There are different types of urinary incontinence.

— **Stress urinary incontinence** is the loss or leaking of urine when there is an increase in abdominal pressure. For example, when you cough, laugh, sneeze, change position or are physically active.

— **Urge urinary incontinence** is the sudden intense need to urinate without the ability to delay, resulting in the loss or leaking of urine before you reach the toilet. Urgency or urge incontinence occurs when your bladder is overactive or contracting without you wanting it to.

— **Mixed incontinence** is a combination of urinary problems related to both stress and urge urinary incontinence.

— **Overflow incontinence** is when your bladder never completely empties, causing urine to leak. This can occur in men with prostate enlargement, scarring of the urethra caused by treatment or at the neck of the bladder due to injury or infection.

What causes urinary problems?

Before your prostate cancer treatment, you may or may not have experienced urinary problems. The main cause for urinary problems before treatment is an enlarged prostate causing obstruction (blockage) to the bladder. After treatment, if there are urinary problems, they are usually related to the effects that treatment has had on your urinary system, which are unwanted and can be unpleasant. These are known as urinary side effects. For example, surgery will physically change your urinary system, while radiotherapy can cause irritation, inflammation and swelling to the bladder, prostate, urethra and rectum (back passage).

Understanding urinary side effects can help you when you are seeking support and advice.

It is important to talk to your healthcare team about any urinary problems you are experiencing.
Common reactions to urinary side effects from treatment

For many men, coping with urinary side effects after prostate cancer treatment can be challenging. If you are experiencing urinary side effects, particularly incontinence, you may be feeling emotions such as embarrassment, anxiety, frustration and social isolation. Fear of leakage can be enough to stop men from taking part in their normal social activities.

If you have someone you trust (e.g. your partner, close friend), talking with them, and seeking help and advice from members of your healthcare team can help you cope with possible urinary side effects.

Urinary side effects can be managed, and in many cases, resolved.

Understanding urinary side effects can help you when you are seeking support and advice.

Urinary side effects following treatment

SURGERY

When your prostate gland is removed entirely by surgery, a procedure called radical prostatectomy (open, laparoscopic or robotic), two things occur during the surgery that can cause urinary side effects.

— A gap is created between the bladder and urethra, which is then surgically reconnected.
— The bladder neck (where the bladder and urethra join) can be affected and this can cause urinary problems. Also, the external sphincter may be weakened, or very rarely, damaged during surgery, and this can cause urinary problems as well. This is why pelvic floor exercises before your surgery, and after removal of your catheter, which can strengthen the external sphincter, can help with managing possible urinary problems after surgery. (Note: do not perform pelvic floor exercises while the catheter is in place, this allows the surgical area time to recover).

Some urinary side effects that you might experience following surgery include:

— incontinence (accidental leaking of urine)
— incomplete emptying (a feeling of not fully emptying your bladder)
— hesitancy (difficulty beginning your urinary stream)
— intermittency (a stop/start urinary stream)
— dribbling (slight urinary leakage after urinating is completed)
— weak urinary stream (slow flow with minimal force)
— straining (having to push or strain to begin your urinary stream)
— frequency (needing to urinate every two hours or less)
— urgency (strong sudden urge to urinate and inability to delay it)
— nocturia (need to urinate overnight)
— pain (any discomfort, such as burning, stinging or pain while urinating).

Stress urinary incontinence is the most common urinary side effect following prostate cancer surgery.

For some men, these side effects start improving soon after the catheter is removed, while for others it can take 6 to 12 months after surgery for normal bladder function to fully return and urinary side effects resolve. A small percentage of men will experience permanent incontinence. There are treatment options available for permanent incontinence. Discuss your situation with your healthcare team if it applies to you.
Urinary side effects following treatment

Many factors can affect continence following surgery such as your weight, the stage of your cancer, the surgical technique required for your individual situation, or if you were experiencing any urinary problems before your surgery. For older men (over 70 years old), it may be slower initially for them to regain their continence, but there is some evidence that by 3-6 months, there is no difference between younger and older men in terms of urine control after surgery.

Very rarely, the bladder neck (where the bladder joins the remainder of the urethra) can develop a narrowing known as bladder neck stenosis (or stricture).

Problems caused by a stenosis may include:
- a weak urinary stream
- hesitancy
- a feeling of incomplete emptying of your bladder
- spraying of urine when urinating
- urinary retention.

**URINARY CATHETER**
A urinary catheter is a thin plastic tube that runs from your bladder through your penis and drains urine into a bag on the outside of your body. The catheter is held in place by an inflated balloon inside your bladder. Generally a catheter is left in place for 1 week following your surgery but this may vary based on your individual situation.

**RESOURCES**
PCFA has resources on side effects of treatments for prostate cancer. For further information, please see www.pcfa.org.au.
Urinary side effects following treatment

RADIOThERAPY
There are two main types of radiotherapy – external beam radiotherapy (EBRT) and brachytherapy. The difference is whether the treatment is applied from outside the body (EBRT) or delivered from within the prostate (brachytherapy).

External beam radiotherapy
External beam radiotherapy (EBRT) uses high energy X-ray beams that are directed at the prostate from the outside to destroy cancer cells.

Urinary side effects following EBRT can be described as ‘early’ or ‘late’. Early side effects are those that occur during or shortly after radiotherapy treatment, and usually settle a few weeks after treatment finishes. Late side effects are those that take months or years to develop, and can be permanent. These side effects can vary from mild to more severe forms and be age-related rather than due to the treatment. However, most men experience mild forms of these side effects and many have none.

If you are already experiencing urinary problems before starting EBRT, these problems may get worse. Please talk to members of your healthcare team about concerns you have about existing or possible urinary problems following treatment.

Possible early urinary side effects of EBRT include:
— urgency (strong sudden urge to urinate and inability to delay it)
— frequency (needing to urinate every two hours or less)
— pain (any discomfort such as burning, stinging or pain while urinating)
— nocturia (need to urinate overnight)
— intermittency (a stop/start urinary stream)
— dribbling (slight urinary leakage after urinating is completed)
— straining (having to push or strain to begin your urinary stream).

Possible late urinary side effects of EBRT include:
— weak urinary stream (slow flow with minimal force)
— nocturia (need to urinate overnight)
— urgency (strong sudden urge to urinate and inability to delay it)
— intermittency (a stop/start urinary stream)
— dribbling (slight urinary leakage after urinating is completed)
— straining (having to push or strain to begin your urinary stream)
— urinary stricture (narrowing of the urethra due to scarring that can cause side effects already mentioned).

While urinary incontinence may occur after radiotherapy, this side effect is less common than after surgery. Pelvic floor exercises can help. Talk to members of your healthcare team for information (e.g. Continence nurse).

Brachytherapy
Brachytherapy is when radioactive material is given directly into the prostate at either a low dose rate (LDR) or high dose rate (HDR). LDR and HDR relate to the speed with which the dose is delivered, not the actual dose itself.

— Low Dose Rate: It is given by implanting permanent radioactive seeds directly into the prostate. The seeds give off a focused amount of radiation to the prostate with the aim of destroying the cancer cells.

— High Dose Rate: It is also given by inserting radioactive material directly into the prostate but, unlike LDR seeds, the placement of the material is temporary and for shorter periods – usually for a day or two at a time.

Urinary side effects following brachytherapy may occur due to the effect this treatment can have on surrounding areas such as the bladder and urethra. Similar to EBRT, urinary side effects following brachytherapy can be described as ‘early’ or ‘late’.

The early and late side effects of brachytherapy are the same as those listed in the EBRT section.

Most men will experience urinary side effects following LDR. These may be minimal or mild, and usually peak at approximately 6 to 8 weeks, after which side effects then gradually ease and resolve. A small percentage of men may still experience urinary side effects 6 months or longer following implantation. For men who had HDR, urinary side effects usually peak between 1 to 3 weeks and improve at approximately 4 to 6 weeks following treatment.

A small number of men may experience urinary retention (the inability to urinate) due to the swelling of the prostate following brachytherapy. You may be given medication to assist with this immediately following your treatment. The swelling can cause obstruction to your urinary flow from the bladder. Occasionally, a urinary catheter is required to continuously drain your bladder for a short period until the swelling resolves.

Blood in the urine can occur both immediately after brachytherapy or long term after all forms of radiotherapy. As a result of the brachytherapy procedure, some bleeding may occur. This should settle within 24 to 48 hours after the procedure. Blood in the urine that occurs more than 6 months after all forms of radiotherapy could be a new problem as it may not be related to the treatment, and should be discussed with your healthcare team.
Urinary side effects following treatment

As noted earlier, while uncommon, radiotherapy for prostate cancer may cause urinary stricture. Men who had brachytherapy (high dose rate) are at higher risk of a stricture. Problems caused by a stricture may include:

— a weak urinary stream
— hesitancy
— a feeling of incomplete emptying of your bladder
— spraying of urine when urinating
— urinary retention.

There are a range of things you can do to improve, and help you cope with, your urinary side effects.

Where can I find help?

It’s important for you to learn about the possible urinary side effects from prostate cancer treatment because occasionally they may require urgent medical attention. Please talk to members of your healthcare team for more information.

Possible urinary side effects that require immediate attention include:

— a urinary tract infection (symptoms include fever, pain, burning, stinging while urinating, pain into the kidney area, feeling unwell, smelly or cloudy urine)
— blood in the urine
— inability to urinate.

Your general practitioner

Your GP can help coordinate your care and provide you and your family with support and information to help you make informed choices about treatment. Your GP can help you and those close to you manage your physical and emotional health needs throughout the cancer journey, including help with managing your urinary problems.

Your healthcare team

Generally, there is a member of the healthcare team who will be your main contact person. This person might change during your cancer journey. If you’re unsure who this person is, ask one of the health professionals you’re seeing. Your contact person can talk with other health professionals on your behalf and can make sure all your health care needs are met.

The benefits to you in having a healthcare team include:

— improved communication, coordination and decision making between health professionals about your care
— improved treatment planning because all treatment types and options are considered by a range of health professionals
— improved coordination of services
— improved delivery of services
— improved quality of life.

When working with your healthcare team, you may see the following health professionals:

— **GP**: Your first port of call who can provide referrals to other specialists and who will monitor your health
— **Urologist**: A specialist in treating diseases of the urinary tract system and male reproductive organs
— **Radiation Oncologist**: A specialist in the treatment of cancer using radiation therapy
— **Medical Oncologist**: A specialist doctor who uses different drugs to treat cancer (such as chemotherapy)
— **Endocrinologist**: A doctor who specialises in hormones, body chemistry and bone density

*These health professionals also use hormone therapy, also known as androgen deprivation therapy (ADT), as part of their treatment.
Where can I find help?

— Pathologist: Conducts tests to assess the stage and aggressiveness of cancer
— Radiologist: A specialist doctor who examines scans, X-ray and other imaging results
— Nurse (also known as Urology or Prostate Care Nurse): Provides treatment, support and assistance through all treatment stages
— Cancer Nurse Coordinator: Guides you, your family and the person you are caring for through cancer treatments and liaises with other care providers
— Continence Nurse: Helps you manage any problems related to continence (urinary or bowel) care after treatment
— Pharmacist: Dispenses medications and offers medication advice
— Dietitian: Recommends the best eating plan while in treatment and recovery
— Physiotherapist: Specialises in movement and function of the body, advises on resuming normal physical activities
— Exercise Physiologist: Specialises in the benefits of exercises to help people get fitter for overall health or help people with a medical condition through exercise
— Occupational Therapist: Helps with the physical side of daily life by providing rehabilitation exercises
— Social Worker: Advises on support, practical and legal matters, and provides strategies to cope with emotional, social and spiritual challenges
— Psychologist, Psychiatrist or Counsellor: Provides strategies with decision making, problem solving, and dealing with psychosocial issues; including providing emotional and practical support, and managing anxiety and depression
— Palliative Care Specialist: Expert in pain and symptom control who works closely with the treatment team
— Sex Therapist: Helps with sexuality issues by identifying the level of sexual functioning available, and enhancing sexual and relationship functioning
— Fertility Counsellor: Specialises in helping people with fertility concerns and issues, and can advise on fertility preservation options before starting treatments.

Health professionals who can help to manage urinary problems

‘I needed more information on dedicated physiotherapy interventions to control incontinence.’

There are specialist healthcare professionals who can assist with urinary problems you may be experiencing.

It can be helpful for you to talk with your urologist about your urinary side effects from prostate cancer treatment. There are medical treatments, including surgery, to help manage continence (e.g. artificial urinary sphincters and male sling surgery).

Continence nurses and continence physiotherapists from your healthcare team can advise you on all matters to do with incontinence. Continence Nurse Advisors can be contacted through your healthcare team or Continence Foundation of Australia has listings of where to find your local advisor (www.continence.org.au).

Continence Nurse Advisors can assist with:
— pelvic floor exercise education
— toileting practices during recovery from treatment
— continence product assistance for managing symptoms
— assistance and education with self-help techniques
— financial assistance advice (you may qualify for local or federal funding schemes)
— information and resources
— homecare matters such as:
  o waste disposal, infection control measures such as use of disinfectant hand wash, bathing and hygiene in the home
  o advice on fittings and fixtures commodes, rails to assist in toileting and arranging a home care assessment. If you are eligible you may receive assistance with the cost of these home alterations.

Continence Physiotherapists can assist with:
— pelvic floor exercise education
— toileting practices during recovery from treatment, particularly correct posture
— assistance and education with self-help techniques
— development of individual pelvic floor and general exercise programmes.
Where can I find help?

**Questions you could ask**

Listed below are some questions you might want to ask members of your healthcare team about urinary problems following prostate cancer treatment:

— What can be done about my urinary problems?
What would you recommend?
— What are the alternatives to the approach that you’re recommending?
— What are things that I can do to improve urinary problems?
— What are the lifestyle changes I need to make to improve my urinary problems?
— Are there food, drinks or activities I should avoid? What are they? How do they make my urinary problem worse?
— If I chose medical treatment to manage my urinary problems, how quickly do they work? And are there any side effects?
— Who else could I see to help me with my urinary problems?

These are not the only questions to ask. There might be questions you have that are specific to your needs. The important thing to do is to always ask questions that can help you understand what can be done about your urinary problems so you, with support from your healthcare team, can make the best decision for you.

It can be helpful for you to talk with your urologist about your urinary side effects.
Looking after yourself

There are a range of things you can do to improve, and help you cope with, your urinary side effects. If you require assistance with any of these self-help measures, contact the health professionals or organisations listed in this section.

— **Continence products:** There are a range of continence products to help manage urinary incontinence. Pads are an effective first choice. Supermarkets and pharmacies stock ranges specifically designed for men. Pads are to be worn with firm-fitting underwear, not boxer shorts. Ensure you change pads regularly, keeping your skin clean and dry to avoid irritation.

‘There was a continence nurse who explained a lot of the things that were supplied like the incontinence aids… for the five years since I’ve had the operation, I’ve had to find what suits me by experimenting with the products that were available.’

Continence products can be costly. Continence or urology nurses can provide advice about continence products including information on possible financial assistance schemes to assist with costs. The Continence Aids Payment Scheme (CAPS) can provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).

**NOTE:** Ensure you have a continence pad with you for the day of your catheter removal following radical prostatectomy. It is quite common to experience urinary leakage at this stage.

— **Pelvic floor exercises:** These are essential and should ideally commence prior to and following prostate cancer treatment. The pelvic floor muscles help control your bladder and strengthening them using the correct technique is vital. If you are unsure of the technique or require further assistance, a continence physiotherapist, continence nurse or urology nurse can assist.

‘I found out about how to do pelvic floor muscles myself, and I found out all that sort of stuff… I did a lot of that work on my own.’

**NOTE:** Do not perform your pelvic floor exercises while you have a catheter in (e.g. following prostate cancer surgery).

— **Avoid constipation:** Eating a diet high in fibre such as wholegrain breads and cereal, fresh fruit and vegetables, and drinking 1.5 to 2 litres of water a day will help to prevent constipation. Constipation or hard stools cause you to strain and this can weaken your pelvic floor muscles. The pressure from a full bowel can cause bladder pain or discomfort. It can also affect the amount of urine your bladder can hold and require you to urinate more urgently or frequently.

— **Quit smoking:** Smoking can affect your bladder in two ways. It acts as an irritant to the bladder, and coughing can weaken the pelvic floor.

— **Avoid drinks or food that cause bladder irritation:** Caffeine (tea, coffee, cola drinks), alcohol, citrus juices, drinks with artificial sweeteners, citrus fruits, tomatoes and tomato-based products, spicy or acidic foods can cause bladder irritation. Water is the most beneficial drink that you can have. You may need to plan when to drink your fluids, for example, by cutting back fluids in the evening to prevent getting up at night.

— **Lose weight if required:** Excess body weight puts extra pressure on the bladder, which can increase urgency urinary symptoms.

— **Diabetes:** If you are diabetic, ensure your blood glucose levels are regulated. Urinary issues can be affected by unstable blood glucose levels.

— **Exercise:** This assists in maintaining a healthy weight as well as preventing constipation. Regular exercise helps you to sleep well, and is beneficial for your overall wellbeing.

— **Rest and relaxation:** Rest is as important as exercise, particularly in the early stages following or during treatment. Many men report their urinary side effects are worse at the end of the day when they are tired or fatigued. Regular periods of rest can prevent this.

— **Toilet maps:** These can be helpful in locating toilet facilities in unfamiliar areas or when planning outings. Maps are available at www.toiletmap.gov.au.

— **Prostate cancer support groups:** These groups are located all around Australia. Seeking support and advice from men who are in similar situations to you can be valuable in coping with urinary side effects.

**MANAGING THE COST OF TREATMENT**

The Australian Government subsidises the cost of listed prescription medicine to all residents and eligible overseas visitors through the Pharmaceutical Benefits Scheme (www.pbs.gov.au/info/about-the-pbs). Not everything relating to your cancer treatment may be covered by the scheme so check with your doctor when they prescribe a medication or refer you to a service. If you have private health insurance, check what your policy will cover so that you are prepared for any possible financial outlays.

Looking after yourself

WHERE TO GET MORE INFORMATION
Listed below are some of the leading organisations and services that can provide you with accurate information and support about urinary problems following prostate cancer treatment.

Prostate Cancer Foundation of Australia
Tel: (02) 9438 7000/1800 220 099 (freecall)
www.pcfa.org.au

Cancer Australia
www.canceraustralia.gov.au

Continence Foundation of Australia
Tel: (03) 9347 2522/1800 330 066
(free helpline staffed by continence nurse advisors)
www.continence.org.au

Australian Government Bladder and Bowel Website
www.bladderbowel.gov.au

Australian Physiotherapy Association
Tel: (03) 9534 9400
www.physiotherapy.asn.au

Cancer Council Helpline
Tel: 13 11 20

Urological Society of Australia and New Zealand
Tel: (02) 9362 8644 or www.usanz.org.au

FURTHER READING
— The Localised Prostate Cancer Pack is a resource for men affected by localised prostate cancer. It provides information on how localised prostate cancer is diagnosed, treatment options, managing side effects and wellbeing.

— The Advanced Prostate Cancer Pack is a resource for men affected by different stages of advanced cancer, including locally advanced disease. It provides information on how advanced prostate cancer is diagnosed, treatment options, managing side effects and wellbeing.


Other resources
For more information about prostate cancer and symptom management, PCFA has a number of resources. Please visit PCFA website www.pcfa.org.au or call: (02) 9438 7000/1800 220 099 (freecall).

Please note: If calling from overseas, the country code for Australia is +61
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abdomen</td>
<td>The part of the body that includes the stomach, intestine, liver, bladder and kidneys. The abdomen is located between the ribs and hips.</td>
</tr>
<tr>
<td>Adjuvant therapy or adjuvant treatment</td>
<td>Treatment given after the primary treatment to increase the chances of a cure. In cancer, adjuvant treatment often refers to chemotherapy, hormonal therapy or radiotherapy after surgery, which is aimed at killing any remaining cancer cells.</td>
</tr>
<tr>
<td>Advanced prostate cancer</td>
<td>Prostate cancer that has spread to surrounding tissue or has spread to other parts of the body.</td>
</tr>
<tr>
<td>Alternative therapy</td>
<td>Therapy used instead of standard medical treatment. Most alternative therapies have not been scientifically tested, so there is little proof that they work and their side effects are not always known.</td>
</tr>
<tr>
<td>Anaesthetic</td>
<td>A drug that stops a person feeling pain during a medical procedure. A local anaesthetic numbs only a part of the body; a general anaesthetic puts a person to sleep for a period of time.</td>
</tr>
<tr>
<td>Bladder</td>
<td>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.</td>
</tr>
<tr>
<td>Brachytherapy</td>
<td>A type of radiotherapy treatment that implants radioactive material sealed in needles or seeds into or near the tumour.</td>
</tr>
<tr>
<td>Cancer</td>
<td>A term for diseases in which abnormal cells divide without control.</td>
</tr>
<tr>
<td>Carer</td>
<td>A person who helps someone through an illness or disability such as cancer.</td>
</tr>
<tr>
<td>Catheter</td>
<td>A hollow, flexible tube through which fluids can be passed into the body or drained from it.</td>
</tr>
<tr>
<td>Cells</td>
<td>The building blocks of the body. A human is made of millions of cells, which are adapted for different functions. Cells can reproduce themselves exactly, unless they are abnormal or damaged, as are cancer cells.</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>The use of drugs, which kill or slow cell growth, to treat cancer. These are called cytotoxic drugs.</td>
</tr>
<tr>
<td>Clear Margin</td>
<td>When a malignant tumour is surgically removed some surrounding tissue will be removed with it. If this surrounding tissue does not contain any cancer cells it is said to be a clear margin.</td>
</tr>
<tr>
<td>Clinical trial</td>
<td>Research conducted with the person's permission, which usually involves a comparison of two or more treatments or diagnostic methods. The aim is to gain a better understanding of the underlying disease process and/or methods to treat it. A clinical trial is conducted with rigorous scientific method for determining the effectiveness of a proposed treatment.</td>
</tr>
<tr>
<td>Complementary therapy</td>
<td>Therapy used together with standard medical treatment. Examples include counselling, relaxation therapy, massage, acupuncture, yoga and meditation, aromatherapy, and art and music therapy.</td>
</tr>
<tr>
<td>Constipation</td>
<td>Inability to have regular bowel movements.</td>
</tr>
<tr>
<td>Cultural engagement</td>
<td>Actively involve people with respect to their cultural needs.</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>The identification and naming of a person's disease.</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Opening the bowels very frequently. Motions may be watery.</td>
</tr>
<tr>
<td>Dietitian</td>
<td>A health professional who specialises in human nutrition.</td>
</tr>
</tbody>
</table>
Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Erectile dysfunction</td>
<td>Inability to achieve or maintain an erection firm enough for penetration.</td>
</tr>
<tr>
<td>Erection</td>
<td>When the penis becomes enlarged and rigid.</td>
</tr>
<tr>
<td>External beam radiotherapy (EBRT)</td>
<td>Uses x-rays directed from an external machine to destroy cancer cells.</td>
</tr>
<tr>
<td>Fertility</td>
<td>Ability to have children.</td>
</tr>
<tr>
<td>General Practitioner (GP)</td>
<td>General practitioners diagnose, refer and treat the health problems of individuals and families in the community. Also commonly referred to as family doctors.</td>
</tr>
<tr>
<td>Grade</td>
<td>A score that describes how quickly the tumour is likely to grow.</td>
</tr>
<tr>
<td>Hormone</td>
<td>A substance that affects how your body works. Some hormones control growth, others control reproduction. They are distributed around the body through the bloodstream</td>
</tr>
<tr>
<td>Hormone therapy/treatment</td>
<td>Treatment with drugs that minimises the effect of testosterone in the body. This is also known as androgen deprivation therapy (ADT).</td>
</tr>
<tr>
<td>Incision</td>
<td>A cut into a body tissue or organ.</td>
</tr>
<tr>
<td>Impotence</td>
<td>See erectile dysfunction.</td>
</tr>
<tr>
<td>Incontinence</td>
<td>Inability to hold or control the loss of urine or faeces.</td>
</tr>
<tr>
<td>Intravenous</td>
<td>Into a vein. An intravenous drip gives drugs directly into a vein.</td>
</tr>
<tr>
<td>Localised prostate cancer</td>
<td>Prostate cancer that is at an early stage and is still contained within the prostate gland.</td>
</tr>
<tr>
<td>Locally advanced prostate cancer</td>
<td>Cancer which has spread beyond the prostate capsule and may include the seminal vesicles but still confined to the prostate region.</td>
</tr>
<tr>
<td>Lymph nodes</td>
<td>Also called lymph glands. Small, bean-shaped collections of lymph cells scattered across the lymphatic system. They get rid of bacteria and other harmful things. There are lymph nodes in the neck, armpit, groin and abdomen.</td>
</tr>
<tr>
<td>Malignant</td>
<td>Cancerous. Malignant cells can spread and can eventually cause death if they cannot be treated.</td>
</tr>
<tr>
<td>Metastatic prostate cancer</td>
<td>Small groups of cells have spread from the primary tumour site and started to grow in other parts of the body – such as bones.</td>
</tr>
<tr>
<td>Multidisciplinary team</td>
<td>A team approach to cancer treatment and planning.</td>
</tr>
<tr>
<td>Non-nerve-sparing radical prostatectomy</td>
<td>Nerve bundles on both sides of the prostate are removed during surgery to remove the prostate.</td>
</tr>
<tr>
<td>Palliative care</td>
<td>An approach that improves the quality of life of the person and their families facing problems associated with a life-threatening illness. Prevention and relief of suffering is provided through early identification and assessment and treatment of pain and other problems such as physical, psychosocial and spiritual.</td>
</tr>
<tr>
<td>Pathologist</td>
<td>A person who studies diseases to understand their nature and cause. Pathologists examine biopsies under a microscope to diagnose cancer and other diseases.</td>
</tr>
<tr>
<td>PBS</td>
<td>Pharmaceutical Benefits Scheme</td>
</tr>
<tr>
<td>Pelvic</td>
<td>The area located below the waist and surrounded by the hips and pubic bone.</td>
</tr>
</tbody>
</table>
# Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pelvic floor muscles</td>
<td>The floor of the pelvis is made up of muscle layers and tissues. The layers stretch like a hammock from the tailbone at the back to the pubic bone in front. The pelvic floor muscles support the bladder and bowel. The urethra (urine tube) and rectum (back passage) pass through the pelvic floor muscles.</td>
</tr>
<tr>
<td>Perineal (Perineum)</td>
<td>The area between the anus and the scrotum.</td>
</tr>
<tr>
<td>Penis</td>
<td>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).</td>
</tr>
<tr>
<td>Primary care</td>
<td>Primary Care is a sub-component of the broader primary health care system. Primary care is provided by a health care professional who is a client’s first point of entry into the health system (for example: a general practitioner, practice nurse, community nurse, or community based allied health worker). Primary care is practised widely in nursing and allied health, but predominately in general practice.</td>
</tr>
<tr>
<td>Prognosis</td>
<td>The likely outcome of a person’s disease.</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>Cancer of the prostate, the male organ that sits next to the urinary bladder and contributes to semen (sperm fluid) production.</td>
</tr>
<tr>
<td>Prostate gland</td>
<td>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.</td>
</tr>
<tr>
<td>Prostate specific antigen (PSA)</td>
<td>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.</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>Treatment that is intended to address psychological, social and some spiritual needs.</td>
</tr>
<tr>
<td>Quality of life</td>
<td>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.</td>
</tr>
<tr>
<td>Radical prostatectomy</td>
<td>A surgical operation that removes the prostate.</td>
</tr>
<tr>
<td>Radiotherapy or radiation oncology</td>
<td>The use of radiation, usually x-rays or gamma rays, to kill tumour cells or injure them so they cannot grow or multiply.</td>
</tr>
<tr>
<td>Self-management</td>
<td>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 wellbeing.</td>
</tr>
<tr>
<td>Shared decision making</td>
<td>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.</td>
</tr>
<tr>
<td>Side effect</td>
<td>Unintended effects of a drug or treatment.</td>
</tr>
<tr>
<td>Stage</td>
<td>The extent of a cancer and whether the disease has spread from an original site to other parts of the body.</td>
</tr>
<tr>
<td>Standard treatment</td>
<td>The best proven treatment, based on results of past research.</td>
</tr>
<tr>
<td>Support group</td>
<td>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.</td>
</tr>
</tbody>
</table>
## Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supportive care</td>
<td>Improving quality of life for people with cancer from different perspectives, including physical, social, emotional, financial and spiritual.</td>
</tr>
<tr>
<td>Surgeon</td>
<td>A doctor who performs surgery to remove cancerous tissue.</td>
</tr>
<tr>
<td>Surgery</td>
<td>Treatment that involves an operation. This may involve removal of tissue, change in the organisation of the anatomy or placement of prostheses.</td>
</tr>
<tr>
<td>Survivorship</td>
<td>In cancer, survivorship focuses on the health and life of a person with cancer beyond the diagnosis and treatment phases. Survivorship includes issues related to follow-up care, late effects of treatment, second cancers, and quality of life.</td>
</tr>
<tr>
<td>Testosterone</td>
<td>The major male hormone which is produced by the testicles.</td>
</tr>
<tr>
<td>Unilateral nerve-sparing radical prostatectomy</td>
<td>Nerve bundles on one side of the prostate are left intact during surgery to remove the prostate.</td>
</tr>
<tr>
<td>Therapy</td>
<td>Another word for treatment, and includes chemotherapy, radiotherapy, hormone therapy and surgery.</td>
</tr>
<tr>
<td>Urethra</td>
<td>The tube that carries urine from the bladder, and semen, out through the penis and to the outside of the body.</td>
</tr>
<tr>
<td>Urologist</td>
<td>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.</td>
</tr>
</tbody>
</table>
UNDERSTANDING URINARY PROBLEMS FOLLOWING PROSTATE CANCER TREATMENT

SOURCES


PCFA is a broad-based community organisation and the peak national body for prostate cancer in Australia. We are dedicated to reducing the impact of prostate cancer on Australian men, their partners, families and the wider community.

We do this by:

— Promoting and funding world leading, innovative research in prostate cancer

— Implementing awareness campaigns and education programs for the Australian community, health professionals and Government

— Supporting men and their families affected by prostate cancer, through evidence-based information and resources, support groups and Prostate Cancer Specialist Nurses.