UNDERSTANDING SEXUAL ISSUES 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 sexual issues and erectile dysfunction.

PCFA provides a range of resources to support men, partners and their families with prostate cancer and has an extensive support group network across Australia. 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: +61 2 9438 7000 or freecall 1800 22 00 99 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.

Copyright© 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

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 AM (Cancer Council Australia)
— Ms Carolyn Russell (Radiation Oncology Nurse Specialist)
— Mr David Sandoe OAM (PCFA)
— Ms Jennifer Siemsen (Prostate Cancer Specialist Nurse)
— 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

Photography:
Mr Gavin Jowitt
Welcome. We hope you find the following content informative and clear.
This book is for men who are about to receive or have received treatment for prostate cancer. It contains information to help you understand important issues about managing sexual issues after your treatment. It may also be helpful for your partner to read this booklet.

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 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 according to 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 to someone else’s.

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:
— what is normal male sexual function
— erectile dysfunction
— how prostate cancer and treatments can affect your sexual function
— medical treatments for erectile dysfunction
— looking after yourself – your lifestyle
— where to get further information and support.
To fully understand how your prostate cancer or prostate cancer treatment may affect you, it is helpful to know about normal male sexual function.

There are four stages of healthy male sexual performance:
1. sexual desire or libido
2. erectile function
3. orgasm and ejaculation
4. resolution and refractory period.

SEXUAL DESIRE OR LIBIDO
Sexual desire, libido and sex drive are all essentially a man’s desire for sex.

There are a number of factors that can affect sexual desire, both physical and emotional. These can include:
— stress
— anxiety or depression
— relationship problems
— erectile dysfunction
— premature ejaculation
— pain
— certain types of medication.

The hormone testosterone is produced mainly in the testes and is the main driver of sexual desire. When the testosterone levels drop, sex drive will diminish. Testosterone levels decrease with age or as a result of illness or treatment, and in particular after hormone therapy for prostate cancer. For more information about hormone therapy see page 13 – or refer to the PCFA booklet Understanding hormone therapy for prostate cancer (www.pcfa.org.au).

ERECTILE FUNCTION
There are two cylinders of spongy tissues that run either side of the penis (corpus cavernosum). The third cylinder (corpus spongiosum) runs along the underside of the penis and surrounds the urethra (urine tube).

CROSS SECTION OF A PENIS

During an erection, a man first becomes sexually aroused. The brain sends messages down the spinal cord and through nerves located near the prostate to tell the blood vessels to let more blood into the spongy cylinders. As these cylinders expand and fill with blood, an erection occurs.

NOTE: A failure of this process, for any reason, is referred to as erectile dysfunction (ED). In medical terms, ED is described as the inability to achieve or maintain an erection firm enough for sexual activity or penetration.

ORGASM AND EJACULATION
After continued sexual stimulation, men usually experience orgasm. Sexual pleasure peaks, accompanied by rhythmic pelvic muscle contractions followed by ejaculation of semen. Semen is then pushed through the urethra and out of the end of the penis.

The muscle or valve at the opening of the bladder closes during ejaculation to stop the backflow of semen into the bladder. This valve also stops urine and semen passing down the urethra at the same time.

Note: Before ejaculation, sperm is mixed with fluid from the seminal vesicles and the prostate. Sperm and seminal fluid together make semen.

RESOLUTION AND REFRACTORY PERIOD
After orgasm and ejaculation the erection subsides. The man then enters a recovery period, during which another erection or orgasm is not possible for a period of time. This resting time becomes longer with age. A young man may be able to regain an erection within several minutes whereas for an older man this time period may range from hours to days.
Erectile dysfunction – important information

Prostate cancer treatments can affect various aspects of your sexual function, but the most significant is your ability to have an erection. While your prostate doesn’t directly contribute to your ability to have an erection, it is surrounded by the bundles of nerves and blood vessels that are important to erections.

Erectile dysfunction (ED) is relatively common. Approximately one third of males over the age of 40 experience some degree of ED, with problems increasing with age.

ED can be associated with:
- medical conditions – diabetes, cardiovascular disease or high blood pressure
- lifestyle factors – smoking, excessive alcohol, obesity, or limited exercise
- psychological or emotional issues – stress, anxiety or depression.

ED is also a common side effect of prostate cancer treatments:
- All treatment options for prostate cancer can cause a reduction in erectile function.
- Advanced prostate cancer can destroy the ability to have erections.

Your age and whether or not you are having regular sex before treatment can affect how well your erectile function returns afterwards. For example, younger men having regular sexual activity before treatment are more likely to recover their erections compared to older men who are already experiencing erection problems and who have only occasional sexual activity. If you are already experiencing erection problems related to another factor such as cardiovascular disease, you are likely to experience a further reduction in erectile function or no erectile function following treatment.
How prostate cancer and treatments can affect your sexual function

All prostate cancer treatments, including surgery, radiation therapy and hormone therapy can affect your sexual function in a variety of ways.

In advanced prostate cancer, the cancer itself can also cause erectile dysfunction by invading the bundles of nerves that lie close to the prostate.

The following section will discuss the commonly used treatments for prostate cancer and how they can affect erectile function.

PROSTATE CANCER SURGERY – RADICAL PROSTATECTOMY

Surgery involves the removal of the entire prostate gland (the operation is called a radical prostatectomy). This treatment option is generally offered to men with localised prostate cancer and, in some instances, to men with locally advanced prostate cancer. The side effects relate to physical changes to that area of your body after the prostate gland has been removed. Learning about the possible side effects from surgery is particularly important because some side effects can be permanent. When your prostate gland is removed with a radical prostatectomy (open, laparoscopic or robotic), a number of things occur during the surgical procedure that can impact on your sexual function:

— Changes during orgasm: The removal of the prostate can cause changes during orgasm.

What to expect:

Your entire prostate gland is removed along with the seminal vesicles. It is important to understand that after surgery you will have a ‘dry’ orgasm because semen is no longer produced. There is no ejaculate during orgasm but you will still feel the muscular spasms and pleasure that produce the orgasm. The lack of semen and sperm means that you will not be able to conceive children naturally in the future (see below).

Other changes could include the following:

— Painful orgasm: Pain is felt during orgasm but little is known about its cause. This usually settles after a few orgasms.
— Leaking urine on orgasm: There may be some involuntary release of urine during orgasm.

Men report different experiences with dry orgasm; some describe a more intense orgasm while others feel orgasm is not as pleasurable. Pain may be experienced in the short term but this generally improves as healing to the area occurs.

NOTE: Infertility occurs in all men after radical prostatectomy. If you plan to have children following treatment, discuss this with your healthcare team. If fertility is important to you, you could ask to be referred to a service that provides fertility-preserving options such as sperm banking (having some of your sperm stored) before you start treatment. That way, fathering a child using your stored sperm may be possible in the future.

Tips:

— Speak with a continence nurse or physiotherapist as they can offer you techniques to improve any problems you may have.
— Empty your bladder before intercourse or use condoms if you leak urine during orgasm.
— Talk with a health professional such as a psychologist or sex therapist/counsellor who can give you strategies to help you manage your feelings about, and reduce the impact of, any changes during orgasm.

— Erectile dysfunction: It is likely you will have some difficulties getting and maintaining an erection after the surgery. How long this will last depends on a number of factors such as whether the erectile nerves were preserved at the time of surgery. The nerves that enable you to have an erection are on either side of the prostate.

What to expect:

If cancer has not grown near the nerves, a nerve-sparing operation may be able to be performed when removing the prostate. This means the chance of you regaining the ability to have an erection naturally is increased. If these nerves are permanently damaged or removed, erectile difficulties may be ongoing. It is important that you know what treatments are available that can help. Members of your healthcare team can provide you with information appropriate to your needs.

Tips:

— Medications – Some medications in tablet and injectable form can be prescribed to manage erectile difficulties. These medicines do have some side effects, and may not suit everyone. Tablet medications will only work if you have had nerve sparing surgery, but the injections can work even if the nerve has not been spared.
— Implants/devices – If you don’t want to use medications, devices that draw blood into the penis (e.g. vacuum erection device) or the use of penile implants (e.g. flexible rods or inflatable tubes) could be ways of getting an erection.
— Think about other ways that you could enjoy sex without penetration (e.g. oral sex, kissing, masturbation or mutual masturbation). Many men can still achieve orgasm without a full erection.
— Talk with your sexual partner(s) about what feels good for you and ask what feels good for them.
— Talk to your treating healthcare team about being referred to a professional (e.g. psychologist, sex therapist) or service that specialises in sexuality matters.

— Change in penis size: A possible side effect of surgery is a reduced length and width of the penis, while erect and/or flaccid/soft.

‘A side effect, if you have a radical prostatectomy, is the size of your penis [can] shrink and that’s not a side effect that anybody talks about.’
How prostate cancer and treatments can affect your sexual function

What to expect:
Many men report penile shortening and shrinkage following surgery. It is thought there are a number of factors that may contribute to this, including scar tissue formation, reconnecting of the urethra to the bladder, and damage or interruption to the blood supply of the nerves. The reasons for penile shortening and shrinkage are not yet fully understood.

Tips:
— Talk with a health professional such as a psychologist or sex therapist/counsellor who can give you strategies to help you manage your feelings about changes to the appearance of your penis, if this does occur.
— Incontinence: The removal of the prostate gland may affect your ability to control the flow of urine from the bladder. This is because the urethra (the tube that urine passes through as it leaves the bladder) runs through the prostate gland. The mechanisms for urinary control (the bladder neck and the urinary sphincter) are located very close to the prostate and can be affected during the surgery.

What to expect:
Many men experience some degree of urinary incontinence in the short term following surgery. This usually resolves over time. When the urinary sphincter is affected, people can experience stress urinary incontinence – losing control of the bladder during physical activities (e.g. exercising) or strain (e.g. coughing, sneezing). All men will have a temporary urinary catheter for a short period after surgery. This is a thin, soft plastic tube that runs from inside the bladder to a bag outside of your body to collect the urine. Men normally need a catheter for a week after surgery, but sometimes up to three weeks. After the catheter is removed, it is not unusual to have some mild urinary incontinence. Improvement can occur quickly, but if you are still troubled after 6 months, then further treatments can help. Talk to members of your healthcare team who are supporting you if you are concerned.

INTERNAL AND EXTERNAL URINARY SPHINCTERS

A) Full bladder

B) Emptying bladder
How prostate cancer and treatments can affect your sexual function

Tips:
— Talk to a continence nurse who can offer suggestions about the best continence products for your needs. The Continence Aids Payment Scheme (CAPS) may provide financial assistance for continence products (see www.bladderbowel.gov.au/caps/capsfaq.htm).
— Talk with a continence nurse or physiotherapist for information on pelvic floor muscles training. Pelvic floor muscles are important for continence control (see www.bladderbowel.gov.au/adults/pelvicmen.htm), and are best learned and started before surgery, and continued afterwards.

You can obtain more information about surgery from the Understanding surgery for prostate cancer resource available from PCFA (www.pcfa.org.au).

OTHER SURGERY: TURP (TRANSURETHRAL RESECTION OF THE PROSTATE)
TURP surgery involves cutting away some of the tissue from inside the prostate while leaving the outside of the gland in place. This type of surgery is sometimes used to control urinary symptoms in men with advanced prostate cancer. A side effect is ‘retrograde ejaculation’, when semen is forced back into the bladder during ejaculation due to damage to the internal sphincter muscle (valve) located near the prostate. The valve cannot close shut, so semen flows back into the bladder. It is then passed out with urine the next time you go to the toilet; potentially giving your urine a cloudy appearance. This is a harmless effect which occurs in most men having this type of surgery.

RADIATION THERAPY (EXTERNAL BEAM RADIATION TREATMENT OR EBRT)
EBRT uses high energy x-ray beams that are directed at the prostate from the outside. Generally people are having this treatment in a hospital setting daily, Monday to Friday, for 7-8 weeks. During your EBRT treatment, you can continue to do what you would normally if you’re able; however, the multiple hospital visits and side effects associated with treatment may interfere with some day-to-day activities.

What to expect:
— Inflammation to the surrounding areas can cause pain. A small leakage of urine on ejaculation can occur. This is generally a short term side effect and improves as inflammation settles.
— Due to damage to the prostate cells that produce ejaculation fluid, you can notice a decreased amount of fluid or dry ejaculation.
— Unlike surgery, radiation therapy doesn’t usually have immediate effects on erectile function. Erectile problems typically occur in the longer term, commencing six months after treatment and progressing over the following years. Ageing and progressive damage to the blood vessels and nerves to the penis contribute to this.
— Radiotherapy will not affect your libido directly but the whole process may mean that you do not feel like having sex during the weeks of, or after, the treatment. There is no reason to avoid sex if you feel ready.
— If you wish to have children in the future, you will need to discuss alternatives such as having some of your sperm stored before treatment starts (this is called sperm banking). You can ask to speak with a fertility counsellor or be referred to a service that specialises in fertility issues.
— Hormone therapy is often used in conjunction with radiation therapy treatment, which can increase the impact on erectile function as well as libido.

BRACHYTHERAPY
Low dose rate (LDR): 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. LDR brachytherapy is generally a treatment for men with localised prostate cancer.

Note: There is a very small chance of passing a radioactive seed during sexual activity. A condom is recommended for use for the first two months after implantation. If your partner is pregnant, use condoms for the whole pregnancy as a precaution.

What to expect:
— Placement requires surgery that may take a few hours. You may have the treatment as a ‘day-only patient’ or have an overnight stay.
— Your semen may be discoloured or blood-stained for the first few weeks after placement, due to the bruising or bleeding from the prostate caused by treatment. This usually resolves with time.
— You may have pain on ejaculation as the prostate contracts with orgasm. This is a short term side effect.

High dose rate (HDR): is 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. The procedure takes place at a hospital but may require a longer stay than LDR brachytherapy. HDR brachytherapy is generally a treatment option for men with intermediate risk or locally advanced prostate cancer, and is often given in conjunction with EBRT.

What to expect:
— The side effects of high dose rate brachytherapy are similar to those of low dose rate brachytherapy.
— Often men have hormone (androgen deprivation) therapy or external beam radiation therapy in conjunction with high dose rate brachytherapy. Side effects from these treatments on sexual function may also be experienced.

You can obtain more information about brachytherapy from the Understanding brachytherapy for prostate cancer resource available from PCFA (www.pcfa.org.au).
How prostate cancer and treatments can affect your sexual function

HORMONE THERAPY

'I'd been used to waking up every morning virtually all of my life with an erection and basically as soon as I started the hormone treatment that ceased. I'm not saying I had intercourse or anything every day of my life, but it was just something that was part of me and I found that difficult.'

Prostate cancer is driven by hormones. By reducing these 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).

There is also a surgical hormone treatment called orchidectomy, in which the testicles are surgically removed. The testicles are responsible for a high percentage of testosterone production, so removing them starves the prostate cancer cells of testosterone.

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

What to expect:

Hormone therapy side effects can be difficult to predict. It is important that you tell your healthcare team about the side effects you’re having as they may be able to offer you ways to manage them (e.g. medications, techniques).

— Lowering testosterone levels may cause a reduction in sex drive and erectile difficulties.

Tips:

— Work with a health professional (e.g. psychologist, sex therapist) who specialises in sexuality matters.
— Explore ways of being intimate with your partner that are not related to sex.
— Erectile dysfunction (ED) is the inability to achieve or maintain an erection firm enough for penetration. ED can be variable, with some men still able to achieve erections but not for long periods or with the ability to reach orgasm.
Infertility

All treatments for prostate cancer can affect your fertility. Discuss with your healthcare team how your treatment will affect your fertility. Even if you aren’t thinking about fertility now, having children or more children may be something you want to do later. If your doctor doesn’t raise fertility issues, you can ask your doctor or a member of your healthcare team for information about what can be done before commencing treatment, depending on your situation.

Tips:
— If fertility is important to you, you could ask to be referred to a service that provides fertility-preserving options such as sperm-banking before you start treatment. That way, fathering a child using your stored sperm may be possible in the future.
— Talk to a health professional (e.g. sex therapist, fertility counsellor) about changes to your fertility and ways of managing these changes.

Treatments for erectile dysfunction

There is a range of treatments for erectile dysfunction (ED). It is very important that you discuss your options with your healthcare team. Some types of treatments for ED can affect other medications you may be taking or have effects on other medical conditions you may have. Your healthcare team will be able to advise and assist you.

Your options involve taking medications or using devices to help your erectile function. These may be offered to you individually or as a combination, for example penile injections combined with a penile ring. Your healthcare team will plan this with you based on a range of factors including the prostate cancer treatment you received, what your previous erectile function was, what your expectations are, and when you would like to resume sexual activity following treatment.

MEDICATIONS

Tablet medication: The first treatment option offered is usually a group of medications known as PDE5 inhibitors. These medications allow you to achieve an erection by causing greater blood flow to the penis following sexual stimulation or sexual arousal. How quickly the medication works and how long it lasts will depend on your individual situation and which of the medications you are taking. The medication may not work the first few times it is used, and it is recommended you trial the medication several times at the right dose before deciding on the success of this treatment option.

NOTE: You should not take PDE5 inhibitors if you are also taking medications in the nitrates group, which are used for chest pain or prevention of chest pain. These nitrates can be given as tablets, sprays or patches. Discuss your medical conditions and current medications with your doctor.

Erectile dysfunction PDE5 inhibitor medications must only be used with a doctor’s prescription and under medical supervision.

Penile injection medication: Penile injections are often used and are an effective option for men with ED following prostate cancer treatment.

These medications are injected into the penis when you require an erection. They work by allowing the blood vessels in the penis to open up; enabling more blood to flow in, while stopping blood from draining away. Penile injection therapy does not require you to be sexually stimulated first. Erections can occur in up to 10 minutes and generally last for up to 30-60 minutes.

You can be taught to inject yourself; however, the technique does require practice and it is recommended that you are trained by a healthcare team member who specialises in this area. Achieving the correct dose of the medication that works for you and having the correct injection technique is critical to the effectiveness of this option.

NOTE: Erectile dysfunction medications can have side effects. Please refer to the prescription information and notify your healthcare team of any side effects you may experience.
Treatments for erectile dysfunction

DEVICES

Penile rings: These can be used on their own if you can achieve an erection but can’t maintain it long enough for penetration. The rings are made of rubber and are placed onto the base of your penis close to your pubic bone. They enable you to maintain the erection by preventing blood from flowing away out of the penis. You should remove the ring after 30 minutes as there is a risk of damage to the penis if it’s left on for longer periods of time.

Vacuum erection device: This can be used if you are unable to achieve or sustain an erection. It is a clear plastic tube that is placed over the penis and then sealed off. A vacuum is created by a pump-like action which draws blood into the penis and creates an erection. You then place a penile ring around the base of the penis near the pubic bone to sustain the erection.

Healthcare team members who specialise in erectile dysfunction can advise you where to purchase these devices and how to use them correctly and safely. Perfecting the technique can take some time, practice and patience.

Surgical devices (Penile Implants/Prosthesis): A penile prosthesis is generally offered when other options have not been successful. This more invasive option involves surgery during which a prosthesis is implanted within the penis to create what is known as a “mechanical erection”. The spongy tissue that runs along each side of the penis is removed and the prosthesis placed there. Healthcare team members who specialise in erectile dysfunction can provide you with further information on the range of different prostheses available and their suitability to your individual situation.

PENILE REHABILITATION – FOLLOWING RADICAL PROSTATECTOMY

There is emerging evidence that undergoing a program called ‘penile rehabilitation’ following radical prostatectomy can help erectile function to return more quickly.

Penile rehabilitation programs aim to encourage blood flow to the spongy cylinders that run each side of the penis and improve oxygen supply to the tissues of the penis. This prevents permanent damage to the tissues and potentially speeds the return of erectile function following treatment.

Programs for penile rehabilitation can include:

— the use of tablet medications (PDE5 inhibitors) either before or after treatment
— penile injection medication
— vacuum erection devices
or
— different combinations of the above.

The program will consist of a plan to achieve a certain number of “artificial erections” per week following treatment. An artificial erection is an erection obtained not for the purpose of intercourse. Recent research suggests improved results are achieved if a rehabilitation program is undertaken in the early stages following surgery.

Like all treatment plans, a penile rehabilitation program will be based on you and your partner’s individual needs and situation. Discuss with your partner and healthcare team before treatment about whether a penile rehabilitation program is an option for you. A referral to a specialist in this area may be arranged for you through your healthcare team.
Looking after yourself

YOUR EMOTIONS
Sex is often thought of as a physical activity, whereas sexuality is more about how you see yourself and feel about yourself in a sexual way.

As a man, the physical side effects of treatment can be a challenge for you in a variety of ways. You may feel that your masculinity, self-identity and sense of sexuality change due to the physical loss of erections and sexual desire. You might not be feeling your best emotionally as you try to cope with your cancer diagnosis, or you may be dealing with fatigue or low mood as a result of treatment. This can all affect your wellbeing, feelings of self-worth, and your relationships.

For some men, coping with these emotions can be extremely challenging. If you or your partner feels that either of you are not coping, discuss this with your healthcare team or seek support from the support services listed at the end of this booklet.

YOUR RELATIONSHIPS
Your sexual relationships are individual and private. Some men with prostate cancer are in a committed long term relationship, while others are embarking on a new relationship. Whatever your situation, both you and your partner need to discuss what is important to each of you.

Thinking and talking about what your normal sex life is and how your treatment may affect this is a good place to start. For some, sexual activity isn’t important, while for others the ability to have an erection is very important.

It is recommended that you both acknowledge that, whichever treatment option you choose, there will be side effects impacting your sexual function and your sex life.

It is vital for you both to discuss your expectations following treatment, as sexual problems will affect both of you. Involving your partner can be part of the solution to coping with these challenges.

Discussing your sex life with your healthcare team can be difficult, but it is important you are informed before treatment.

Medical help for erectile dysfunction can achieve improved results if commenced early following treatment. If this is important to you, begin planning with your healthcare team before treatment.

You will need to discuss with your healthcare team when it is safe for you to recommence sexual activity based on your individual situation.

Prostate cancer support 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 side effects.

YOUR LIFESTYLE
There is a range of things you can do that may assist in improving your erectile dysfunction (ED). However please speak to your healthcare team members before making any lifestyle changes as they may affect your individual situation. The healthcare team can assist if you require any advice on changes you may wish to make.

Lifestyle changes can have a positive effect on a range of side effects (not just your ED) you may experience throughout your cancer journey.

— Quit smoking: smoking has a harmful effect on blood circulation; good erectile function requires good circulation.

— Eat a healthy, balanced diet: this can assist in lowering cholesterol; high cholesterol can block arteries and reduce the good circulation and blood flow required to achieve erections.

— Exercise: regular exercise has many benefits including assisting with maintaining a healthy body weight, prevention of fatigue and assisting in overall wellbeing and mood.

— Cut down on alcohol: long term heavy drinking can affect erections due to damaged nerves, liver damage and hormone imbalances. Plan to drink responsibly (no more than two standard drinks on any day). For more information visit the website: www.alcohol.gov.au.
UNDERSTANDING SEXUAL ISSUES FOLLOWING PROSTATE CANCER TREATMENT

Questions you could ask

Listed below are some questions you may want to ask your doctor or members of your healthcare team.

— How will my treatment affect my sex life?
— How will my treatment affect my fertility?
— What should I do if I would like to plan a family following treatment?
— What can I do before treatment to assist with the side effects?
— What can be done after treatment to treat any side effects on my sex life?
— Are there other men I can speak to about their experience with prostate cancer?

Where can I get support and information?

YOUR GENERAL PRACTITIONER (GP)
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 sexual issues. Your GP can make a referral to a psychologist, nurse, social worker, sexual health counsellor, physiotherapist, or specialist psychosexual service which can advise and assist you.

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 will necessarily 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.

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

ORGANISATIONS AND SERVICES
Listed below are some of the leading organisations and services that can provide you with accurate information and support about issues following prostate cancer treatment.

— Prostate Cancer Foundation of Australia: providing information, resources and a list of support groups across Australia. Tel: (02) 9438 7000/1800 220 099 (freecall) www.pcfa.org.au
— Cancer Australia: providing national leadership in cancer control and improving outcomes for Australians affected by cancer. www.canceraustralia.gov.au
— Cancer Council Helpline: providing practical and emotional support, financial and legal assistance, information services and more. Tel: 13 11 20
— Impotence Australia: providing information about impotence, treatments and accessing support. Tel: (02) 9280 0084/1800 800 614 (freecall) E: admin@impotenceaustralia.com.au www.impotenceaustralia.com.au
— Andrology Australia: providing information about prostate cancer and male reproductive health. Tel: 1300 303 878 E: info@andrologyaustralia.org www.andrologyaustralia.org
Where can I get support and information?

- **Australian Government Bladder and Bowel Website:** information to assist with the prevention and management of bladder and bowel problems.  
  www.bladderbowel.gov.au

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

- **Australian Physiotherapy Association:** peak body representing the interests of Australian physiotherapists and their patients.  
  Tel: +61 (03) 9534 9400  
  www.physiotherapy.asn.au

- **Urological Society of Australia and New Zealand:** peak professional body for urological surgeons in Australia & New Zealand.  
  Tel: (02) 9362 8644  
  www.usanz.org.au

- **Fertility Society of Australia:** providing information about fertility issues and accessing services.  
  Tel: (03) 3645 6359  
  www.fertilitysociety.com.au

- **Beyondblue:** The National Depression Initiative – providing information about, and support for, anxiety and depression.  
  Tel: 1300 224 636  
  www.beyondblue.org.au

- **Black Dog Institute:** providing treatment and support for mood disorders such as depression.  
  Tel: (02) 9382 4523  
  Email: blackdog@blackdog.org.au  
  www.blackdoginstitute.org.au

- **Talk It Over:** Men’s Line Australia – providing professional telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way.  
  Tel: 1300 789 978  
  www.menslineaus.org.au

- **Relationships Australia:** providing relationship support services for individuals, families and communities.  
  Tel: 1300 364 277  
  www.relationships.org.au

- **Lifeline Australia:** providing all Australians experiencing a personal crisis with access to 24 hour crisis support and suicide prevention services.  
  Tel: 13 11 14 (24 hour service)

- **Society of Australian Sexologists:** representing health and allied health professionals working in the area of sex therapy and sexual health/sexology.  
  www.assertnational.org.au

**FURTHER READING**

- **Localised prostate cancer information pack:** Prostate Cancer Foundation of Australia. (2013). (You can get a free copy of this pack by contacting PCFA – Tel: (02) 9438 7000/1800 220 099 (free call) Email: enquiries@pcfa.org.au  
  Website: www.pcfa.org.au

- **Advanced prostate cancer information pack:** Prostate Cancer Foundation of Australia. (2014). (You can get a free copy of this pack by contacting PCFA – Tel: (02) 9438 7000/1800 220 099 (free call) Email: enquiries@pcfa.org.au www.pcfa.org.au


**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 (free call).

**Please note:** If calling from overseas, the country code for Australia is +61.
<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>Description</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>
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.