

# C

Care and Support  
Post-Treatment  
for prostate  
cancer



SECTION 1:

# PROSTATE CANCER SUPPORT

Prostate cancer affects more than your physical health, it also takes a toll on your emotional well-being. Support, communication, and understanding are all very important at this time in your life. Your family and friends may be struggling too. They may be unsure of how to deal with their own feelings and concerns.

The information in this section is intended to help both you and your loved ones cope with prostate cancer.

## Communication

The prostate cancer diagnosis is just the beginning of the process; you will soon be undertaking many medical tests and decisions. Now, more than ever, you need the support of family and friends.

Resist the temptation to shut people out. Talk about your feelings, fears, and any anxieties. Bottling up these emotions can put extra stress on your body.



Feelings of anger, depression, confusion, and betrayal are all perfectly normal. Working through them with another person or network of support can ease the process.

It's also essential to educate yourself and stay updated on your condition and treatment options. The pamphlet **Basics on Treatment** includes helpful information. The more you know, the more confident you will feel to make the right decisions about your health and future.

## Emotional Support

Being diagnosed with prostate cancer may feel lonely. Try to remember that you don't have to deal with everything on your own. In fact, your friends and family may feel isolated as well if they are not included in parts of the process.

There are many support options available to you.

- Family and friends
- Church and spiritual groups
- Prostate cancer support groups and online support communities. Learning from someone else's experiences can provide valuable insight into how to deal with your own.

- Your doctor and specialist(s). If you feel you need additional advice or information, do not be afraid to request it.
- Private counselling through a psychologist or social worker. Your doctor can arrange an appointment.

Go with whatever makes you feel comfortable and remember that managing your emotional health is an important part of dealing with the disease.



## A Network of Support at Your Fingertips

The Prostate Cancer Canada Network (PCCN) is a national association of prostate cancer support groups that has been serving Canadian men and their families for over 15 years. The PCCN works to:

- Help men and their families understand and cope with a prostate cancer diagnosis.
- Provide up-to-date information and individual peer-to-peer support.
- Provide opportunities for men and their loved ones to share their experiences and personal stories.

- Promote the importance of early detection through local public awareness campaigns.
- Distribute information to prostate cancer groups across the country interested in learning more about the disease.
- Assist men in making informed decisions.
- Advocate for increased funding for prostate cancer research, treatment and programs.

## About PCCN Support Groups

The PCCN is made up of affiliated prostate cancer support groups across Canada although each group operates independently.

The support groups provide services at a grassroots level through monthly peer meetings, special educational events, outreach programs, and presentations at community events.

Group members and leaders do not give medical advice but freely share their own stories. They participate in discussions guided by medical experts, and share information about treatment options and advances. It is important to keep in mind that every person and every cancer is unique. Information obtained through other group members is useful as a guide but may not directly apply to you.

Most PCCN support groups meet monthly. Partners and family members are welcome at general meetings, but some groups choose to hold separate meetings for their loved ones. These groups encourage opportunities for sharing personal feelings and experiences, as well as dealing with burnout and other related issues as they cope with their loved one's disease.

Wherever you live in Canada, we welcome you to join our network of people living with prostate cancer. To find a support group near you, or sign up for a newsletter, visit [prostatecancer.ca](http://prostatecancer.ca) or call 1-888-255-0333.

### Planning for the Future

To know the options you have for treating and managing your disease, look into your health insurance plan(s) and make sure you understand them and the fine print.

Depending on the stage of your cancer, you may wish to talk to your healthcare team about preplanned healthcare directives (the type of medical treatment you want in the future if you are unable to express your wishes) and appointing a power of attorney (someone who can act on your behalf in legal or financial matters). Please visit the Canadian Virtual Hospice website [virtualhospice.ca](http://virtualhospice.ca) for further information.



### For Family, Friends, and Caregivers

Serious illness of any kind doesn't just affect the person who has been diagnosed; it impacts the people closest to them as well. The following section includes helpful advice on coping with a loved one's prostate cancer diagnosis.

#### Communicate

Communicating openly with your friend or family member lets them know that you are there for them. There may be times when they're not ready to discuss how they feel; it is important to be patient and supportive during this time.

The best approach is to be ready and willing to lend an ear when he needs you, and to respect his privacy. Trust your gut feeling on when to bring up sensitive subjects like infertility, incontinence, and impotence. It may be helpful for you, as the caregiver or friend, to attend support group meetings with the person diagnosed. Hearing stories of others who have been through a similar experience can be informative and comforting, and may ease some of your own anxieties about the disease.

#### Stay Involved

You may feel helpless when a loved one is diagnosed with prostate cancer, but there are many things you can do to make things easier for them. Offer a ride to appointments, to be a second pair of ears in meetings with doctors or to keep track of medical appointments and examinations. Staying involved can reaffirm your commitment to being there for your loved one.

#### Educate Yourself

You will be in a better position to offer support when you have an understanding of the diagnosis and what the person you love is dealing with. Ask questions and educate yourself.



Serious illness of any kind doesn't just affect the person who has been diagnosed; it impacts the people closest to them as well.



SECTION 2:

# MANAGING TREATMENT SIDE-EFFECTS

Most treatments for prostate cancer can cause both short-term and long-term side effects. There are four main categories of side-effects:

- Trouble with urination
- Bowel problems
- Side-effects of hormone therapy
- Problems related to sexual function

The following section will outline what to expect with these side-effects, and how they may be managed or treated.

### Urinary Difficulties

Incontinence is the loss of the ability to control urination. Any treatment that removes the prostate or destroys prostate tissue can affect urination. This is because the prostate is close to the bladder and it surrounds the tube that allows urine to flow outside the body (the urethra).

Urinary incontinence is a relatively common side-effect of radical prostatectomy. It is usually temporary (lasting a few weeks to a few months) but in



a small number of men, incontinence may be permanent. Leakage of urine may occur without warning, or only with heavy lifting or sudden physical movement e.g. sneezing. Other urinary difficulties may occur with radiation therapy e.g. frequent urination, burning and pain, blood in the urine or an intense urge to urinate.

## Management of Urinary Difficulties

### Lifestyle Changes

Drinking fewer liquids, avoiding caffeine and alcohol, not drinking before bed, and losing weight can help relieve some of the urinary symptoms.

### Kegel (Pelvic Floor) Exercises

Doing these exercises can strengthen the muscles you squeeze to stop urinating, which can lessen incontinence.



### Medication

Some medications such as anticholinergic drugs (e.g. oxybutynin), can reduce bladder irritability and decrease bladder spasms. This, in turn, may relieve urinary urgency and frequency and some forms of incontinence.

Some men have trouble urinating because of a blockage in the urethra. These individuals have a very full bladder at all times, which may result in “overflow incontinence” – where the bladder can no longer hold any additional urine. These men may benefit from medications that improve bladder emptying.

### Surgery

If lifestyle changes and medication do not improve urinary difficulties, surgery may be of benefit. There are several different surgical options:

- **Eliminating Blockage in the Urethra**

Sometimes scar tissue can build up in the urethra and cause it to narrow, restricting urine flow and making it difficult to empty the bladder fully. This can be repaired by cutting into the scar tissue or by stretching the urethra.

- **Urethral Sling Procedure**

A surgically implanted sling compresses the urethra below the sphincter (the muscles used to control the flow of urine from the bladder).

- **Artificial Urinary Sphincter Implant**

A cuff is placed around the urethra to compress it. The cuff is inflated or deflated with a mechanical valve.

- **Bulking Agents**

Substances such as collagen can be injected into the bladder neck to reduce urinary leakage, although this is not very effective in men.

## Bowel Side-Effects

Radiation therapy to the prostate also affects the wall of the rectum and can cause bowel inflammation, urgency to go to the toilet, diarrhea, cramps, blood in the stool and faecal incontinence (loss of regular control of the bowels). This is normally temporary but may be permanent in rare cases.

Treatment may include dietary changes, medication, bowel training, local remedies such as steroid suppositories, and in rare cases, surgery. New imaging techniques and more precise methods of delivering radiation have reduced the risk of these complications.

Radical prostatectomy surgery has a very small risk (about one in 1000 cases) of injury to the rectum. A temporary colostomy (an opening in the abdomen for bowel movements to come through into a bag) may be necessary. This arrangement is most commonly temporary, until the rectal injury site is healed.

Some medications such as hormone therapy may cause nausea, diarrhea and general gastrointestinal upset.

## Hormone Therapy Side-Effects

Hormone therapy can cause a wide variety of side-effects including hot flashes, fatigue, weight gain, loss of muscle or bone mass, erection difficulties, loss of sex drive and lower blood counts.

## Treatment and Management of Hormone Therapy Side-Effects

### Hot Flashes

These can be controlled with medication or by making dietary and lifestyle changes.

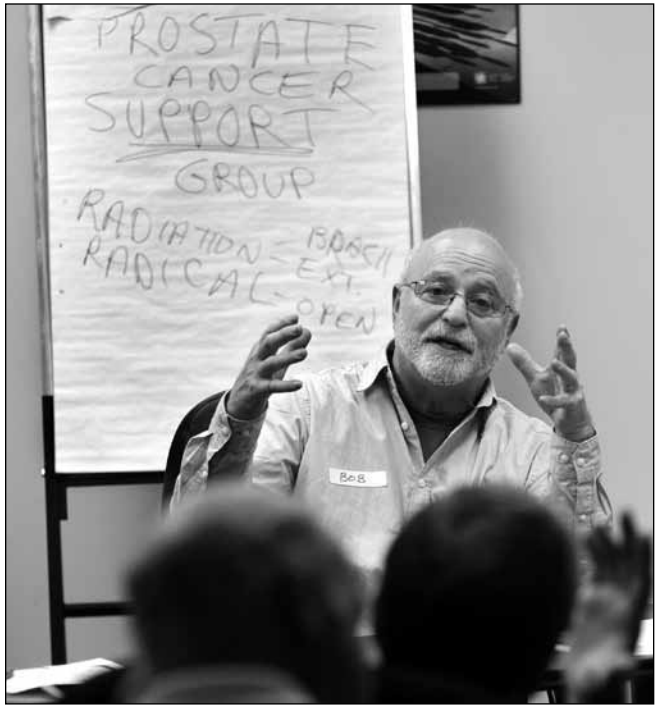
### Fatigue and Weight Gain

Exercise (both aerobic and weight-bearing) and proper nutrition are good ways to reduce fatigue and weight gain.

### Loss of Muscle or Bone Mass

Men using hormone therapy are at particular risk of muscle loss and mineral loss in the bones that can make them fragile and vulnerable to fractures – a condition called osteoporosis. This can be slowed or even prevented through regular exercise and healthy eating.

A “bone mineral density test” can help determine the risk of osteoporosis. Men at low risk may opt to take calcium and Vitamin D. Those at high risk, or those who already have osteoporosis, may choose to take medications such as pamidronate (Aredia®) or zoledronic acid (Zometa®).





### Side-Effects Related to Sexual Function

Whether you are single or in a relationship, changes in how you perceive yourself, family role, and patterns of sexual intimacy often occur during and after prostate cancer treatment. Maintaining open and honest communication and getting timely medical assistance and counselling are essential when it comes to weathering these changes, which can include infertility, decreased sex drive, and erectile dysfunction. Although these side-effects can be challenging, many men feel that working through these issues can eventually strengthen their relationships.

### Infertility

Infertility is the inability to father a child and can be a problem for men who choose to treat their prostate cancer with surgery or radiation therapy.

Surgery for prostate cancer causes infertility as the source of the semen fluid (the prostate gland and seminal vesicles) are both removed, and thus there will be a “dry ejaculate”. However, if you have had this procedure, you can still orgasm.

Infertility is also common after radiation therapy as the semen produced may not properly transport sperm. If you wish to father children after prostate cancer treatment you should consider having your semen (containing sperm) frozen.

### Decreased Sex Drive (Libido)

A lowered interest in sex is a common mental and physical side-effect of prostate cancer treatment, particularly hormone therapy. Unlike the typical treatment for decreased libido due to low blood testosterone level, men with prostate cancer should not be given testosterone as this feeds the growth of cancerous cells. Talking things over with your partner or visiting a counsellor or sex therapist may be useful.

### Erectile Dysfunction

Erectile dysfunction is the inability to achieve or maintain an erection adequate for sexual intercourse. Varying degrees of erectile dysfunction are common following radical prostatectomy, even when the surgeon spares the nerve bundles that control erections. Most men treated with nerve-sparing surgery experience an improvement in their erections over time. Some, however, never recover the ability to get a spontaneous erection. Men who have radiation therapy also develop erectile difficulties, but these usually occur more gradually over time.

It will take time, and trial and error to figure out the right solution(s) for you and your partner. Focus on recovery and a healthy lifestyle in the meantime, and maintain a close relationship with your doctor.

### Treatments for Erectile Dysfunction

#### Oral Medications

Medications such as sildenafil (Viagra®), vardenafil (Levitra®), and tadalafil (Cialis®) can help prevent the natural breakdown of the chemicals that open the blood vessels in the penis and cause engorgement of penile tissue and an erection. These medications allow blood to stay in the penis longer and an erection to be maintained. It is important to note that these medications still require the nerves that control erections to be (at least partially) intact.

#### Injectable Drugs

Drugs such as alprostadil, papaverine, or phentolamine can be injected into the side of the penis to relax the blood vessels and cause the penis to fill with blood. This creates an erection even with no sexual stimulation. Men are taught to inject themselves using a very small needle about the size as those used for insulin injections.

### The Medicated Urethral System of Erection (MUSE)

This involves inserting a small suppository of alprostadil into the urethra through the opening of the penis. Once the penis is massaged lightly to speed absorption, blood vessels expand and produce an erection.

#### Constricting Rings

These are adjustable or elastic bands that are placed around the base of the penis before it is aroused. The ring keeps the blood in the penis once an erection is achieved. For safety, these should be used only after consulting your doctor.

#### Vacuum Erection Device (VED)

A VED works by drawing blood into the penis and keeping it there by means of a constricting ring. A VED does not produce a physiological erection and as such, erections neither look nor feel normal, and they do not promote the healing circulation of fresh, oxygenated blood to the organ.

#### Penile Implant

This is an artificial device introduced into the penis during surgery. It can be semi-rigid or inflatable. This is usually only considered after other methods have been tried.

It will take time, and trial and error to figure out the right solution(s) for you and your partner. Focus on recovery and a healthy lifestyle in the meantime, and maintain a close relationship with your doctor.

## SECTION 3:

# WHAT HAPPENS AFTER TREATMENT?

Treatment for prostate cancer is often successful in removing cancer cells and tumours. This is both exciting and relieving, but can also be scary and stressful. Many men worry about the cancer returning and how to get back into their daily routines.

## Follow-up Care

Once you have completed treatment you will still need to be monitored closely by your doctor. It is natural to worry about the cancer coming back and to have anxiety about follow-up testing; however, it is important not to let this stop you from attending your regular appointments.

Your doctor should give you a follow-up plan that will include regular appointments and possibly additional exams, lab tests or imaging tests to give you the best chance at remaining cancer-free. It is also important to report any new symptoms, such as bone pain or problems with urination, to your

healthcare team. With this approach, your doctor will be able to find out as early as possible if the cancer does come back.

## Fatigue

Fatigue, or extreme tiredness, is common among people treated for cancer. For some, fatigue may last for a long time after treatment and can make it difficult to get back to “normal life”. Exercise can help reduce fatigue and a program tailored to your specific needs may help you feel better physically. Exercise has also been shown to reduce stress and improve mental health.

## Lifestyle Changes After Having Prostate Cancer

For many, a serious health scare, such as prostate cancer, makes them focus on their health in ways they had not before. Now may be a good time to re-evaluate your lifestyle and make changes to your diet and/or introduce more or different kinds of physical activity.



## Nutrition after Prostate Cancer

The side-effects of prostate cancer treatment can make maintaining good nutrition difficult. Treatment can make you nauseous, affect your sense of taste, reduce your interest in eating food, or result in weight gain that is hard to lose.

It is important to remember that most of these side-effects will get better with time. Many people find eating smaller portions every two to three hours helps them feel better. It may also be helpful to seek the advice of a dietitian who can tailor a meal plan to your side-effects.

Making a few simple changes, like increasing the variety of healthy foods in your diet, can have long-lasting benefits. Limiting alcohol and maintaining a healthy weight and diet may also lower your risk for secondary cancers as well as improving your overall health.

## Food Safety Precautions for People with Prostate Cancer

Infection is a concern for people living with cancer, especially during times when the immune system is weak. Handling and storing food safely is an important precaution to reduce exposure to unsafe germs and bacteria.

### Food safety tips:

- Wash hands before eating or preparing foods.
- Wash vegetables and fruits.
- Standard guidelines recommend keeping foods colder than 41°F and hotter than 140°F.
- Keep raw meats and meat juices away from other foods.

## Physical Activity after Prostate Cancer

It is common for men to notice a decline in fitness level and muscle strength after treatment. Becoming active again or introducing a fitness routine is an important step to regaining your health. You should talk with your doctor or healthcare team to get their opinion on an exercise plan before starting. Regular physical activity is shown to have a number of health benefits, including:

- Improving cardiovascular health.
- Reducing anxiety and depression.
- Maintaining a healthy weight.
- Improving muscle strength.
- Reducing fatigue and improving energy levels.



Talk with your doctor or healthcare team to get their opinion on an exercise plan.



Notes:

## Prostate Cancer Support Groups

Supporting the newly diagnosed and those living with prostate cancer is one important part of Prostate Cancer Canada's mandate. Over 75 Prostate Cancer Canada Network (PCCN) support groups provide services at the grass roots level, through monthly peer meetings, special educational events and outreach programs. Our informal and friendly settings allow attendees to interact with other prostate cancer survivors and take part in discussions and presentations on various prostate cancer topics.

Participation is free. To find a group near you, visit [prostatecancernetwork.ca](http://prostatecancernetwork.ca) or call **1.888.255.0333**.



Prostate Cancer Canada recognizes the Movember Foundation as a key funder of this resource.



p.1 - Photo by A. Rysyk ©, PhotoSensitive, p.2 - Photo by Tessa Peerless ©, PhotoSensitive, p.3 - Photo by C. Kochman ©, PhotoSensitive, p.4 - Photo by I. Bombier ©, PhotoSensitive, p.5 - Photo by S. Wilson ©, PhotoSensitive, p.6 - Photo by S. Davidson ©, PhotoSensitive, p.7 - Photo by T. Hauser ©, PhotoSensitive, p.9 - Photo by G. Monteith ©, PhotoSensitive, p.10 - Photo by D. Groot ©, PhotoSensitive.

For more information on prostate cancer, please contact:

Tel: 416-441-2131

Toll-free: 1-888-255-0333

[prostatecancer.ca](http://prostatecancer.ca)

For additional copies and information please contact:

**info@prostatecancer.ca** or call **1-888-255-0333**

Information in this brochure is provided for educational purposes only. It is not intended to constitute or replace medical advice.

Charitable Registration Number: BN 89127 0944 RR0001

10/2012

