

An Advanced Prostate Cancer Diagnosis...
Now What?







ABOUT THE CANADIAN CANCER SOCIETY

The Canadian Cancer Society is the only national charity that supports Canadians with all cancers in communities across the country.

Please note: the information presented in this resource is not meant to replace any medical advice provided by your healthcare team. For medical advice please consult with your healthcare provider.

For more information, contact the Canadian Cancer Society.

1-888-939-3333 | info@cis.cancer.ca | cancer.ca

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The Canadian Cancer Society hopes that this resource empowers prostate cancer survivors and their partners, caregivers and family members to take an active role in managing their cancer journey.

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You have come to the right place.

A. WELCOME

> "I have been diagnosed with advanced prostate cancer. Can you help me?"

You've just been told you have advanced prostate cancer. The words "advanced" and "cancer" used together can feel frightening and isolating. You probably have many questions and may not be sure where to turn.

You have come to the right place.

Although you may feel very alone, many people have been — and are — in your situation. This booklet has been designed to provide you with answers to some of the questions you might have, point you in the right direction to find additional information and resources, and support you as much as possible. It has been developed by the Canadian Cancer Society and reviewed by medical experts and people like you, who have gone through what you are experiencing. We hope you find the information in here useful.

B. ABOUT ADVANCED PROSTATE CANCER

> What is advanced prostate cancer?

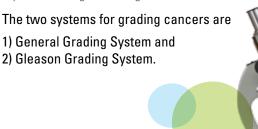
Advanced prostate cancer is cancer that has spread to other parts of the body, most commonly to the bones. It is also called metastatic cancer. Advanced prostate cancer is not curable, but you can receive treatment (usually hormone therapy and sometimes chemotherapy) for months — even years — and enjoy a good quality of life.

One of the first questions you might have is what is the outlook (or prognosis) for you. Your healthcare team considers several factors, including your age and general health, as well as disease stage (how "far" it has gone?) and grade (how "fast" it is growing or spreading?), to estimate a prognosis and determine the best treatment options. Grade is often more important in metastatic prostate cancer compared to locally advanced. Next is a brief explanation of the grading and staging systems used.



Grading

Determining the grade of prostate cancer involves examining a tissue sample of the prostate tumour cells under a microscope. By examining how similar or different the cancer cells are compared to your normal prostate cells, your doctor will be able to determine if you have a high- or low-grade cancer.



1. General Grading System

This grading system classifies prostate cancer cells as low-, intermediate- or high-grade based on the appearance of the cancer cells as compared to healthy prostate cells.

Low-grade

This type of cancer cell is slow-growing and looks similar to normal prostate cells.

Intermediate-grade

This type of cancer cell is more aggressive than low-grade tumour cells and looks abnormal as compared to low-grade cells.

High-grade

This type of cancer cell is extremely aggressive and grows and spreads quickly. They do not resemble healthy prostate cells at all.

2. Gleason Grading System

The Gleason grading system is a measure from 2 to 10 that allows your doctor to determine how aggressive your cancer is. An aggressive cancer is more likely to spread to other parts of your body. A higher number indicates a more aggressive cancer. The Gleason score is the best predictor of the progression and growth of your cancer.

Gleason Grade: To determine your overall Gleason score, the pathologist must first determine the Gleason grade. The Gleason score is the sum of the primary and secondary grade, each is given a score from 1 to 5.

To determine the **primary Gleason grade**, the pathologist looks at the most common tumour pattern and from there looks at what grade the cancerous cells in this pattern are. The bigger the difference in appearances between the healthy and cancerous cells the higher the Gleason grade (up to 5).

The **secondary Gleason grade** is determined the same way however, the pathologist looks at the second most common tumour pattern.



Your healthcare team considers disease stage and grade,

to determine the best treatment options.



While the Gleason score determines how aggressive the cancer is, staging the tumour allows doctors to see how far the cancer has spread. There are two different staging systems, the TNM staging system and the Whitmore-Jewett staging system.

The TNM staging system:

Tells you about the size of the tumour and where it has spread.

- T1: Indicates that the cancer cannot be felt or seen by the naked eye
- T2: Indicates that cancer is confined to the prostate gland
- T3 to T4: Indicates that the cancer has spread past the prostate gland into surrounding tissues

If the cancer has spread to the lymph nodes, this will be indicated by an N

- N1: Indicates a small tumour in the lymph node
- N2: Indicates a medium tumour in one node or several small tumours in several lymph nodes
- N3: Indicates a large tumour in one or more lymph nodes

If the cancer has spread past the lymph nodes, it has metastasized and this is represented by an M

- M1₂: Indicates cancer has spread just past the nodes
- M1: Indicates cancer has spread into the bone
- M1: Indicates cancer has spread to other sites in the body

Whitmore-Jewett staging system: In this system, the tumour is classified by letters (A to D).

- Stage A: Indicates that the cancer cannot be felt or seen by the naked eye
- Stage B: Indicates that the cancer is not detectable by the presence of a tumour
- Stage C: Indicates that the cancer has spread to surrounding tissues and vesicles of the prostate
- Stage D: Indicates that the cancer has spread to bones and organs throughout the body





'Advanced prostate cancer'

describes not just one kind of disease but several

1. Advanced Prostate Cancer

"Advanced prostate cancer" describes not just one kind of disease, but several. It includes cases in which the cancer has:

- Spread outside of the confines of the prostate to surrounding areas — "locally advanced disease";
- Spread to lymph glands and/or other sites within the body (most commonly, bone) – "metastatic disease";
- Recurs (comes back) after initial treatment (which may have been surgery, radiation or hormonal therapy) — "recurrent disease"; and
- Already been treated with hormonal therapy but has now become resistant to hormone treatment — "castrate-resistant disease".

2. Locally advanced prostate cancer

Locally advanced cancer is cancer that is starting to break out of the prostate, or has spread to the area just outside the prostate.

Your treatment will depend on how far the cancer has spread and will either get rid of the cancer or control it over the long-term. If you are given a choice of treatments, you might want to discuss the following with your healthcare provider:

- What each treatment involves (the pros and cons and any side effects);
- Your general health and age (and any other medical conditions you may have such as heart disease); and
- Any clinical trials that might be available.

3. Metastatic prostate cancer

This refers to prostate cancer that has spread beyond the prostate. Lymph glands in the pelvic region (then later in other regions) and bones are the most common sites of metastasis. Other organs such as liver, lungs, brain are less commonly affected.

Investigations including bone scans and "computerized tomography" (also known as "CT scan"/"CAT scan") can help determine how far along the cancer has spread; i.e., what "stage" the cancer is in. The type of treatment you receive will depend on the extent of your disease, your age and general health, and how severe your symptoms are (sometimes you may have no symptoms even with metastatic disease). Generally, you will receive what's known as "systemic treatment". This means that drugs will be given to you by mouth, by needle injection into muscle tissue or under the skin, or by intravenous injection. These drugs will act against prostate cancer tissue throughout your body, regardless of the location of the cancer.

The most commonly used first-line drugs lower the testosterone levels in the body, thereby "starving" the prostate cancer cells and slowing their growth. This is known as androgen deprivation therapy (ADT) and sometimes chemotherapy will be used early on in the treatment of metastatic prostate cancer.

The type of treatment you receive will depend on the extent of your disease, your age and general health, and how severe your symptoms are.



4. Recurrent prostate cancer

If you have cancer that has persisted or returns after radiation therapy or surgery, in the same location or elsewhere, your doctor may talk to you about the following treatments:

- Hormone therapy is the main treatment. It is not a cure, but it can control prostate cancer growth for many years.
- Some patients may benefit from the early use of chemotherapy in addition to hormone therapy.
- If you have had radical prostatectomy, radiation therapy (specifically external beam radiation), may be used, unless this treatment has already been tried in the prostate area. (It may still be used for bone metastases).
- If you had radiation as part of your initial treatment, surgery
 (transurethral resection of the prostate (TURP), "salvage"
 cryoablation or "salvage" radical prostatectomy or "salvage"
 high intensity focused ultrasound) may be an option when cancer
 recurs or persists in the prostate area itself (but not when it has
 spread elsewhere, i.e., "metastasized").



Learning about advanced prostate cancer can help you make an informed decision.

Several new treatments have recently become available.

5. Castrate-resistant prostate cancer

Some men have tumours that do not respond, or have stopped responding, to testosterone-lowering hormone treatments. If you have this kind of cancer, you have "castrate-resistant prostate cancer".

To treat castrate-resistant prostate cancer, hormone therapy which is also known as androgen deprivation therapy (ADT) is continued, because without it, the cancer would grow faster. In addition to ADT, you may also receive the following other therapies:

- Powerful anti-androgens may be the next step, or chemotherapy drugs. They have been shown to improve survival and quality of life.
- A bone-seeking radioactive injection, may be used where bone metastases predominate.
- Radiation therapy may relieve urinary symptoms or bone pain.
- Surgery known as transurethral resection of the prostate (TURP) can relieve urinary symptoms.
- Bisphosphonate drugs or biological therapy can strengthen bone and prevent osteoporosis due to hormone therapy. It also reduces the risk of bone complications.

Several new treatments have recently become available. You may want to talk to your doctor about any new drugs which have shown very good response for castrate-resistant prostate cancer.

Your prostate cancer will be monitored closely and may involve the following procedures:

- Regular prostate specific antigen (PSA) tests and digital rectal exams.
- Monitoring PSA doubling time (this may mean having a PSA test done every 3-6 months). PSA doubling time refers to how long it takes for a man's level of prostate specific antigen to double.
- Occasional repeat biopsies.
- Follow-up bone scan and/or CT scan to monitor disease progression.





Symptoms & Treatments





The symptoms you're likely to experience will depend on where the cancer has spread.

> What symptoms are common with advanced prostate cancer?

The symptoms you're likely to experience will depend on where the cancer has spread. They could include none, any or all of the following: fatigue, pain, urinary problems, kidney problems, bowel problems, broken bones, sexual problems, anemia, hypercalcemia (i.e., too much calcium in your blood), lymphedema (a blockage in your immune system, called the lymphatic system), and eating problems.

Sometimes men develop something called "spinal cord compression" (SCC). This happens when prostate cancer has spread to the bones of the spine (the vertebrae). The symptoms of SCC are:

- pain or soreness anywhere along your back or neck
- a narrow band of pain around your stomach or chest
- pain that moves down your arms or legs
- weakness in your arms or legs or difficulty standing or walking

- numbness or feeling as if you have pins and needles in your legs, arms, fingers, toes, buttocks, stomach area or chest, that doesn't go away
- problems with bladder or bowel control

SCC is a serious condition, so if you think you may have SCC, make sure you see your healthcare team right away. This list may seem daunting, but bear in mind that you may not develop all of the symptoms listed here.

> What treatments are available?

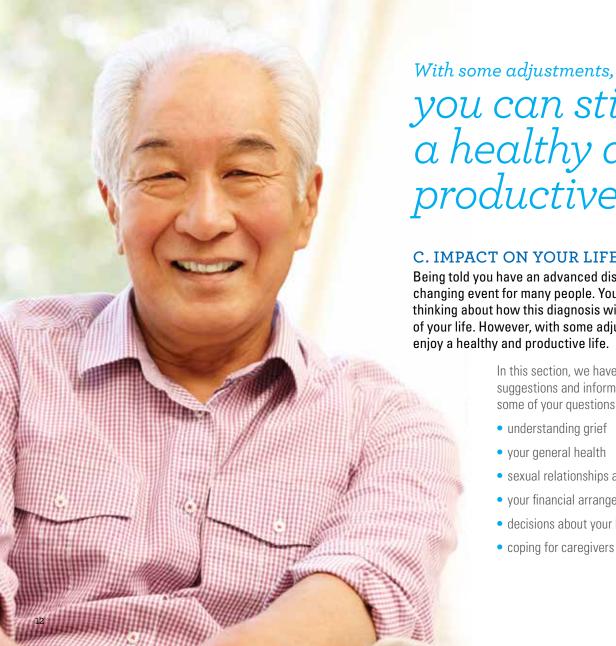
The type of treatments you can expect to have will depend on the type of prostate cancer and your symptoms. You may be offered one or more of the following:

- pain-relieving drugs (if pain is a problem for you)
- bisphosphonates (drugs that treat pain caused by cancer that has spread to the bones or to reduce the risk of bone complications from cancer)
- chemotherapy (anti-cancer drugs which kill cancer cells)
- radiotherapy (which shrinks the cancer)
- clinical trials (which is a type of research that tests new drugs to see how well they treat an illness)
- complementary therapies (things like acupuncture, massage, reflexology – i.e., therapies which accompany your medical treatment to help you feel better). Make sure you tell your doctor if you are taking any complementary therapies, as they might have an impact on the conventional treatments you are receiving.

For more information on each of these treatments, visit cancer.ca/prostate.







you can still enjoy a healthy and productive life

C. IMPACT ON YOUR LIFE

Being told you have an advanced disease is usually a lifechanging event for many people. You will understandably be thinking about how this diagnosis will impact different areas of your life. However, with some adjustments, you can still enjoy a healthy and productive life.

> In this section, we have put together some suggestions and information that may answer some of your questions on:

- understanding grief
- your general health
- sexual relationships and intimacy
- your financial arrangements and assets
- decisions about your healthcare
- coping for caregivers

There is no right or wrong way to "do" grief.

Understanding grief

Being diagnosed with an advanced disease can be very difficult for most people. You may be in shock and you will almost certainly go through a range of different emotions, most of which are related to grief. You may feel sad, numb, angry, indifferent, anxious and many other emotions. These feelings may change frequently and with differing levels of intensity. If you are single, you may find yourself feeling very isolated and having to reach out more to friends and professionals for comfort and support. If you are in a relationship, you may find yourself feeling guilty for thinking you are being a burden to your partner and worrying about the impact on them emotionally and financially.

Grieving is a complex process and doesn't follow logic or specific timeframes. Being diagnosed with advanced prostate cancer may make you feel as though you have lost control of your body — and your life. You may be grieving unfinished business and unfulfilled expectations. However, knowing you have only limited time left can make you decide to do things now that you have been putting off for a long time. Think about what those things might be. How can you build a legacy in the time you have left? What memories would you like to cherish or can you still build? How can you try to maintain a decent quality of life in spite of your diagnosis? As difficult as it can be, try to think about what positive actions you can take now to make you feel more at peace with your situation. Be patient and gentle with yourself and don't be afraid to reach out to others who might want to support you, but don't know how. Tell them how they can help, even if it just means spending quiet time with you. Sometimes a respectful silence can be healing and "enough" for some people.





There is no right or wrong way to "do" grief. Having an advanced disease means you are straddling a delicate balance between hope and realistic acceptance. This isn't easy and you will undoubtedly have good days and bad days. You may wish to join a support group where you can meet other men in a similar situation to you.

To find a group near you, visit csl.cancer.ca or call 1-888-939-3333. If you are supporting or caring for a man with advanced prostate cancer, you can also receive information and support from a support group.



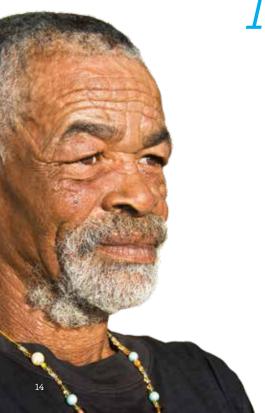
that you try to either maintain or develop positive lifestyle behaviours

Your general health

As much as possible, try to eat healthy, stay active, get sufficient rest, and maintain contact with supportive people. For example, 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.

Although your illness may make you feel very tired, it is important that you try to either maintain or develop positive lifestyle behaviours that can help you cope.



Be open with your partner





Sexual relationships and intimacy

You may find that your diagnosis has an impact on your sexual relationships and on intimacy. If you have a partner, they might want to join you in a support group. Prostate cancer is often known as a "couple's disease" because of the impact treatments can have on sexual functioning, including erectile dysfunction (ED), decreased sex drive (libido) and infertility. If you can, try to be open with your partner and, if appropriate, talk to your healthcare team about what options are available to you. You and your partner may need to make some adjustments to this part of your relationship, but, if you can define intimacy broadly, you may find that there are different, but equally satisfying ways, to enjoy a healthy sexual relationship.

Erectile dysfunction

Erectile dysfunction (ED) is the inability to achieve an erection or maintain it long enough for sexual intercourse. Some treatments for prostate cancer can cause ED:

Radical prostatectomy, surgery
that removes the prostate gland, the
seminal vesicles and part of the urethra,
is the most common cause of erectile
dysfunction. The severity depends on
the procedure's impact on the arteries
and nerves that control erections. Most
men who receive "nerve-sparing" surgery
experience improvement over time
(recovery may take a couple of years).
Some men never recover the ability to
have a spontaneous erection.

- Radiation or brachytherapy can damage nerves and blood vessels, causing ED. Many men can achieve an erection with prescription medication.
- Hormone treatments lower testosterone levels, which can cause ED and lower libido. Men with prostate cancer should not receive testosterone therapy, since this can encourage the growth of cancerous cells. Ask your doctor about treatment options.

Treating erectile dysfunction

There are several treatments available to help treat ED. Discuss your options with your doctor.



Medical Treatment for Erectile Dysfunction

| Treatment | Advantages | Disadvantages |
|--|--|--|
| PDE5 Inhibitors (Cialis, Levitra, Staxyn, Viagra) | Success rate for full intercourse 40–60% Minimally invasive (easy to take) Maintain spontaneity | May not work Cost Can't be taken with nitrate medications Won't work if erection nerves removed |
| Penile Injections | Success rates up to 85% Can work even if erection nerves removed/damaged Useful if can't take PDE5 inhibitors | Penis discomfort May not work Cost Risk of prolonged, inappropriate erection Scar tissue in 10–15%, which can curve penis Fainting (rare) |
| Medicated Urethral System for Erection | 57% success rate No needle Can work even if erection nerves removed/damaged Useful if can't take PDE5 inhibitors | Penis discomfortMay not workCost |
| Vacuum Constructive Devices | Success rates 85–92% Do not require medication or surgery | Cost Can cause bruising Can't be left on longer than 30 minutes Can't use with blood thinners Penis may be cool to the touch so not a natural feel |
| Penile Prosthesis | 85% satisfaction rates reported One-time surgery Avoids risk of curved penis caused by penile injections More relaxed foreplay with no change in skin sensation | Infection in approximately 2% of men, requiring removal of the prosthesis 15% of implants fail, and surgery is required to repair/remove prosthesis; may be embarrassing with new partner |

Source: Jamnicky, L., Nam, R. The Canadian Guide to Prostate Cancer, Second Edition. Mississauga: John Wiley & Sons Canada, Ltd. 2013. Page 196.

Decreased sex drive (libido)

Reduced sex drive is a common side effect, physical and psychological, of prostate cancer treatment (especially radiation therapy). Men with prostate cancer should not have the usual treatment of testosterone therapy, since it encourages cancer growth.

Consider consulting a professional counsellor or sex therapist, on your own or with your partner, especially if anxiety may be contributing to the ED. A counsellor or therapist can help couples reconnect, communicate and explore different ways to enjoy intimacy.

Infertility

Infertility, or the inability to father a child, is a potential side effect of prostate cancer surgery or radiation therapy.

Surgery removes the prostate gland and seminal vesicles, the source of semen. Men who have had a radical prostatectomy can still experience orgasm, without ejaculating.

After radiation therapy, the semen may not transport sperm properly. Men who want to father children should consider freezing their semen (containing sperm) before treatment begins.

If you can, try to be open with your partner and, if appropriate, talk to your healthcare team about what options are available to you. You and your partner may need to make some adjustments to this part of your relationship, but, if you can define intimacy broadly, you may find that there are different, but equally satisfying ways, to enjoy a healthy sexual relationship.

By defining intimacy broadly,

you may find different ways to enjoy a healthy sexual relationship





Your financial arrangements and assets

You may have already made a Will. Being diagnosed may prompt you to re-consider some of the things you have in there. If you're someone for whom the thought of writing a Will is difficult and fearful, you are not alone. Many people put off making a Will as they don't want to think about death. However, some people find it gives them peace of mind to have their affairs "in order", including tackling difficult subjects like funeral arrangements, Power of Attorney, and advance care directives, etc.

You may find the following tips helpful when writing a Will:

- Make a list of all your possessions, including things like your jewellery, savings, certificates, vehicles, etc.
- Make a list of items that you wish go to specific people.
 Make sure you mention and attach this list to your Will.
- Have two competent adults of legal age witness your signature when you sign your Will.

Once you've written your Will, it's important that you inform a trusted person or the executor of its location. An executor is a person who will be responsible for managing your estate after your death. Make sure you choose someone you trust and who is aware of and able to carry out this responsibility.

Decisions about your healthcare

Although it is difficult to do so, you may need to give some thought to decisions about your healthcare and who you might want to make decisions on your behalf, should you become too ill to do this yourself. This is called a healthcare directive, also known as a living will or advance care plan. A healthcare directive is a legal document that specifies what treatment decisions should be made for a patient, should they become unable to communicate or make decisions for themselves. Most Canadian provinces and territories have legislation which recognizes a person's right to make decisions regarding their own care and treatment. Please visit the Virtual Hospice's website (www.virtualhospice.ca) or the Canadian Hospice Palliative Care Association website (www.advancecareplanning.ca) for more information.

Coping for Caregivers

If you are the caregiver of a man with advanced prostate cancer, you too may be going through your own whirlwind of emotions. One caregiver described it as being "hit with a truck". You may feel a huge sense of loss, grief, sorrow, anger, isolation, and exhaustion. All of these feelings are normal and to be expected.

In addition to supporting your loved one, it's important to focus on taking care of yourself so you're not overwhelmed. Finding time to do the things you enjoy, eating a healthy diet, exercising and getting a good night sleep are a few things that can help you cope with the diagnosis as a caregiver.

For more information for caregivers see our booklet 'Taking Care of You the Caregiver' You are entitled to take the time

you need to work through your feelings.

D. FINDING SUPPORT

> Talking about your diagnosis

Talking about a cancer diagnosis can be challenging, emotionally draining, or comforting. You might be worried about how people will react. Perhaps, you're feeling too overwhelmed to talk or want a listening ear to get things off your mind and bounce ideas off others.

People handle the knowledge that they have a serious health problem in different ways. There is no "right" way. You are entitled to take the time you need to work through your feelings. You may find that you don't want to talk to anyone about your diagnosis. That is fine too.

We have compiled some suggestions and ideas that you may find helpful. Feel free to pick and choose whatever works for you.



Talking to your family and friends

- If you are part of a couple, your partner may be the first person you think about talking to. Your partner will hopefully be your strongest support during this time, but they too may find the situation difficult
- If you have adult children, they may also be a strong source of support and comfort.
- If you are single, you may have one or more close friends and/or family members who you feel comfortable talking to.

- Sometimes, however, you don't feel comfortable talking to people you know. You may prefer the anonymity of a health professional or a peer survivor — someone who knows what it's like to be in your shoes.
- When you are ready and if you choose, you may want to think about who else you want to talk to about your diagnosis. Make a list of people and set aside private time with each person. Before you begin talking, turn off the TV, your cell phone and any other distractions. Try to avoid any interruptions.



"I'd like to share some news I recently got."

- You can start the conversation with a phrase such as "I'd like to share some news I recently got" or "There's something I need to talk to you about."
- How you decide to approach talking about your diagnosis is up to you, but try not to get isolated.
- You can refer people to the Canadian Cancer Society website (cancer.ca) or
 other resources if you don't wish to repeat the same information about cancer
 or treatment several times. You can also write down specific questions and
 ask your healthcare team later.
- Be prepared for a wide range of reactions. Some people will be supportive
 and helpful. Others may avoid expressing their feelings or asking questions,
 or they might become overly cheerful around you. Still others, afraid or not
 knowing what to do, may avoid you. While this is hurtful, it may be how
 they cope. Reach out to people you'd like to have contact with, but you
 may have to accept that they might not know how to be supportive.
- Acknowledge others' feelings and be open to discussion, now and later.
 But keep in mind that once you've told people you have cancer, you can still choose not to talk about it if you're not feeling up to it.
- Your loved ones may benefit from joining a support group for family members. Talk to them about this and ask your healthcare providers or your hospital for information on local support groups.







If you have young children, tell them

- Although you may dread telling your children, it is usually best to be honest. Children are perceptive; they will sense that something is going on. It is important that they hear about it from you.
- When talking to young children, try to use words that they'll
 understand (for example, "medication" instead of "chemotherapy").
 Ask often if they understand, and repeat information if needed.
 Ask your children what they know about cancer and where
 they learned about it.
- Encourage children to ask questions and share their feelings.
 They might be afraid, for example, that cancer is contagious, or that they did something to cause your illness. Reassure them that this is not the case.
- Having another trusted adult present (such as your partner or a relative) lets kids know that they have support from others as well.
- If you have older and younger children, or if your kids' personalities are guite different, talk to them separately.
- Help kids prepare by explaining how the cancer may change their lives and daily routines.
- Try to be optimistic. If your children ask about death, focus on the
 present and the treatments that you will start soon. Let them know
 that you will give them updates as your treatment progresses.
- Let your children's teachers, coaches and other adults in their lives know what is happening. They can provide support and alert you if your kids are having difficulties.



Talking to others who have had prostate cancer can be very helpful...

Talking to your employer and co-workers

- Although you may prefer to keep a cancer diagnosis private at work, it could be difficult if you're frequently going to medical appointments, or you're absent for a long period of time for cancer treatment and recovery. Your appearance may also change, prompting people to ask about your health.
- Talk to your manager or human resources department. You do not need to share all of the details, but if your illness and treatment affect your work, they may need to make accommodations or re-assign some or all of your usual tasks.
- If your co-workers will be affected by your absence, you may
 want to hold off on talking to them until you know how long
 you'll be away. Your manager can explain to the team how
 your workload will be handled until you return.
- Be prepared for a wide range of reactions. Some people may resent the added work they must do in your absence. Some will be uneasy or afraid. Others may be very supportive and go out of their way to accommodate you.
- If you have questions about your medical benefits, talk
 to the human resources staff. Ask if there are other resources
 available to you, such as counselling through an Employee
 Assistance Program (EAP).

Talking to others

- Talking to others who have had prostate cancer can be very helpful. Often, people with first-hand experience can understand what you are going through in a way that family members, friends and others cannot.
- Support groups can be a source of hope, camaraderie, comfort and knowledge. Ask your healthcare team or hospital about support groups for prostate cancer.
- Spouses and other family members can also join support groups to talk about their experiences and gain knowledge.



You are not alone.

> Who can help you?

Health and social care professionals

Being told you have advanced prostate cancer can be a very difficult and isolating experience. You are not alone. You will have a multi-disciplinary team of health and social care providers who can help you, including doctors, nurses, specialists, physiotherapists, counsellors/psychotherapists, social workers, and occupational therapists. Each one of them can support your health needs in a unique way. Don't be afraid to reach out to them.



Try to be open about your thoughts and feelings and tell them what you need.





Family and friends

Your family and friends can also help you, but only you can decide who to approach and how, so you get the support you need. They may be struggling too. If you can, try to be open with them about your thoughts and feelings and tell them what you need. This will help you — and them — feel less alone. Receiving a difficult diagnosis can test or strengthen relationships. It is normal to feel like you're on an emotional roller-coaster and to need time to adjust to a different life situation. Try to be patient with yourself and others and practice good self-care.

If you feel you are struggling with difficult feelings of grief, do not feel you need to cope alone. Everyone is different and for some people, being alone is important and part of their healing journey. For others, being alone can be dangerous, especially if sadness turns into clinical depression, when you feel hopeless, empty and despairing.

If this is the case for you, please seek help from your family doctor right away. You may also wish to speak with a crisis centre. You can find a list of locations across Canada here: www.crisisservicescanada.ca

Support groups

Some people find that they want to speak to someone in a similar situation who knows what it's like to be in their shoes. The Canadian Cancer Society has support groups across the country that meet on a regular basis to support people like you. Find out more at csl.cancer.ca.

Spiritual support

Hearing that you have a serious diagnosis like cancer can make people think deeply about their lives, often questioning whether they have fulfilled their life's purpose. Sometimes people feel like they can benefit from seeking out spiritual support, perhaps from a spiritual advisor from their place of worship, a counsellor/psychotherapist, or a support group.

Many people find the process of engaging in a "life review" can be uplifting. This can involve using creative approaches such as making a photo collage, recording your voice, taking a video, writing poetry, etc. as a way of capturing important memories. The process of developing it can be healing and a therapeutic experience for you.

Many men live for many months and years when they receive treatment.

> If you are told you have advanced prostate cancer, does this mean you're going to die?

This may be one of your biggest fears. Right now, there is no cure for advanced prostate cancer. However, many men live for many months and years when they receive treatment. Your doctor or caregiver may mention the need for palliative care. This may frighten you and make you think people are giving up on you. Rest assured that this is not the case. Palliative care is an approach that helps you to live well in spite of having an advanced disease. It is designed to reduce distress, provide support and comfort, and improve your quality of life. For more information on palliative care please visit the Canadian Virtual Hospice's website at www.virtualhospice.ca.



Your Action Plan

Suggestions to better prepare you for the appointments

E. YOUR ACTION PLAN

> Preparing for your appointment

Going to doctors' appointments after being diagnosed with advanced prostate cancer, can sometimes seem overwhelming. Here are a few suggestions to better prepare you for the appointments.

- Your doctor will likely cover all the important points, but keeping track of the questions you want answered can help you stay focused during the appointment. Write down all the questions you have ahead of time and take them to your appointment. Some questions to consider asking your doctor are on the next page.
- Bring a family member or friend with you to the appointment. They can keep track of the information and ask important questions too.
- You may want to bring a tape-recorder with you to your doctors' appointments. By recording the conversation, you can play it back afterwards when you are calmer and better able to understand what was said.
- Remember to discuss mental wellness with your doctor. Anxiety
 and stress are common in cancer patients so it's important to
 talk to your doctor about how you can combat these side effects.
- Remember, your doctor is there to help. It's important to have open and honest conversations about your concerns surrounding treatment options and outcomes of your cancer diagnosis.



| | Frequently asked questions to consider asking your health provider | > Comments, notes, questions & concerns |
|----|--|---|
| | What are the risks if my cancer is not treated soon? | |
| 2 | How would the various treatments affect my quality of life? | |
| | The Would the various trouting arrow my quality of me. | |
| 3. | What is your experience with this/these treatment(s)? | |
| 1 | NA/bat are the absence by ill being much large with in continuous | |
| 4. | What are the chances I will have problems with incontinence, erectile dysfunction, or rectal issues? | |
| _ | \\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\\ | |
| ხ. | When will my treatment begin and how long is it expected to last? | |
| 6. | How can I live well with prostate cancer? What are some | |
| | changes I can make to my diet/lifestyle to help improve treatment outcomes and quality of life? | |
| | | |
| 7. | Is there more than one treatment option for my type of prostate cancer? How will I choose the right treatment? | |
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F. APPENDIX

> Personal and hospital information

| Name: |
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| Address: |
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| Phone: |
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| Email: |
| Date of diagnosis: |
| Hospital name: |
| ID #: |
| Health card #: |
| Private/semi-coverage: |
| Policy #: |

> Healthcare team contact information

| Name | Position | Email | Phone |
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> Important dates

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| | Treatment given/com | Treatment given/comments/advice received |

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> Medications

| Type Of Medication | Dose | How Often | End Date |
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> Side effects

| Start Date | Side Effect |
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Useful resources and organizations

Canadian Cancer Society

We're here for you.

When you have questions about treatment, diagnosis, care or services, we will help you find answers. Call us at 1-888-939-3333.

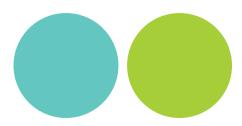
Ask a trained cancer information specialist your questions about cancer. Call us or email info@cis.cancer.ca.

Connect with people online to join discussions, get support and help others. Visit CancerConnection.ca.

Browse Canada's most trusted online source of information on all types of cancer. Visit cancer.ca.

Find your local community services in an easy-to-use, searchable database of cancer-related programs and services across Canada. Visit csl.cancer.ca.

Our services are free and confidential. Many are available in other languages through interpreters.



Canadian Virtual Hospice

The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, healthcare providers, researchers and educators. You can find articles on a range of topics related to palliative care, as well as videos, recommended books, the opportunity to ask a professional a question, etc.

Website: www.virtualhospice.ca

Canadian Hospice Palliative Care Association

Hospice palliative care aims to relieve suffering and improve the quality of living and dying. The Canadian Hospice Palliative Care Association is the national voice for Hospice Palliative Care in Canada. You can find information, resources and a national directory of hospice palliative care services.

Website: www.chpca.net

Legacies

Provides publications and resources on caregiving, community development and Canadian history. Publications include books for family and professional caregivers, community and personal development, and recording family histories.

Website: www.legacies.ca

Service Canada

Visit this website to find out how you can qualify for Employment Insurance Sickness Benefits and/or Compassionate Care Benefits.

Website:

www.servicecanada.gc.ca/eng/sc/ei/benefits/sickness.shtml

Government of Canada - Seniors Canada

You can find information on advance care planning, wills and estates, services for veterans and caregivers.

Website: www.seniors.gc.ca



For more information, contact the Canadian Cancer Society.

1-888-939-3333 | info@cis.cancer.ca | cancer.ca





cancer.ca