



Taking Care of You the Caregiver

HELPING PROVIDE SUPPORT



Providing Support

This resource is designed to help you, the caregiver, better understand how you can support your family member or friend as they face prostate cancer.

When a man is diagnosed with prostate cancer, the emotional responses to the diagnosis may not be predictable and are as wide and varied as the men involved. Family and friends will also feel the impact of the diagnosis. Certainly the experience for partners may be more intense and may closely match the patient's experiences. The reality is when a man is diagnosed with prostate cancer the attention falls naturally – and often squarely – on him. The critical challenge faced by a caregiver is finding support and taking care of oneself to ultimately maintain personal health and energy levels.

Whether you're a male or female, gay or bisexual, from the black community, are religious or not, you as the caregiver will face challenges taking care of yourself and your loved one through the cancer journey.

This resource is designed to help you, the caregiver, better understand how you can support your family member or friend as they face prostate cancer (for simplicity, often referred to as the "patient" here). Also, how you can care for yourself, and what emotional and practical suggestions you can follow to help you and your loved one cope with this diagnosis.



WHAT IS A CAREGIVER?

A caregiver is someone who provides support to a person with cancer. The type and level of support will depend on the patient's needs and may include:

- **Emotional support** – e.g., listening, validating concerns, normalizing feelings, etc.
- **Practical support** – e.g., helping with bathing, helping to get around, helping to make appointments with the various health providers, etc.
- **Financial and legal support** – e.g., helping to set up a will, reviewing legal concerns, assisting with finding help for the costs of treatment, etc.

A caregiver is someone who provides support to a person with cancer.

The role of caregiver is not limited to a spouse or partner. A caregiver might be an adult child, a sibling, a friend, or even a colleague. The relationship to the patient will certainly affect the level and type of support a caregiver can provide. Consider arranging to have several caregivers. This will help to distribute the work and draw on different people's strengths.

As caregiver, it is important to remember that long standing issues and conflicts may arise and have the potential to impact daily routines. Remember that the patient's needs are the caregiver's principal concern. Therefore, it's important to consider if you are able to sit down with other caregivers and work out a plan that is acceptable to all. Are you able to come up with a creative plan that takes into account people's abilities and resources? Can you suggest regular check-ins to see how things are progressing or if you feel that they need to be adjusted? Caregiving can test the strength of relationships, but they can also provide an opportunity for healing and for showing the patient that they are loved and that they matter.

WHAT IF I DON'T WANT TO BE A CAREGIVER?

Let's face it: not everyone can or wants to be a caregiver. Remember, there is no right or wrong answer to this decision. **You** are the only one who knows if caregiving is an appropriate choice. If it is not a good fit for you, perhaps you can suggest someone who is available to help. Is it possible to do a few things and share the other tasks? For example, are you better at providing practical support, but find the emotional side of things too difficult? How can you supplement or replace the support you can give? What outside agencies or supports exist to help you?

The important thing is that you are honest with yourself and honest with the patient. Try to find a time to talk to him (ideally face-to-face) about your concerns, what you are able to do, and suggest other ways you might provide support. You may witness feelings of rejection or defensive behaviours from the patient. Remain calm and above all keep your side of the conversation positive. Focus on your positive feelings towards the patient and how you and others can help. If there are doubts about your suggested level and type of assistance, offer to "pilot" a particular approach for a while and then review its effectiveness. You don't need to have everything settled at the beginning – you can try different things and adapt as needed.



Your family & friends

may need some help in knowing what to say or more importantly what not to say.

COMMUNICATING THE DIAGNOSIS

Talking about cancer can be frightening and difficult for many people, including the patient. Sadly, some men and caregivers have found that they lose friends and relatives at this time because these individuals just can't cope with the diagnosis. This can add to the feelings of isolation and grief that often accompany a cancer diagnosis.

What can you say? What will work? It is ideal if families can be open and honest about their feelings and allow painful emotions to come to the surface and be treated as normal and acceptable. Much will depend on your usual family dynamics. It is important that children are included and communication is open and honest – this is both respectful and healthy. Children, like adults, will know that something is wrong. Trying to hide the truth from them or sugar-coating the facts may eventually lead to confusion and even damage their ability to cope with the news.

Your family and friends may need some help in knowing what to say or more importantly what not to say. Tell them what is important for you. Let them know if you just need them to listen, or if you need more practical help from them. Let them know that sometimes silence is just fine, that they do not need to pressure themselves to come up with something "helpful" or "comforting." Speak up; don't be afraid to tell someone that the topic is bothering you or that you simply do not want to discuss the issue any further. This is true for the patient as well as the caregiver(s).



COMMUNICATING WITH YOUR LOVED ONE

Being diagnosed with a serious disease represents a loss for many people: you and the person you're caring for may be grieving or struggling with important decisions regarding their health, finances or family. It is important to ask the patient what they need but also to be respectful that they might not want to talk about their illness and may need some time alone to absorb this news. Try not to be offended if this is the case. When they are ready to talk, express your feelings and concerns in an honest and open way. Try to discuss the important issues of the moment. Remember, everything does not have to be settled immediately. Spend time deciding how together, your loved one and you will face this difficult time.

While you work through this challenging phase of your lives, make sure you are aware of any signs and symptoms of possible depression, which might suggest the need to speak to a doctor. Signs and symptoms of depression include:

- Feelings of helplessness and hopelessness
- Loss of interest in daily activities
- Appetite or weight changes
- Sleep changes
- Anger or irritability
- Loss of energy
- Self-loathing
- Reckless behaviour
- Concentration problems
- Unexplained aches and pains

Any dramatic change in your or the patient's demeanour, appearance or mood could be taken as a sign you're not coping well and might benefit from seeing a healthcare provider.

*Seek help from a
healthcare provider
if you need advice
or suggestions.*

It's important to remember

*the things you enjoyed as a couple
and continue them as much as possible.*

RELATIONSHIP CHANGES AS A COUPLE

A prostate cancer diagnosis can change the dynamic of not only your physical relationship with your loved one but also the emotional aspects. Some gender roles might be altered, for example, you as the caregiver might have to take on more responsibilities such as being the main breadwinner, running more errands in addition to caring for your sick partner. These new responsibilities and the changes to intimate relations that come with prostate cancer diagnosis and treatment might take a toll on your relationship. It's important to remember the things you enjoyed and did as a couple and continue them as much as possible. Keep much of the old routine if you can. Also, have honest conversations about the new pressures and intimate challenges and expectations from the relationship. This will help ease the pressure and set new expectations. Seek help from a healthcare provider if you need advice or suggestions.





HELPING THE MAN MAKE DECISIONS

As a caregiver, you are providing care to someone *in a way that takes their needs and preferences into account*. It is important to remember that the patient must remain an active participant in the process. Without realizing it, caregivers may unconsciously take over control of the situation and place the patient into a receptive position, long before such intervention is required. Preservation of personal dignity and free will are paramount at all times and in all areas of the patient's healthcare. It is imperative that the patient retain their right to make informed decisions about their care path while they are able.

Questions are an important tool in helping to keep the patient at the forefront of all discussions. Remember that no question is too small or silly to be asked. ASK! It is a personal right to have all of the pertinent information. Information is the knowledge that will enable informed decision making. Help whenever you can to facilitate discussion and greater understanding. Help with decision making when asked but **never** force your decision on the patient. Talk to the patient and help him make decisions that best suits his needs and comfort level.

As a caregiver, you are providing care to someone in a way that takes their needs and preferences into account.



Contact the **Prostate Cancer Information Service** if you need to talk to someone or access medical information confidentially – call 1-855-722-4636; email support@prostatecancer.ca



SOME PRACTICAL THINGS YOU CAN DO AS A CAREGIVER

There are a number of practical things you can do in your role as a caregiver.

The list below may offer some suggestions. You can probably think of some others:

- Keep all medications listed and organized for easy retrieval.
- Keep a list of all treatments and the dates administered.
- Keep a list of all health professionals (and other service providers) and their contact information handy.
- Put up a calendar with important dates (or keep a small notebook for easy transport in case of an emergency).
- Make a note of all of your discussions with health professionals.
- Record the consultations with health professionals (you can use a smartphone, for example) so that you can re-play this afterwards.
- Find some positive things to do with the patient on a regular basis so that the disease doesn't take over his (or your) life.
- Keep making happy and meaningful memories.
- Find out if there are any support groups in your area that you can tap into: go to www.prostatecancer.ca/PCCN or call 1-888-255-0333.
- Contact Prostate Cancer Canada for any information or advice – email info@prostatecancer.ca; website www.prostatecancer.ca.
- Contact the Prostate Cancer Information Service if you need to talk to someone or access medical information confidentially – call their toll-free number at 1-855-722-4636 or email them at support@prostatecancer.ca.
- Develop a plan of action so you and the patient talk about “what if?” scenarios and how you might address them. Your plan should include difficult but important topics such as how to develop a will, how to take care of finances, advance care planning, etc.
- Make sure you take care of yourself so you don't get burnt out – Who else can help you?

For some men, emotional support

will be even more important than practical support.

SOME EMOTIONAL THINGS YOU CAN DO AS A CAREGIVER

For some men, emotional support will be even more important than practical support. Examples of emotional support can be:

- Listening open-mindedly to the man's concerns, fears and experiences.
- Being non-judgmental and accepting of the man's experience.
- Avoiding rushing in to "fix" problems.
- Being empathic and validating concerns.
- Being silent, when that might be the best response.
- Being truthful but sensitive in your delivery.
- Asking the man what he needs from you.
- Helping him to clarify treatment options.
- Remind the patient that you are facing this together, he is not alone.





You will need to look after yourself to avoid getting sick and to enable you to offer the best support you can

CARING FOR THE CAREGIVER

As a caregiver, your life will change from how it was before the patient's diagnosis. You may welcome some of these changes – or you may resent them. However you feel about your new role, you will need to look after yourself to avoid getting sick and to enable you to offer the best support you can.

Some tips to help keep you physically well are:

- Eat frequent healthy meals and snacks throughout the day, even if you have no appetite or feel busy.
- Drink plenty of water.
- Be physically active, whether it's going to the gym or taking a 20 minute walk outside.
- Make sure you get at least seven hours of restful sleep each night. If you're having trouble sleeping at night, make sure you schedule a nap(s) during the day.
- Find some quiet time and do something you enjoy such as reading a book, watching television or taking a bath.

You are an important part

of the patient's cancer journey.

Some suggestions to keep you emotionally and mentally well are:

- Use relaxation techniques frequently such as deep breathing and meditation.
- Talk to a trusted friend or family member about your feelings.
- Take a break from being a caregiver and make time for things you enjoy.
- Join a support group. It sometimes helps talking to others who have gone or are going through a similar experience.
- Ask people for help when you need it.
- Recognize it's ok to cry when you feel the urge to. It can relieve buildup tension.

You are an important part of the patient's cancer journey. As a caregiver, you want to be responsive to the needs of the patient, but you also need to tune in to your own needs so that you don't become exhausted and depressed. The following section looks at how to gauge your levels of stress and what to do if they get too high.

The American Cancer Society has developed a Caregiver Self-Assessment Questionnaire which can help you identify your level of stress and whether you might need some additional help.



Caregiver Distress Checklist: How are YOU?

Caregivers are often so concerned with caring for their relative's needs that they lose sight of their own well-being. Please take just a moment to answer the following questions. Once you have answered the questions, go to the next page to do a self-evaluation.

During the past week or so, I have ...

1. Had trouble keeping my mind on what I was doing.

Yes No

2. Felt that I couldn't leave my relative alone.

Yes No

3. Had difficulty making decisions.

Yes No

4. Felt completely overwhelmed.

Yes No

5. Felt useful and needed.

Yes No

6. Felt lonely.

Yes No

7. Been upset that my relative has changed so much from his/her former self.

Yes No

8. Felt a loss of privacy and/or personal time.

Yes No

9. Been edgy or irritable.

Yes No

10. Had sleep disturbed because of caring for my relative.

Yes No

11. Had a crying spell(s).

Yes No

12. Felt strained between work and family responsibilities.

Yes No

13. Had back pain.

Yes No

14. Felt ill (headaches, stomach problems or common cold).

Yes No

15. Been satisfied with the support my family has given me.

Yes No

16. Found my relative's living situation to be inconvenient or a barrier to care.

Yes No

17. On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress. _____

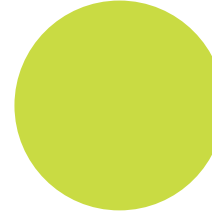
18. On a scale of 1 to 10, with 1 being "very healthy" to 10 being "very ill," please rate your current health compared to what it was this time last year.

Comments:

(Please feel free to comment or provide feedback if you plan to share this with a healthcare professional).



Part of caring for someone else is caring for yourself.



SELF-EVALUATION

To determine your score

1. Count up all your “Yes” responses EXCEPT do not count # 5 or 15 yet.
2. Now, look at Questions #5 and 15. If you responded “Yes” to these questions, do NOT count these with your “Yes” count. If you responded “No” to either or both questions, add these to your “Yes” count. (For example, if you had 4 “Yes” answers on the rest of the questions, and you answered “No” to question #5 and “No” to question #15, your total score would be 6).

To interpret your response

Chances are that you are experiencing a high degree of distress:

- If you answered “Yes” to either or both questions 4 and 11; or
- If your total “Yes” score = 10 or more; or
- If your score on question 17 is 6 or higher; or
- If your score on question 18 is 6 or higher

If you are having a high degree of distress

- Consider seeing a doctor for a check-up for yourself.
- Look for some relief from caregiving (talk to the patient’s doctor, social worker, or cancer care team about resources available in your community).
- Consider joining a support group for caregivers. Online and phone support is available
- Contact the Prostate Cancer Information Service at 1-855-722-4636 or by email at support@prostatecancer.ca for more information and referrals.

If your distress level is low

It isn’t unusual for caregivers to have some of these problems for a short time. But they may mean that you’re at risk for higher levels of distress. When caregivers don’t attend to their own needs and allow other pressures to take over, they may lose the ability to continue to care for their loved one. Part of caring for someone else is caring for yourself.

Now What?

There is no shame in asking for help. Asking for help can be a good thing. You may need more than one kind of help to manage caring for your loved one. See a doctor if you have serious distress, or if you can't accomplish your day-to-day activities. We also encourage you to print out this checklist and talk it over with a doctor, nurse, social worker, or other professional on your loved one's cancer care team.



ABOUT PROSTATE CANCER CANADA

Prostate Cancer Canada is the leading national foundation dedicated to the elimination of the disease through research, advocacy, education, support and awareness.

Our goals are twofold – to fund research that will uncover better diagnostic and treatment options and to provide comprehensive support services for those living with prostate cancer.

Prostate Cancer Canada hopes that this resource supports prostate cancer patients and their caregivers in managing their cancer journey.

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.

KEY REFERENCES:

American Cancer Society. (2014). Distress Checklist for Caregivers. <http://www.cancer.org/treatment/treatmentsandsideeffects/emotionalsideeffects/copingchecklistforpatientsandcaregivers/distress-checklist-for-caregivers>

American Cancer Society. (2014). What it takes to be a caregiver. Atlanta, GA: American Cancer Society. <http://www.cancer.org/acs/groups/cid/documents/webcontent/003199-pdf.pdf>



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