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Prostate Cancer

Information guide
and
Personal record

Prepared for you by

Ottawa Regional Cancer Foundation
Fondation du Cancer de la région d'Ottawa

Hôpital Montfort Hospital

*Comwall Community Hospital
Hôpital communautaire de Conwall
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The Ottawa Hospital Cancer Centre

Canadian Cancer Society

Colorectal Cancer Information Guide and Personal Record

National Cancer Institute

Canadian Prostate Cancer Network

The Canadian Prostate Health Council
What Cancer Cannot Do

Cancer is so limited…
It cannot cripple love,
It cannot shatter hope,
It cannot corrode faith,
It cannot destroy peace,
It cannot kill friendship,
It cannot suppress memories,
It cannot silence courage,
It cannot invade the soul,
It cannot steal eternal life,
It cannot conquer the Spirit.

Author unknown
My personal information

NAME ____________________________________________________________
Address ____________________________________________________________

Telephone: Home ___________________________________________________
Work _____________________________________________________________
Other ____________________________________________________________

Health Card # _______________________________________________________ 
Private Insurance Card # ____________________________________________
The Ottawa Hospital # ________________________________________________
Other Information __________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Personal contacts

NAME ____________________________________________________________
Relationship _______________________________________________________
Address ____________________________________________________________

Telephone __________________________________________________________
or ________________________________________________________________

Person going with me to appointments or driving me (if different from above)
NAME ____________________________________________________________
Telephone __________________________________________________________
or ________________________________________________________________

NAME ____________________________________________________________
Telephone __________________________________________________________
or ________________________________________________________________

In case of emergency, please notify (if different from above)
NAME ____________________________________________________________
Telephone __________________________________________________________
or ________________________________________________________________
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**How do I use this Information Guide and Personal Record?**

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A brief overview of prostate cancer and its treatment is given in this guide. More information is provided to you in the book Understanding Prostate Cancer by Dr. Fred Saad and Dr. Michael McCormack that is included in this package.

A glossary of relevant terms is found in Section 10. Terms that are in italics in the text are defined in the glossary.
How do I use this Information Guide and Personal Record?

• What is the Prostate Cancer Information Guide and Personal Record?

• How can I use the Prostate Cancer Information Guide and Personal Record?

• Who will be part of my prostate cancer treatment?
What is the Prostate Cancer Information Guide and Personal Record?

This guide will:

- Provide you with some basic information about prostate cancer, its treatment and the possible effects of prostate cancer on you and those close to you.
- Help you to organize the information you collect about your prostate cancer and make sense of this information.
- Allow you to add personal information about your prostate cancer to help you find answers to your specific questions.
- Help you to understand the cancer care system.
- Allow you to share the information you have gathered with your health-care team.

How to use the Prostate Cancer Information Guide and Personal Record

Living with prostate cancer can be overwhelming and confusing. This guide contains some basic information as well as a list of resources that can further assist you. This information is organized into sections that address different needs. Your family and friends may also use the information in your guide.

Guide sections include

- A list of common questions.
- Answers to commonly asked questions.
- A glossary is included in Section 10.

People with prostate cancer want various types of information, in different amounts and at different times. As you collect information that is helpful to you, it can easily be added to your guide.

You can take your guide to medical appointments so that

- You can use it as a reference.
- Your health-care professionals can see the information that you have collected so that they can help you to understand the information.
Other considerations

- It is important to remember that you are carrying confidential information about yourself and you must keep it secure at all times.
- You can also photocopy any part or section of the guide (for example, if you need additional pages to record appointments you can photocopy a blank sheet).
- It is important to remember that you do not need to complete or keep up-to-date every section in the guide. You can use this guide in whatever way it best helps you.

Who will be part of my prostate cancer treatment?

Having treatment for prostate cancer can be a complex process for both you and your family. This Information Guide and Personal Record provides a source of information about prostate cancer as well as a way to keep track of all the appointments, treatments, medication, and people related to your medical care.

Your care will be provided by a team of health-care professionals who will help you to decide on a treatment plan that is best for you. Depending on the kind of treatment you receive, your health-care team may include urologists, medical oncologists, radiation oncologists, nurses and radiation therapists.

Your treatment team may also include social workers who provide support and counselling to you and your family and will refer you to any community resources you may need. Depending on your situation you may also be entitled to receive services from Champlain Community Care Access Centre (CCAC). The CCAC Case Manager will make these arrangements. Physiotherapists and occupational therapists can provide a treatment plan to help you physically function at your best. A dietician can give you advice about eating well.

Because you are likely to be seeing several healthcare providers and may be receiving care in more than one place, section 2 of this guide will help you to keep track of your care and treatment.

If you have any questions about your cancer or treatment, or if there is any information in this guide that you don’t understand, don’t hesitate to ask your nurse, doctor or other healthcare provider. If you need help obtaining any of the services mentioned in the binder, such as financial assistance, ask to be referred to a social worker or to someone else who can help you.

We hope you will find this guide helpful in understanding and taking part in your care.
SECTION 2

Keeping Track

• My health-care team

• Business card holder

• Summary of my prostate cancer diagnosis

• My appointments

• Questions for my health-care provider(s)

• My test results

• My symptom diary

• My medication record

• Personal notes and diary
# My Health-care Team

## Doctors involved in my care

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Doctor</td>
<td></td>
</tr>
<tr>
<td>Urologist</td>
<td></td>
</tr>
<tr>
<td>Radiation Oncologist</td>
<td></td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td></td>
</tr>
</tbody>
</table>

## Others involved in my care

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse(s)</td>
<td></td>
</tr>
<tr>
<td>Social Worker(s)</td>
<td></td>
</tr>
<tr>
<td>Case Manager(s)</td>
<td></td>
</tr>
<tr>
<td>Community Nurse(s)</td>
<td></td>
</tr>
<tr>
<td>Pharmacist/Drug Store</td>
<td></td>
</tr>
<tr>
<td>Optometrist/Ophthalmologist</td>
<td></td>
</tr>
<tr>
<td>Chaplain</td>
<td></td>
</tr>
</tbody>
</table>

## Complementary-care providers
(Such as massage therapists, chiropractors, exercise specialist, physiotherapist, and occupational therapists)

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

## Other supports
(e.g. neighbours, volunteer driver, clergy)

<table>
<thead>
<tr>
<th>Role</th>
<th>Name</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>
Summary of my prostate cancer diagnosis

Many people on your health-care team will ask you similar questions about your prostate cancer. You may find it helpful to complete this section so that you will have a record that you can share when these questions are asked. You may need your doctor or nurse to help you. Section 3 contains the information describing prostate cancer, which may be helpful to refer to when you fill out this part.

1. Date of Diagnosis:__________/YY _________/ MM _______/ DD

2. Have you had a procedure or surgery that involved your prostate? If so, what kind and when (approximate date)?
   • Tests
     a. PSA - see page 14
     b. Transrectal ultrasound __________/YY _________/ MM _______/ DD
     c. Needle biopsy __________/YY _________/ MM _______/ DD
   • Surgeries
     a. Radical prostatectomy __________/YY _________/ MM _______/ DD
     b. Transurethral resection of the prostate (TURP) __________/YY _________/ MM _______/ DD
   • Radiation therapies
     a. External beam radiation therapy __________/YY _________/ MM _______/ DD
     b. Brachytherapy (internal radiation therapy) __________/YY _________/ MM _______/ DD

3. What did your doctor tell you was found during the procedure(s) or operation?

________________________________________________________________

4. What stage was your prostate cancer when you were first diagnosed? What grade was it? What Gleason score?

________________________________________________________________

5. Other (including medical history):

________________________________________________________________

Note: You may want to request from your physician a copy of your prostate biopsy pathology results to keep with your records.
My appointments

Date ____________________ Reason for visit ____________________________________
Health-care provider __________________ Name of clinic _______________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) _________________
Questions, answers or comments _______________________________________________

Next appointment ____________________________________________________________

• • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • •

Date ____________________ Reason for visit ____________________________________
Health-care provider __________________ Name of clinic _______________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) _________________
Questions, answers or comments _______________________________________________

Next appointment ____________________________________________________________

• • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • • •

Date ____________________ Reason for visit ____________________________________
Health-care provider __________________ Name of clinic _______________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) _________________
Questions, answers or comments _______________________________________________

Next appointment ____________________________________________________________
My appointments

Date ____________________  Reason for visit _______________________________________
Health-care provider ________________  Name of clinic _____________________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ________________
Questions, answers or comments _______________________________________________

Next appointment _____________________________________________________________

Date ____________________  Reason for visit _______________________________________
Health-care provider ________________  Name of clinic _____________________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ________________
Questions, answers or comments _______________________________________________

Next appointment _____________________________________________________________

Date ____________________  Reason for visit _______________________________________
Health-care provider ________________  Name of clinic _____________________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ________________
Questions, answers or comments _______________________________________________

Next appointment _____________________________________________________________
My appointments

Date ___________________ Reason for visit __________________________________________
Health-care provider ___________________ Name of clinic _______________________
Location ______________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ___________________
Questions, answers or comments ___________________________________________________

Next appointment ________________________________________________________________

Date ___________________ Reason for visit __________________________________________
Health-care provider ___________________ Name of clinic _______________________
Location ______________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ___________________
Questions, answers or comments ___________________________________________________

Next appointment ________________________________________________________________

Date ___________________ Reason for visit __________________________________________
Health-care provider ___________________ Name of clinic _______________________
Location ______________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ___________________
Questions, answers or comments ___________________________________________________

Next appointment ________________________________________________________________
My appointments

Date ___________________ Reason for visit ____________________________________________
Health-care provider ___________________ Name of clinic ____________________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________
Questions, answers or comments ___________________________________________________

Next appointment ________________________________________________________________

Date ___________________ Reason for visit ____________________________________________
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Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________
Questions, answers or comments ___________________________________________________

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Date ___________________ Reason for visit ____________________________________________
Health-care provider ___________________ Name of clinic ____________________________
Location _________________________________________________________________
Transportation arrangement (i.e., relative, friend, volunteer driver) ____________________
Questions, answers or comments ___________________________________________________

Next appointment ________________________________________________________________
<table>
<thead>
<tr>
<th>Date</th>
<th>Question</th>
<th>Answer</th>
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<tr>
<td>Date</td>
<td>Question</td>
<td>Answer</td>
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<tr>
<td>Name of test</td>
<td>Date</td>
<td>Reason for test</td>
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</tbody>
</table>
# MY TEST RESULTS

<table>
<thead>
<tr>
<th>Name of test</th>
<th>Date</th>
<th>Reason for test</th>
<th>When I can expect results</th>
<th>Result of test</th>
<th>Copy in my binder</th>
</tr>
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<tbody>
<tr>
<td></td>
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<td>Yes</td>
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</tr>
</tbody>
</table>
Keeping track of symptoms helps you to:

- Report to your health team more accurately;
- Recognize possible trends in your symptom development;
- Identify what makes your symptoms worse and what makes them better;
- Keep a record of medication and other treatments used and how they are working.

### My Symptom Diary

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Symptom</th>
<th>What was I doing?</th>
<th>How bad is the symptom?</th>
<th>What did I do to make the symptom better?</th>
<th>Did it help?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount:</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Other:</td>
<td></td>
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<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount:</td>
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<td>Other:</td>
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<td>Other:</td>
<td></td>
</tr>
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</table>
## MY SYMPTOM DIARY

<table>
<thead>
<tr>
<th>Date and Time</th>
<th>Symptom</th>
<th>What was I doing?</th>
<th>How bad is the symptom?</th>
<th>What did I do to make the symptom better?</th>
<th>Did it help?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Example: Pain, breathlessness, fatigue, nausea, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = least bad</td>
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<td></td>
</tr>
<tr>
<td></td>
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<td></td>
<td>10 = the most severe</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Example: physical activity, emotional event, sleeping, eating, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = least bad</td>
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<tr>
<td></td>
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<td>Example: physical activity, emotional event, sleeping, eating, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
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<td>1 = least bad</td>
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<td>10 = the most severe</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Example: physical activity, emotional event, sleeping, eating, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = least bad</td>
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<td>10 = the most severe</td>
<td></td>
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</tr>
<tr>
<td></td>
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<td>Example: physical activity, emotional event, sleeping, eating, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = least bad</td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>10 = the most severe</td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td>Example: physical activity, emotional event, sleeping, eating, other</td>
<td>1 2 3 4 5 6 7 8 9 10</td>
<td>Medication amount: Other:</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>1 = least bad</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>10 = the most severe</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
This form is to keep track of the medications you are taking. You should list any non-prescription medications or therapies (vitamins, Tylenol, or herbal remedies), as well as prescription medications you are using, in this section.

<table>
<thead>
<tr>
<th>NAME OF MEDICATION and dosage instructions</th>
<th>Time of day taken</th>
<th>Reason for taking</th>
<th>Doctor</th>
<th>Side effects</th>
<th>Advice for side effect relief</th>
<th>Date started</th>
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Personal notes and diary
Personal notes and diary
Personal notes and diary
Making sense of a prostate cancer diagnosis

• A patient’s story

• What is the prostate gland?

• What is prostate cancer?

• How serious is my cancer?
  Staging and grading prostate cancer

• How do I make sense of all of the information?

• What is a common reaction to a diagnosis of prostate cancer?

• How should I share my diagnosis?

• How do I cope with prostate cancer?
Having to deal with a diagnosis of cancer is very stressful and something no one chooses to do. I was no different than anyone else.

My initial reaction, when told I had prostate cancer, was a bit of an emotional roller coaster: fear, anxiety, anger, frustration. What am I going to do? How is this going to affect my life?

Now, I realize having these feelings was not unusual. But, at the time, it didn’t make the process of deciding what to do any easier.

For me, dealing with cancer is a very personal matter and we all have to deal with it in our own way. What works for one person may not work for another.

I would like to share some of the things that have helped me in my journey with cancer.

From the beginning I decided I wanted to be an active participant in the process. I did my best to educate myself and learn as much as I could about prostate cancer, its treatments and the side effects, so that I could make decisions that would be best for me. I sought out information from a variety of sources, my urologist, radiation oncologist, family physician, local and national support groups, cancer agencies and the internet. If I didn’t know, I asked. If I was getting too much information, I let them know.

Most importantly I recognized the importance of striving to maintain a positive attitude, being willing to talk about my cancer, and reaching out to others to offer and accept support from family, friends and associates.

I wish you the best in your cancer journey.

*Murray Gordon*
*Carp, Ontario*
What is the prostate gland?

The prostate is part of the male reproductive system. It is the size and shape of a large walnut and is located just below the bladder at the base of the penis. The prostate surrounds the urethra—the tube that carries urine from the bladder out through the penis. The main function of the prostate gland is to produce the seminal fluid that is part of semen. In addition to the prostate’s role in producing semen, it also plays a part in controlling the flow of urine. Muscular fibers in the prostate contract to slow the flow of urine.

What is prostate cancer?

Cancer occurs when normal body cells become abnormal and grow in an uncontrolled way. As a result, the abnormal growth of cells can form a tumour. There are two types of tumours; malignant (cancerous) and benign (non-cancerous) tumours. Prostate cancer is a malignant tumour that starts in the prostate gland. Prostate cancers start in the glandular tissue of the prostate and are most often adenocarcinomas. Compared with other types of cancer, prostate cancer can be relatively slow growing. Prostate cancer is the most common cancer in Canadian men.
What are the major causes of prostate cancer?

The cause of prostate cancer is unknown. However, it is known that the growth of cancer cells in the prostate, like that of normal prostate cells, is stimulated by male hormones, especially testosterone. Testosterone is produced almost entirely by the testicles (95%), with only a small percentage produced by the adrenal glands (small glands that sit above each kidney).

Some risk factors for prostate cancer include:

- **Family history** – Risk is higher if a first degree relative (brother, father) have had prostate cancer.
- **Ethnicity** – The incidence of prostate cancer is highest in men of African descent and lowest in men of Asian descent.
- **Inactivity and Obesity** – They appear to increase risk, possibly through the effects on hormones.
- **Diet** – The effects of a high fat diet are being studied but no clear evidence has emerged.
- **Age** – As a man gets older, his risk of developing prostate cancer increases.

Some men develop prostate cancer without any of these risk factors.

What are the symptoms of prostate cancer?

Prostate cancer can be present over a long time without causing any signs or symptoms. At the early stages there may be minimal or no symptoms, but over time symptoms may develop and could include the following:

1. **Early symptoms**
   - Decrease in the force of the urinary stream
   - Difficulty passing urine
   - Inability to urinate (obstruction)
   - Urgent need to urinate (frequency)
   - Increase in night time urination
   - Blood in your urine (hematuria)
   - Pain during ejaculation.
   * It is important to note that these early symptoms are more commonly associated with.
2. Symptoms present with advanced and metastatic disease
   - Weight loss
   - Constant tiredness
   - Low red blood cell count (anemia)
   - Bone pain is the most frequent symptom of cancer that has spread.

How serious is my cancer?
Staging and grading prostate cancer.

Once a definite diagnosis of cancer has been made, it is important to know the stage and grade of your cancer. To describe your prostate cancer and plan the right treatment, doctors give it a number, or stage, based on how far along it is. The stage is based on the size and location of the cancer, whether or not it has affected the lymph nodes, and/or whether it has spread to other parts of the body. Localized prostate cancer means the cancer has stayed within the prostate gland. Locally advanced prostate cancer means that most of the cancer is in the prostate but some has started to move outside, usually to nearby organs and lymph nodes. Advanced prostate cancer means that the cancer has spread to distant parts of the body. This is called metastasis. The most common site of the spread is to the bone, especially to the back, hips, thighs or neck.

How is my prostate cancer staged?

In a minority of men the following tests may be requested. In most cases the staging is complete with the digital rectal exam (DRE) and biopsy and no further testing is required.

1. Bone scan – A picture that is taken using radioactive material that can show whether cancer has spread to the bone.

2. Magnetic Resonance Imaging (MRI) of pelvis – A picture produced by a computer and high-powered magnet that shows the prostate and nearby parts of the body.

3. Computerized Tomography (CT) – A picture produced by a computer from x-rays showing the prostate and other nearby parts of the body.
How is prostate cancer graded?

The Gleason grading system is used to describe the appearance of the cancerous prostate tissue. The pathologist examines the tissue taken during the biopsy and compares the cancerous cells to normal cells. In Gleason Grade 1, the cancer cells appear to be close to normal prostate cells (well differentiated). This can mean the tumour is not expected to be fast growing. On the other hand, in Gleason Grade 5, cells look fairly irregular and very different from normal prostate cells (poorly differentiated). Typically, higher Gleason grades correspond to a faster growing tumour.

To obtain a Gleason score, the two most easily seen grades are assigned a score from 3 to 5 and then the two scores are added together. The resulting Gleason score will be a number from 6 to 10. Because Gleason scores on their own can be confusing, you will need to talk to your doctor about your results.

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<th>Gleason Score</th>
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<td>7</td>
<td>intermediate grade</td>
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<td>8-10</td>
<td>high grade (more aggressive)</td>
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The most common method of staging prostate cancer is the TNM classification system. It is based on the tumour size (T), the lymph node involvement (N) and the presence or absence of metastasis (M). Additional letters or numbers may be placed after the ‘T’, ‘N’ or ‘M’ to provide more specific details.

Once the TNM description is determined, they are sorted into groupings and assigned an overall stage from 0 to 4. These numbers help identify if the cancer is at an early stage or an advanced stage.

What are lymph nodes?

Lymph nodes are located throughout the body in bunches including the neck region, the underarms, the space between the lungs (mediastinum), throughout the abdominal region, and in the groin. They are part of the immune system and help to rid the body of harmful invaders such as bacteria by filtering lymph fluid. The presence of cancer cells in lymph nodes generally indicates that the cancer is more likely to spread to other parts of the body.
How do I make sense of all the information?

When you are diagnosed with prostate cancer, you will receive a great deal of information from many sources. It is important to keep the following points in mind:

• Consider how much information you want to receive about your cancer and its treatment. Some people want as much information as they can possibly get and others may only want a little. You may ask a family member or friend to be responsible for gathering information.

• Write down questions as you think of them. Take your notes with you to each appointment so your health-care team can help you find the answers and information that you need.

• Bring along a friend or family member to important appointments to listen and take notes. It’s sometimes hard to listen, understand and remember everything that you are being told.

• Write down instructions or ask for them in writing.

• Sometimes friends and family members try to help by giving you information that you don’t feel you can take in. Thank them for their help and tell them that you will read the information when you are feeling up to it.

• If you have questions about information that you have read, do not hesitate to ask your health-care providers. It is often difficult to judge if information is coming from reliable sources or how it might be useful to you.

• It is important to remember when reading information that there may be differences between American and Canadian standards of care, insurance and health-care systems.

Remember: Not everything you read will apply to you. Read so that you can know the types of questions to ask about your situation. Also, information needs change as people progress through their cancer treatment. Sometimes patients do not want to read anything at the start, but later will feel the need to know more. Some patients rely on family members and friends to gather information for them.
What is a common reaction to a diagnosis of prostate cancer?

A diagnosis of prostate cancer brings with it many different reactions, which may make clear thinking and problem solving difficult. The first reaction may be a feeling of shock, disbelief and fear. “Am I going to die?” is a common reaction. A sense of panic and anxiety can take over.

Some individuals with prostate cancer may have difficulty sleeping, changes to their appetite, and be preoccupied with their worries and concerns about the cancer diagnosis. Feelings of anger, sadness and grief may come to the surface. The time of diagnosis may be particularly difficult as there is a sense of uncertainty about the future.

Each person deals with this situation differently. It may be helpful to talk about how you are feeling and learn how you might deal with these feelings. Once a plan of treatment is determined, many men feel a sense of relief.

How should I share my diagnosis?

Sharing your diagnosis with others allows family and friends to be supportive to you through this difficult time and people who have support seem to do better. It also allows those close to you to understand more about the prostate cancer so that they too can begin to deal with your illness.

Reasons for telling:

As you tell others, it may help you to understand the information you have been given.

Secrets are avoided. People who find out from someone else do not know if they have permission to talk to you. It is also possible they may not have the most accurate information.

Close family and friends may need to know, as it may cause them greater distress to be left out.

It may lift the burden of keeping it to yourself.
How to tell family and friends:

There is no easy way to talk about your cancer diagnosis. Here are a few tips to think about when sharing this news:

First give the headline:

“I have undergone a series of tests and my doctor has told me I have prostate cancer.”

Give them any other information you have:

“I expect to be starting treatment soon…”

Allow them to ask questions:

“Do you have any questions?” You may not always have the answers but you can tell them when you do.

Tell them how you are feeling:

“I’m frightened and need your support.”

Tell them what they can do:

“I need you to tell Susan and John about my diagnosis.”

Often family and friends feel helpless as to what they can do to help. It will be up to you to let them know that you need them as an important part of your support team. You may not be certain what you need specifically but only that their support will be important.

How do I cope with prostate cancer?

Here are some tips to help you cope with your prostate cancer diagnosis:

• Acknowledge your emotions. Some people believe they have to maintain a positive attitude all the time because it will have an effect on the cancer and their prospects of recovery. This is not reality. Low periods do occur, no matter how good you are at coping.
• Make caring for yourself a priority. Putting your own needs first is important as you begin to deal with the cancer. It does not mean that you are selfish.
• Build your team. Do not be afraid to ask your partner, your family or your friends for help when you need it. They are dealing with your cancer as well and want to support you through it.
• Take on one issue at a time: Leave the things that can be left; try not to jump ahead.

• Develop a good working relationship with your health-care team: Ask questions and share your feelings, develop a sense of trust, include your family doctor.

• Take time and be patient. Some things do not have immediate solutions and do not require action.

• Make changes slowly: only do the things that make sense to you. Any change is difficult, do not add stress by expecting too much of yourself.

• Seek out professional help if needed. Talking with a social worker, psychologist, nurse, physician or clergy may help you manage better.

• Speak with others who have had similar experiences. Support groups, or friends and relatives who have had prostate cancer can provide invaluable support, information, and inspiration. Meeting with others who have experienced prostate cancer may ease the way for you.

See Section 9 for information on support groups and other community agencies.
Treatment options and side effects

• A patient’s story

• How will my prostate cancer be treated?

• Dealing with the side effects of treatment
When you wake up in a hospital room and there’s a tiny hole in your gut with fluid oozing out of it, evidently, something untoward has happened. Like surgery. A radical prostatectomy no less. In fact, the one the doctor had promised he would do on me. This, instead of the brain transplant most would say I really needed. Thankfully, urologists don’t work that end of the body. So I got through the prostate cancer thing and now, three years later, with an undetectable PSA, I’ve long since returned to running marathons, coaching hockey and shoveling snow. In fact, four months after the surgery, I wrote a book about the experience: “Assume the position: one guy’s journey through prostate cancer.” For reasons I can’t explain, I wanted to relive every moment from diagnosis to post-op. Perhaps this was the only way to convince myself, by nature a stubborn fellow, that yes, I had prostate cancer. I’d been treated, I survived hospital food, I had few side effects, and I asked lots of questions every step of the way. I also had a choice. I could be miserable and self-pitying, or I could consciously work at being upbeat, using humour to deflect the nasties. Humour worked. Sometimes I imagine how I might have coped without it, for surely there’s nothing inherently funny about having prostate cancer. It was (is) a serious and scary business. Yet, I was grounded every time I paid for hospital parking fees. Now that hurt.

Richard Bercuson is an Ottawa writer and teacher. His book “Assume the position: one guys’ journey through prostate cancer” is available through his website www.richardbercuson.ca or Prostate Cancer Association Ottawa. All proceeds go to the PCAO.
How will my prostate cancer be treated?

You and your doctor will need to discuss what the best treatment plan is for you. It is important that you understand the benefits and possible side effects of each option. The choices you make may depend on the stage of the cancer, how far it has spread and your general state of health.

A treatment plan for prostate cancer may include one or more of the following:

- Active surveillance
- Surgery
- Radiation therapy – External beam or brachytherapy
- Hormonal therapy
- Chemotherapy

Active surveillance

Active surveillance is an option when you and your doctor have decided to have no active treatment at present. This may be an option in situations when the tumour is small and slow-growing or when other significant health problems may be present. In such situations, the risks of treatment may outweigh the benefits. You will be followed closely with regular PSA (prostate specific antigen) tests and DRE (digital rectal exam) testing, usually every 3 to 6 months, to monitor the progression of the cancer. Further biopsies of the prostate may also be done, usually on an annual basis. Active treatment options will be considered if symptoms begin to develop, if the PSA rises in a worrisome way, if the prostate exam changes significantly, or if a biopsy shows a higher grade of prostate cancer.

Active surveillance may be an option when the cancer is in the early stages and does not pose an immediate risk to your overall wellbeing. Without active symptoms it allows you to continue on with day-to-day activities as normal, without the impact of prostate cancer treatments. The risk, however, is that it is possible for the cancer to progress in between visits with the doctor. This is believed to be a very low risk. Some men might experience feelings of worry and anxiety.
The goal of prostate cancer surgery is to remove the cancer and prevent it from spreading. The surgery is called a radical prostatectomy, which involves the complete removal of the prostate gland and the surrounding tissues, the seminal vesicles, and a portion of the urethra. The surgery is an option when the cancer is confined to the prostate gland, and when both the stage and Gleason score are low. Pelvic lymph nodes may also be removed during the surgery.

General and/or spinal anesthesia will be used for your surgery. The surgeon will make an incision in the lower abdomen. In order to remove the prostate, it is necessary to cut the urethra below the prostate, as well as the bladder neck above the prostate. The prostate is then removed along with the surrounding tissue. The seminal vesicles are also removed since cancer cells may migrate along this route. Once the prostate is removed, the bladder is reattached directly to the urethra. Your surgeon will preserve your external sphincter in an effort to provide you with the ability to control your urine flow. This is the muscle which surrounds the urethra and contracts to close it, preventing incontinence. The surgeon inserts a catheter to drain urine from the bladder while you heal. The catheter is usually left in place for 1 to 3 weeks.

If appropriate, surgeons will use a nerve-sparing technique. During this procedure, the nerves that support erections are identified and separated from either side of the prostate. This technique may reduce the risk of erectile dysfunction. You should speak to your surgeon about the procedure to be used. All tissue removed during surgery is sent to the pathologist to determine the precise extent and stage of the tumour.

In our treatment centre, a laparoscopic or robot-assisted laparoscopic approach may be used. You may discuss this with your surgeon. You will likely be in hospital for 2 to 3 days and will need 3 to 6 weeks of convalescence afterwards.

Long-term complications of radical prostatectomy surgery may include erectile dysfunction (impotence), urinary incontinence, and urethral stricture (narrowing of the urethra).

This is a partial list of risks only. It does not replace a full discussion of benefits, risks and complications with your treating physician.
Radiation therapy – External beam and brachytherapy

Radiation therapy is the treatment of cancer with radiation. It may be used to treat prostate cancer that is confined to the prostate gland or that may have moved to nearby tissue. Radiation beams target the prostate to kill cancer cells, shrink tumours or to prevent cancer cells from spreading. In more advanced prostate cancer, radiation may be used to relieve pain when the cancer has spread to other parts of the body. There are two types of radiation treatment—external beam radiation and brachytherapy.

In external beam radiation, radiation is directed from an external source onto the affected area. Preparation for the radiation treatment includes the use of a Trans Rectal Ultrasound (TRUS) to place gold seeds into the prostate to mark the prostate. This will provide a guide for the treatment. The placement of gold seeds is followed by a CT scan to visualize the prostate and finalize the planning. The treatment itself is painless and usually lasts 2 to 4 minutes. There may be 35 treatments over the period of approximately 7 weeks. Many patients compare the treatments to having an x-ray. You will not feel any pain or any other sensation during the treatment. Because you will need to be carefully positioned on a firm table before you receive each treatment, you should allow up to an hour for each radiation therapy treatment when scheduling transportation or other appointments.

Possible side effects of radiation therapy during treatment may include fatigue, skin reactions and hair loss in the areas touched by radiation, a sense of urgency or burning in urination, diarrhea or anal irritation. Longer-term complications of this treatment may include permanent erectile dysfunction, more frequent bowel movements and rectal bleeding.

Brachytherapy is a treatment in which tiny, radioactive seeds approximately the size of a piece of rice are inserted directly into the prostate. The seeds give off radiation from within the prostate to destroy the tumour cells. Transrectal ultrasound (TRUS) is used to guide the physician so the seeds can be correctly placed.

This treatment is generally an option for those men with a less aggressive prostate cancer, whose Gleason score is less than 7 and prostate size is under 50 c.c. (grams) as determined by ultrasound. There is typically no need for hospitalization for this procedure, so patients are able to return home the same day. The radioactive seeds are not removed once inserted and continue to be radioactive for up to a year. They cannot be felt by the patient, nor does the patient give-off significant radiation to others. Nonetheless it is recommended to avoid close contact with very young children and pregnant women during the first 2 months.
Possible side effects of this procedure may include frequent urination and discomfort with urination, weak urinary stream, diarrhea, anal irritation, and rectal bleeding.

Long-term complications may include permanent erectile dysfunction, obstructive voiding symptoms and, in rare cases – urinary incontinence, rectal bleeding, urinary obstruction.

This is only a partial list of risks. It does not replace a full discussion of benefits, risks and complications with your treating physician.

**Hormonal therapy (Hormonal deprivation therapy)**

Hormonal treatment may be prescribed after radical prostatectomy, alone or in combination with radiation treatments. *Hormone therapy* involves daily medications and regular injections of hormones—usually every three months—that prevent the testicles from producing testosterone. As testosterone contributes to the progression of prostate cancer, a reduction in testosterone can help slow the growth of the cancer. Treatment can be prescribed over a few months for localized cancers, or over longer periods for advanced cancers, and may be effective in controlling the cancer for a period of several years. A short course of hormonal treatment is sometimes prescribed to shrink large or more aggressive tumours before radiation therapy in an attempt to boost the success of radiation. Permanent reduction in testosterone can be obtained by an *orchiectomy*—surgical removal of the testes.

Hormone therapy will cause side effects that may include loss of sex drive, hot flashes, fatigue, anemia, mood swings, breast enlargement and loss of bone and muscle mass. Erectile dysfunction is an indirect result of treatment due to the loss of sex drive.

**Chemotherapy**

*Chemotherapy* is the treatment of cancer with drugs. This treatment tends to be used for more advanced cases of prostate cancer, where the cancer has spread to other places, and when other types of treatment have failed to control the cancer. How frequently the treatment is given will depend on the drugs being used, how well the treatment is tolerated and how the cancer responds to the chemotherapy. Individual patients respond differently to chemotherapy.
Most chemotherapy is given by intravenous injection. Normally, you can expect to receive your chemotherapy as an outpatient at the cancer centre or a hospital clinic. Patients are rarely admitted to hospital for chemotherapy treatment. You can expect to be given written information by your nurse at the cancer centre about the specific chemotherapy you will receive.

Side effects from chemotherapy may include hair loss, nausea, fatigue, low white blood cells which results in a higher risk in infection. These side effects tend to be short-term throughout the course of treatment.

**Clinical trials**

Clinical trials, also called research studies, test new drugs, new ways of giving drugs or radiation, new approaches to surgery, and new methods such as gene therapy. Each clinical trial attempts to answer specific scientific questions that will ultimately lead to better treatment. All trials are strictly monitored to ensure that the participant receives the best available care. Standard treatments are those which have been well studied in clinical trials and which have been proven to be helpful for the most patients. The best way to learn whether or not an appropriate trial is available in Ottawa is to discuss this option with your physician.

Participating in a clinical trial is voluntary. You must consider all your choices when deciding to join in a clinical trial and keep in mind that although the decision to participate is entirely yours, you may not be able to choose all of the treatment(s) you will receive. You should expect to receive treatment that is anticipated to be at least as good as current conventional (standard) therapies.

It is important to know that if you do not wish to participate in a clinical trial, you will continue to receive the best possible standard of care.
Dealing with the side effects of treatment

You are likely to experience some side effects of prostate cancer treatment. For many men, these side effects resolve. For others they go on to become long-term or permanent side effects.

The following is some general information on a few of the more common side effects that you may experience. It is important to discuss management with your nurse or physician; they may have other helpful suggestions for you. For information resources available, please see Section 9.

**Urinary side effects**

For those men who undergo surgery (prostatectomy), urinary incontinence may occur as a result of shortening of the urinary sphincter or damage to the nerves that help the sphincter work normally. This can result in small amounts of urine leaking out uncontrollably after a sneeze, cough, laugh, change in positioning (e.g. sitting to standing) or other physical activity. For many men, incontinence after radical prostatectomy tends to be short-term and resolves on its own with time. This occurs as the remaining sphincter muscles strengthen. For a small number of men, this condition may be permanent requiring further medical attention.

A stricture or narrowing of the urethra can occur at the base of the bladder where the urethra is reattached to the bladder after the removal of the prostate gland. This narrowing can lead to a blockage in the flow of urine out of the bladder. Urine left in the bladder can lead to incontinence due to overflow. Because the bladder is almost always full, the slightest increases in pressure on the bladder can lead to incontinence. This may require a procedure to stretch the narrowing and scar tissue.

With radiation therapy urinary symptoms, if any, are likely to begin later as a result of inflammation and irritation that builds up during the radiation treatments. These symptoms include urinary frequency, urgency, bleeding and pain in the urethra. Again, speaking to your doctor can lead to a discussion of various options available to help overcome the urinary symptoms. Symptoms usually resolve within a few weeks of the end of treatment.

Treating incontinence depends on its cause, type and severity. Treatment may include surgery, medicine, and pelvic floor exercises (Kegel exercises) to help strengthen the muscles of the pelvis.
Erectile dysfunction

Erectile dysfunction, also known as impotence, is the inability to have or keep an erection. Each treatment for prostate cancer has some risk of impact on sexual functioning. This is due to the anatomy and location of the prostate which is close to the male sexual organs. Men will vary in the degree of erectile dysfunction they experience, if any. Surgery to remove the prostate involves manipulation and often removal of the erectile nerves that run closely along the prostate. These very delicate nerves can receive trauma leaving most men with some loss of erectile function for the first few months following surgery or permanently. Erectile function can vary through the healing period with some men being able to function soon after surgery and then seeing this function diminish due to scarring and inflammation around the nerves themselves. Many men require long-term/lifelong treatment if they want to achieve a satisfactory erection.

The impact of radiation treatment on erectile function can be seen gradually. Radiation causes injury to local nerves and blood vessels slowly over time. This increasing damage can lead to a slow progressive loss of erectile function. The extent of the prostate disease also plays a role in the radiation treatment required. When the prostate cancer is more extensive, a larger area may be treated, and more side effects may be experienced.

A strategy called “Penile Rehabilitation” may be discussed with you. This involves the use of daily low doses of medications such as Viagra, Cialis or Levitra given for several months after your surgery to help with possible return of erectile function. Additionally, penile injection therapy may also be added to try to stimulate earlier return of erectile function. Many physicians believe that this strategy helps speed up recovery of erections. Some men will not regain erectile function in spite of these treatments.

Infertility

Surgery for removal of the prostate, radiation therapy, chemotherapy and hormone therapy can all lead to infertility. Surgery, which involves removal of the prostate and seminal vesicles, will lead to the inability to ejaculate (though a man may still reach orgasm). Radiation therapy will damage the sperm cells causing mutations and in most cases preventing the ability to conceive in the year after radiation. There is no increased risk of birth defects one year after radiation. Hormone therapy blocks the functions of testosterone—the male sex hormone—thus leading to loss of sex drive and infertility. For those men who may wish to father children it is very important to speak to your physician prior to any treatment for prostate cancer. Sperm banking may be recommended prior to treatment.
Bowel side effects

The proximity of the prostate gland to the rectal wall of the bowel can leave the bowel vulnerable to effects from the treatment of prostate cancer. Long-term bowel side effects are not common for men undergoing surgery for prostate cancer. Bowel function can be slow to return after surgery but most men find they return to normal bowel habits 2 to 3 weeks following surgery.

Radiation therapy can have long-term effects on bowel function that accumulate over the course of treatment and beyond. Concentrated radiation to the prostate and adjacent rectum can result in short-term bowel symptoms associated with proctitis (inflammation of the rectum) leading to diarrhea, rectal bleeding, and frequent passage of mucous. As treatments continue over time diarrhea, rectal bleeding, rectal pain and rectal urgency are side effects that can result from radiation to the rectum. Bowel side effects can lead to lasting changes in daily routines. Treating bowel side effects should be discussed with your physician. Most of these symptoms resolve within 6 weeks of the end of radiation.

Hormonal side effects

Side effects from hormone treatment are related to the withdrawal of testosterone leading to a range of effects: loss of erections or the desire for sexual relations, hot flashes, mood swings, changes in the distribution of body hair, lethargy, weight gain, loss of muscle mass, bone thinning, breast enlargement, depression and tiredness.

Side effects can be discussed with your physician. They can sometimes be reduced by reassessing the drugs used and varying the treatment plans. Medication to help with hot flashes and prevent bone loss can be prescribed.

Fatigue

Fatigue is different from feeling tired. Many people who are living with prostate cancer experience mild to extreme fatigue. Fatigue is an excessive feeling of tiredness that may not be relieved by extra amounts of sleep or rest. You may find yourself having difficulty in performing everyday tasks, even simple self-care tasks such as bathing and eating.

Fatigue has many causes such as prolonged emotional stress, a diet without enough iron, side effects from your treatments, or anemia. The following suggestions may help you to make the most out of your day.
Reassess your daily goals to make them realistic and reachable.

- Record in your symptom diary (page 16) your fatigue patterns throughout the day. Plan your day to minimize those activities that fatigue you the most.
- Spread your activities throughout the day. Rest between activities; let others help you with meals, housework, or errands. Do not do more than you can manage. Ask for help with tasks when you need it.
- Rest and sleep are important but don’t overdo it. Too much rest can decrease your energy level. Long afternoon naps (greater than 1 hour) can interfere with the quality of your nighttime sleep.
- Stay as active as you can. Exercise has been shown to decrease fatigue and promote feelings of wellbeing. Daily exercise will maintain your muscles and promote energy conservation. Some people find it is best to exercise early in the day. Start with 10 minutes per day and increase, as you are able.
- Drink plenty of liquids. Eat as well as you can.
- Do activities that you enjoy and make you feel good.
- Fatigue is often made worse by stress. Anticipate that your treatment may be tiring and stressful and plan ahead.

What can I do to feel my best during treatment?

- Taking an active role in your treatment may give you a sense of being in control.
- Have a friend or family member accompany you to treatments.
- Expect to feel tired and make plans to rest frequently.
- Exercise daily, in whatever way you are able: daily exercise prevents the deterioration of muscle and maximizes the recovery from surgery and treatment.
- Have a treat to look forward to: dinner at a favourite restaurant, a drive in the countryside.
- Talk to someone who has been there. It might be a big help and also lessens the stress on you and your family.
Making treatment decisions

• A patient’s story

• Making decisions about treatment

• Ottawa Personal Decision Guide
A patient’s story

My journey with cancer started in 1990 when I had surgery for skin cancer. The skin cancer reoccurred in 1997 in another location, and was treated with surgery. I have been clean of skin cancer since then.

My next journey with cancer started in 2004 when my yearly medical determined that my PSA count had doubled since 2003. I underwent an ultrasound and no abnormalities were identified. A follow-up PSA 6 months later showed a PSA result of 13.8 (more than double the previous reading of 5.2).

I was sent to an urologist at the Cancer Centre and had a prostate biopsy in September 2005. All ten samples taken were negative. However, during a 3 month follow-up PSA blood test, my PSA level had risen to 20.2. Another biopsy was done and five out of ten samples were positive, confirming a stage T1c cancer with a Gleason score of 7 out of 10.

On May 2, 2006, I had surgery to remove my prostate and I was given an 80% chance of a complete cure. Unfortunately this did not occur and my PSA levels started to rise in 2007. The recommended treatment was salvage radiation in the prostate area, and I was given 33 treatments over 7 weeks starting in June 2007. Over the next year my PSA level reduced to zero and things looked good.

However, in 2009, my PSA started to rise again. In early 2010 it was continuing to rise every 3 months. Throughout 2010 I had many tests to try and locate the cancer source. In October a tumour was located in my lymph nodes by my left kidney. This was an extremely emotional time for me and my family waiting for scheduled tests and results, and making treatment decisions.

Fortunately my Oncologist and Surgical Oncologist suggested surgery to remove the tumour rather than the standard treatment of hormonal therapy. The surgery was completed successfully on December 7, 2010. My PSA level immediately went to zero and has remained at zero.

Throughout my journey I can only say that my treatment by the doctors and nursing staff has been excellent and I feel lucky to be living in Ottawa where we have an excellent Cancer Centre with a great medical staff.

I am lucky to be able to enjoy life every day with my family and friends and my advise to all men is to get a PSA test on a regular basis!

Yours truly,
Gerry Gilbert
Making decisions about treatment

With a variety of treatment options for men with prostate cancer, it can be challenging to understand which direction to go in with regards to choice of treatment. It is important to remember that each person’s situation is different and treatment decisions must reflect the individual’s medical circumstances, treatment options, side effects, and own personal values. To best make decisions with regards to your treatment it is important to:

• Become informed about prostate cancer, its treatments, side effects, and ways of treating side effects. Search out reputable sources of accurate and relevant information. Consult with medical librarians such as one at the Ninon Bourque Patient Resource Library (see page 79) and other information specialists. Many men find it helpful to do some research of their own to better understand the treatment options that may be best for them.

• Understand your situation—the stage and grade of the cancer and your general overall health are key factors in deciding the best treatment options for you. Keep notes regarding your medical appointments, symptoms and other relevant information.

• Seek out advice and guidance from the doctors who are treating you. Ask for a second opinion if needed.

• Discuss your situation with your spouse, partner, or other important people in your life. They are affected by the cancer diagnosis and the choices you will make.

• Speak with others who have dealt with similar situations but also remember that each person is different and your needs may be very different from someone else who is dealing with prostate cancer.

• Search out prostate cancer support groups for support and information. Speak with nurses, social workers or other health-care professionals.

• If there is no urgency in making decisions, take time to consider the options.

• Use the Ottawa Personal Decision Guide provided in this guide to help you clarify your decisions. Ask for help from health-care professionals if you need assistance.
Ottawa Personal Decision Guide

**What is the Decision Guide?**

The decision guide is a tool that is designed to help individuals think through information to help them make difficult decisions. It is a step-by-step process that helps you to make the decision and then plan how to carry it through. You can share this tool with your health-care providers for any further support or feedback that you may need.

**What are some of the difficult decisions?**

After a diagnosis with prostate cancer, you will be faced with a number of decisions. For example: What is the best treatment for you? What are the best ways to manage side effects? Challenging personal decisions also arise: Who to share your diagnosis with? How to manage your finances? Should you consider complementary therapies? This guide is not focused on any one decision; rather, it can lead you through thinking about any decision that you are dealing with.

**Do I need to use this guide?**

The following signs may mean that you are having a hard time making a decision. The guide may be helpful if you are:

- Feeling unsure about what to do.
- Feeling worried about the outcomes of the decision.
- Feeling upset when you think about the decision.
- Feeling like you can’t get the decision off your mind.
- Wavering between the choices you face.
- Wanting to put off making the decision.
- Questioning what is important to you in making the decision.
- Experiencing physical signs of stress when you think about the decision.

During a time where emotions and anxieties may be quite high, this guide may help you to think through some of the more difficult challenges that you will face throughout your cancer journey.
## Ottawa Personal Decision Guide  
For People Facing Tough Health or Social Decisions

You will be guided through four steps:

1. **Clarify the decision.**
2. **Identify your decision making needs.**
3. **Explore your needs.**
4. **Plan the next steps.**

### 1. Clarify the decision.

<table>
<thead>
<tr>
<th>What is the decision you face?</th>
</tr>
</thead>
<tbody>
<tr>
<td>What is your reason for making this decision?</td>
</tr>
<tr>
<td>When does this decision have to be made?</td>
</tr>
<tr>
<td>How far along are you with your decision?</td>
</tr>
<tr>
<td>Are you leaning toward a specific option?</td>
</tr>
</tbody>
</table>

- I have not yet thought about options
- I am close to choosing an option
- I have already made a choice

- Yes
- No

If yes, which one?

### 2. Identify your decision making needs.

| Do you have enough support and advice from others to make a choice? |
| Are you choosing without pressure from others? |
| Do you know which options are available to you? |
| Do you know both the benefits and risks of each option? |
| Are you clear about which benefits and risks matter most to you? |

- Yes
- No

### 3. Explore your needs.

#### A. Support

<table>
<thead>
<tr>
<th>Who else is involved?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Name:</td>
</tr>
<tr>
<td>Name:</td>
</tr>
</tbody>
</table>

| Which option does this person prefer? |

| Is this person pressuring you? |

| How can this person support you? |

| What role do you prefer in making your choice? |

### Decisional Conflict Scale © 2006 O’Connor

People who answer “No” to one or several questions are more likely to delay their decision, change their mind, feel regret about their choice or blame others for bad outcomes. Therefore, it is important to work through steps three and four that focus on your needs.
**Ottawa Personal Decision Guide**

**For People Facing Tough Health or Social Decisions**

### B. Knowledge
In the balance scale below, list the options and main benefits and risks that you already know. Underline the benefits and risks that you think are most likely to happen.

<table>
<thead>
<tr>
<th>BENEFITS</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Add ★ to</td>
</tr>
</tbody>
</table>

| Option #1 is: | |
| Option #2 is: | |
| Option #3 is: | |

### C. Values
Use stars (★) to show how much each benefit and risk matters to you. 5 stars means that it matters “a lot”. No star means “not at all”.

<table>
<thead>
<tr>
<th>RISKS</th>
<th>How much it matters</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Add ★ to</td>
</tr>
</tbody>
</table>

| Option #1 is: | |
| Option #2 is: | |
| Option #3 is: | |

### D. Certainty
Circle the option with the benefits that matter most to you and are most likely to happen. Avoid the option with the risks that are most important to avoid.

|          | |

---

**Plan the next steps based on your needs.**

**✓ Things making the decision difficult**

<table>
<thead>
<tr>
<th>A. Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>You feel you do NOT have enough support</td>
</tr>
<tr>
<td>You feel PRESSURE from others to make a specific choice</td>
</tr>
</tbody>
</table>

**✓ Things you are willing to try**

| Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends) |
| Find out what help is on hand to support your choice (e.g. funds, transport, child care) |
| Focus on the opinions of others who matter most. |
| Share your guide with others. |
| Ask others to complete this guide. |
| Find areas of agreement. When you disagree on facts, agree to get information. When you disagree on what matters most, respect the other’s opinion. Take turns to listen, mirror back what the other has said matters most to him or her. |
| Find a neutral person to help you and others involved. |

<table>
<thead>
<tr>
<th>B. Knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>You feel you do NOT have enough facts</td>
</tr>
</tbody>
</table>

| Find out about the chances of benefits and risks. |
| List your questions and note where to find the answers (e.g. library, health professionals, counsellors): |

<table>
<thead>
<tr>
<th>C. Values</th>
</tr>
</thead>
<tbody>
<tr>
<td>You are NOT sure which benefits and risks matter most to you</td>
</tr>
</tbody>
</table>

| Review the stars in the balance scale to see what matters most to you. |
| Find people who know what it is like to experience the benefits and risks. |
| Talk to others who have made the decision. |
| Read stories of what mattered most to others. |
| Discuss with others what mattered most to you. |

**☐ Other factors making the decision DIFFICULT**

List anything else you need:

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The wellbeing of you and your loved ones

- The emotional wellbeing of you and your loved ones
- Helping the children in your life to understand
- Sexuality and intimacy
- Getting on with life throughout treatment
- Working throughout treatment and other financial considerations
- Managing financial and personal care issues and concerns
- Paying for medications
The emotional wellbeing of you and your loved ones

The feelings and emotions experienced during treatment for prostate cancer may be unexpected and may surprise you. Remember it is normal to feel worried, anxious, nervous, depressed, or even angry. Prostate cancer never comes at a good time in your life so it will inevitably have an effect on other aspects of your life. Your day to day activities may not have the same level of predictability that they once had and this can be frustrating and unsettling. Plans made for the future may change as you accommodate treatments and doctors’ appointments and this can be disappointing for you, as well as your partner and family members.

You may feel a sense of urgency to obtain treatment as soon as possible. Waiting for diagnostic tests and results, doctors’ appointments, and decisions about treatment can be difficult to cope with. You may be more irritable, preoccupied, and anxious than normal.

Family and friends may be experiencing the same reactions. They will want to support you through this experience and often feel frustrated that they cannot do more for you. Remember that this is a stressful time for all and everyone may be feeling that they are on “emotional overload”.

Prostate cancer will have an impact upon the relationship between the man and his partner. Partners and spouses may be feeling concerned about your physical and emotional health. They may be worried about finances, impact upon your family, and your lifestyle. They too will be helping you deal with the impact and side effects of treatment. With added stress in your day-to-day life there may be misunderstandings and more tensions in your home life.

Suggestions for partners, family, and friends to help you

• Face the cancer together. It is reassuring and comforting for your loved one to know your support will always be there.

• Don’t assume you know what your loved one is thinking or feeling. Talk to each other about your emotional reactions and concerns.

• Communication can also be physical; holding hands or hugging.

• Often everyone feels they have to maintain a positive attitude. Pretending that everything will be all right denies the person with cancer the opportunity to discuss fears and anxieties. Also avoiding discussions about cancer, out of concern to protect each other, results in feelings of isolation.
• It is important to have life go on as close to normal as possible. Don’t let the prostate cancer “move in” and take over your home.

**Suggestions for partners, family, and friends to help themselves**

• Take time for yourself and remember to be good to yourself. This is not selfishness; it’s keeping yourself replenished and healthy in order for you to continue caring for your loved one’s needs.

• Take care of your own body. To avoid stress-related illness, pay attention to your own physical needs by eating a healthy diet, exercising, getting sufficient sleep and finding time to relax. Don’t put off your own medical and dental check-ups.

• Delegate responsibility and accept help from outside the home. Often other family members and friends want to help but are not sure what they can do. This makes them feel useful and helps reduce stress.

• Be assertive. Be realistic about what you can and cannot be responsible for right now.

• Discuss your feelings and reach out for support.

• Give yourself permission to ask questions from health-care professionals. Having answers to your questions can be a great stress reducer.

• Set priorities. Don’t try to do everything.

• Laugh. It is said that 20 minutes of belly laughter is equal to 5 hours of deep meditation.

**Helping the children in your life to understand**

When someone they love is ill, children experience sadness, loneliness, confusion, anger, fear of separation, and of being left alone. They worry about the safety of the family. Depending on their ages, they will react differently. Sometimes they “act out,” withdraw, or overcompensate by taking on too many responsibilities. Children tend to express their emotions in actions rather than words.

Explain, in terms they understand, about your prostate cancer and treatments, and how it may impact them. Be open and honest from the start. Children have wonderful antennas—they pick up when something is wrong. Their imagination may be worse than the reality. Let them know that you will keep them informed if there are changes, and that they can ask any questions. A child has a right to know about
anything that affects the family, as a diagnosis of prostate cancer does. Not telling is a breach of trust. It is also OK to say you don’t know the answer to their question when you don’t have the answer.

Reassure the children that there is nothing wrong with feeling sad, crying, and being angry. Drawing, reading storybooks, and having special play times sometimes allow younger children to express their fears.

Tell them that prostate cancer is not an illness that you can catch from someone else such as the flu, or colds. Assure them nothing they have done, said, or thought caused the prostate cancer to occur.

Things you can do to help the children in your life cope include the following.

• Involve your children in your treatment program.
• Try to keep the family routine as much as possible, including being consistent with discipline.
• Notify teachers and all significant adults in the child’s life such as sitters, coaches, neighbors, as soon as possible. They can offer extra attention and support.
• Communicate with children on a regular basis. Try to reserve consistent time for them.
• Encourage children to keep up their outside activities.

**Sexuality and intimacy**

Affection, physical intimacy, and closeness with a partner or spouse is an essential part of a caring relationship, which becomes even more important in the midst of a medical crisis, such as prostate cancer. Unfortunately some treatments for prostate cancer will have an impact upon the man’s sexual functioning and capacity. This not only becomes the man’s issue to deal with, but also his partner’s. Your sexual relationship is a private part of life so it may be difficult to talk about it openly. However, ignoring the issue does not make it go away.

The following are some suggestions to help you in maintaining a sexually satisfying relationship with your partner.

• Communicate with your partner openly and honestly about the difficulties you may experience. You may be surprised how understanding your partner can be and how open they may be to dealing with the issue together.
• Clarify with your doctor the exact nature of the sexual dysfunction you may experience. Explore what treatments and aids are available to help you. Ask for a referral to a medical specialist if appropriate.

• Be open to new ways of relating romantically and sexually. Be creative and use this time as an opportunity to rejuvenate your relationship.

• Be kind and patient with yourself and your partner.

• Meeting with a counselor who specializes in treating sexuality issues may help you to communicate more easily, and may be able to advise you and your partner how to do things a little differently in your intimate relationship.

• Remember that prostate cancer does not mean the end of your intimate relationships.

Getting on with life throughout treatment

For those who receive a cancer diagnosis it can sometimes feel as though they are forced to put their lives on hold. Plans change and all energy is spent dealing with the cancer. Having a diagnosis of prostate cancer does not mean however that all normal activities must change or stop. For many people, keeping to routines gives a sense of order and control. If you feel you are able to maintain the activities and schedule that you normally do, then it may help you to feel a bit more normal during treatment.

However with surgery and other treatments it may not be possible to do all the things that you did previously and this may be the time to ask family and friends for help. Maintaining hobbies or finding new ones can help you fill your time differently. Be kind to yourself. Find what gives you pleasure and try to do these things when you have the energy to do so.

The rule is: Do those things that you enjoy and are helpful to your physical and mental health, try to avoid or ask others to do those things that are a burden.
Working through treatment and other financial considerations

If you are in the workforce when you receive a diagnosis of prostate cancer, you will need to consider whether you should take a leave from your work. The thoughts of trying to juggle a busy and stressful job, doctor’s appointments, treatment schedules and family commitments can be overwhelming for many. However, if your work is part of your support system or if, financially, you are not able to take a leave, you may choose to continue to work. Depending on your condition, you may want to consider doing reduced hours or going part-time for a while. Your treatment may change your ability to function normally at work or you may need to take prolonged absences depending on your treatment plan. You will need to maintain ongoing discussions with your employer and physician.

Managing financial, personal care issues, and other concerns

You may have specific questions related to financial concerns such as “Can I get disability pay or Employment Insurance Benefits while I am receiving treatment?” Information is listed in the Resources section of this Guide. If you need more information and guidance, the social worker who is part of the health-care team will be pleased to help you. They can provide assistance by informing you about community support for finances, extra help at home, transportation assistance to treatments, power of attorney and will.

Paying for medications

You may have to pay for some medications throughout your treatments depending on your drug coverage plan. Private health insurance plans may possibly pay for most prescriptions however some may not be covered. Ontario Drug Benefits – the government plan for those individuals receiving their Old Age Pension, Ontario Works, or Ontario Disability Program will also cover most drugs for those in receipt of the above-named benefits. If you do not have a health plan that covers prescribed drugs or one that only partially covers the cost you may want to consider applying for the Ontario government’s Trillium Drug Plan. This plan is geared to income and may help pay for part of the cost of prescribed drugs. This may be of particular benefit if you are receiving hormonal treatments as some treatments may be costly. You may speak to the social worker at the Cancer Assessment Clinic or the Cancer Centre for further information or refer to the Resources section in this guide.
Maintaining a healthy lifestyle

- Maintaining a healthy lifestyle
- Benefits of exercise
- Healthy eating
- Complementary treatments
- The role of the family doctor
Maintaining a healthy lifestyle

Adopting healthy lifestyle choices after a diagnosis of prostate cancer may be beneficial in helping you through your treatment experience. Now may not be a time to make dramatic changes however some changes may help you stay as healthy as possible. After treatment, they will help you maintain an overall sense of wellbeing. Now may be a time to consider:

- Improving your eating if you do not already have a balanced diet.
- Maintaining physical activity at a level you can sustain given the treatment you may be having.
- Asking for help in quitting or reducing smoking if you are a smoker.
- Reducing your alcohol consumption if you are indulging too much.

Always consult your doctor before making significant changes to your lifestyle.

The benefits of exercise

In addition to enhancing a healthy lifestyle, exercise can reduce the impact of some of the side effects of treatments for prostate cancer. Exercise has been shown to help reduce fatigue, maintain or improve muscle mass, increase one’s metabolic rate which in turn reduces body fat, as well as reduce depression and anxiety. In some cases it can provide the opportunity for social interaction and group support.

Don’t let the idea of exercise intimidate you. Benefits in health occur when exercise is **MODERATE** and **REGULAR**. Check with your doctor before beginning any program, and plan your exercises with a **SMART** goal in mind. Something that is **S**pecific, **M**easurable, **A**ttainable, **R**ealistic, and **T**imed. Try to find a variety of activities you like. Some should be aerobic type exercises such as walking, cycling, swimming, or skiing. Activities that improve muscular strength and endurance such as weight lifting and activities that improve flexibility (bending and stretching type movements) are important for overall fitness. Try and be active on most days on a regular basis. You can be active at a local community center with a personal trainer or in a group fitness class, on your own at home with a “How to…” book or video, or find a buddy and begin walking everyday and do some stretches when you get home. You will feel great!

- Make a habit of going outside everyday for short walks, even better if you can go with someone whose company you enjoy. Increase the distance, as you are able.
- Do stretching exercises while you are at rest, for example: when watching TV.
- If gardening or light yard work gives you pleasure, try it for short periods.
Healthy eating

Making sense of all the information about nutrition is difficult and can make you feel like you are lost in a jungle.

The full relationship between the foods we eat and prostate cancer is not yet known. The information below is designed to guide you through the process of changing your eating habits and your lifestyle for the better, in the hopes of improving your overall health.

1. **Follow Canada’s Food Guide**
   By following Canada’s Food Guide you will meet your needs for vitamins, minerals, and other nutrients while reducing your risk of obesity, type 2 diabetes, heart disease, osteoporosis and some cancers. This will contribute to your overall health and vitality.

Fruits and vegetables

- Fruits and vegetables are rich in cancer-fighting nutrients called phytochemicals.
- Depending on age, it is recommended to eat at least 7 portions/servings of a variety of non-starchy vegetables and fruits every day.
- Eat at least 1 dark green and 1 orange vegetable each day.
- Choose vegetables and fruit prepared with little or no added fat, sugar or salt.
- Have vegetables and fruits more often than juice.

Grain products

- Eat relatively unprocessed cereals (grains) with every meal.
- Choose grain products that are lower in fat, sugar or salt.

Milk and Alternatives

- Adult men 19 to 50 yrs are recommended to consume 2 servings.
- Adult men over the age of 50 are recommended to consume 3 servings.
- Drink skim, 1% or 2% MF (milk fat).
- Select lower fat milk alternatives.
Meat and Alternatives
• Consume meat alternatives such as beans, lentils and tofu (not set in calcium) often.
• Eat at least 2 servings of fish each week.
• Select lean meat and alternatives prepared with little or no added fat or salt.
• Limit intake of red meat to 500 g (18 ounces) a week.
• Avoid processed meats.

Fats and oils
• Include a small amount (30 to 45 mL) of unsaturated fat each day: this includes oil used for cooking, salad dressings, margarine and mayonnaise.
• Use vegetable oils such as canola, olive and soybean.
• Choose soft margarines that are low in saturated and trans fats.
• Limit butter, hard margarines, lard and shortening.

Alcohol
• If alcoholic beverages are consumed, limit consumption to no more than 2 drinks per day.

Water
• Drink water regularly.
• Increase intake of water in hot weather or when activity level is increased.

Other
• Limit energy-dense foods, sugary drinks and fast foods.

2. Limit your calcium intake.
Diets high in calcium may increase the risk of developing prostate cancer, but high calcium intake does not cause prostate cancer.
You can achieve optimum levels of calcium by choosing no more than 3 daily servings of milk and milk products. Milk and milk products include: milk, cheese, yogurt, pudding. Limit other high-calcium foods: sardines, canned salmon with bones, tofu (processed with calcium sulfate), calcium-fortified beverages (orange juice/soy/rice beverages), almonds, Brazil nuts, sunflower and sesame seeds, white beans, molasses and figs.
Calcium has an essential role in nerve functioning, blood pressure, immune defenses and in the development and maintenance of bone and teeth. It also aids in blood clotting and is necessary for digestion and muscle contraction and relaxation. Calcium should therefore not be completely omitted from your diet.

3. **Flax**  
The role of flax in the primary or secondary prevention of prostate cancer or during cancer therapy remains uncertain. Consuming moderate amounts of dietary flax and flax containing products as part of a diet rich in vegetables and fruits and consistent with Canada’s foods Guide remains prudent advice. Supplemental flax is discouraged in men with prostate cancer or men who are believed to be at high risk of developing prostate cancer until more data is available.

4. **Maintain weight within ideal body weight range**  
Avoid weight gain and increases in waist circumference throughout adulthood.

5. **Be moderately physically active**  
Moderate activity is equivalent to brisk walking for at least 30 minutes every day. As fitness improves, aiming for 60 minutes or more of moderate, or for 30 minutes or more of vigorous, physical activity every day is desired. Limit sedentary habits.

6. **Nutritional supplements**  
The evidence shows that high-dose nutrient supplementation can have unexpected adverse effects. Aim to meet your nutritional needs through diet.

Remember, no single food or nutrient should be viewed as a magic bullet. Following a well balanced diet based on Canada’s Food Guide to Healthy Eating can help you be on your way to a healthier you.

**References**

   Available: publications@hc-sc.pc.ca or 1-800-267-1245
Complementary treatments

Complementary therapies are being accepted more and more as part of the care of people with cancer. Complementary therapies are used to decrease symptoms and to enhance the quality of a person’s life along with conventional medical care. One aim of complementary health-care is to help people take charge of their health-care and lifestyle. They can help you live your daily life in a healthy way, even when faced with a life-changing illness. An experienced complementary therapist will work with you to find treatments that will be most effective for you. It is important to tell your physician, nurse, and pharmacist that you are using complementary therapy.

A selection of complementary therapies frequently used in cancer care

The following list includes very brief descriptions of some therapies. As most complementary therapies are not regulated, the best way to find a therapist is through personal recommendation. Look for personal and professional experience with cancer patients, ask questions, and look for someone who is working full-time in the business. Extended Health-care Insurance covers an increasing number of complementary therapies.

Acupuncture

Acupuncture is an ancient Chinese medical procedure, based on the principle that health related energy flows through the body through energy lines called meridians. Any type of stress or illness can cause blocks in this flow of energy. The insertion of fine needles into various acupoints along these meridians may change or increase energy flow through the body. Symptoms may decrease; energy and a sense of wellness may be improved.

Some promising results from scientific clinical trials are showing that acupuncture may be useful in relieving pain and treating nausea and vomiting related to chemotherapy.

Massage therapy

Massage therapy uses therapeutic stroking and kneading, usually using oil and working in a systematic pattern. The goal is to treat a specific problem and/or to create relaxation in the body. The techniques are designed to relax, or strengthen and stimulate; both may happen at the same time.
Relaxation techniques
Relaxation techniques can help to decrease the anxiety and stress that result from day-to-day life. These methods help you relax, working with the mind and/or the body. They are techniques that can be easily learned, and something that people can do for themselves. You can buy or borrow tapes that can talk you through relaxation exercises. The basis for all relaxation is focusing on breathing. This could include learning deep abdominal breathing or simply learning to focus on the breath coming in and out of the body.

Imagery
Imagery is a technique that uses relaxation to create a sense of health and well being through visualization, touch, smell, taste, movement and hearing.

Meditation techniques
Meditation is a method of relaxation from ancient times. Meditation is stilling of the mind by focusing on one thing at a time, whether it is breathing, counting or repeating one word.

The role of the family doctor in my overall general health
The role of the family doctor during the course of your treatment should remain much the same as before your cancer diagnosis. He/she will receive reports about your appointments, as well as results of any diagnostic or staging test. It may be helpful to specifically ask for copies of test results, appointments, etc. to be sent to your family physician.

Your family doctor serves as a vital link between you and your prostate cancer health-care team by assisting in the coordination of your care, as well as providing information and support for your entire family. It is recommended that, occasionally, throughout the course of your treatment, you make an appointment to see your family physician. Although you can feel overwhelmed with numerous appointments, it is important to remember to attend to all areas of your health.
If you do not have a family physician, it is vital that you find one to be part of your health-care team. The College of Physicians and Surgeons of Ontario has a “doctor search” section on their Website which can help your search: www.cpso.on.ca. If you still cannot find a family doctor, speak to your nurse or social worker for help.
SECTION 8

When my treatment is over

• Follow-up after treatment

• Questions for my physician after completing treatment

• How will I feel at the end of my treatment?
Follow-up after treatment

Regardless of the type of treatment you have for your prostate cancer, you will have regular follow-up appointments with your surgeon or oncologist. You may have diagnostic tests booked prior to that appointment to provide baseline information to your physician. The frequency of visits will depend on the treatment you have received and the length of time since completing the treatment.

Some people find follow-up appointments difficult. Sometimes it helps to bring a trusted friend or family member along for support and an added ear to hear what the doctor has to say.

Your family doctor will continue to coordinate your general overall health-care, while your prostate cancer health team will be your consultants regarding cancer related issues.

Questions for my physician after completing treatment

1. Who will see me for follow-ups? How often?
2. What tests will be done to monitor my condition? How often?
3. What will the tests tell us?
4. Do I need medications?
5. What symptoms should I notify you of? How likely are they to occur?
6. What changes might I experience? Are there long-term side effects of treatment?
7. Are there limitations to doing exercises?
8. Will I be able to return to work?
9. Who else can I talk to about specific problems? e.g. sexual concerns
How will I feel at the end of my treatment?

The end of treatment will bring a period of adjustment—both physical and emotional. While treatment may be demanding and frequent it also brings a sense of reassurance to have contact with the health-care team. It is normal that despite your excitement about finishing treatment you may also be feeling a little anxious and worried. It is not uncommon at this time for some men to have an increased fear about cancer recurrence. This is likely to pass with time the longer you have been finished your treatment. If not, you may want to discuss further with a professional.

Fatigue may be a problem for some men after treatment is complete. Learn to pace yourself. You may have to begin to re-define what is “normal” in your life. Priorities may change. Be good to yourself! Do the things you enjoy, focusing on the things you “want” to do, not on what you should do. Attending a support group with others going through similar situations can provide a place to talk about your concerns and share experiences. It is important to develop and maintain good health habits: eating properly, getting adequate sleep, and exercising.

Family life and roles within the family may have been affected by your experience with cancer and treatments. Discuss your experience and fears openly with family and friends. Recognize that you been through a hard time. If you need additional support, ask for help from professionals such as social workers, nurses, clergy, psychologists, and psychiatrists.
Support and information resources at The Ottawa Hospital Cancer Centre and in the community

The Ottawa Hospital Cancer Assessment Clinic
The Ottawa Hospital, Cancer Centre
Psychosocial Oncology Program
Social Workers
Champlain Community Care Access Centre
Spiritual Care Services

Community resources
Canadian Cancer Society
Prostate Cancer Canada Network (PCCN) Ottawa
Gay buddies with prostate cancer
Finding a Family Doctor
Financial Information
Hospice at Maycourt
Lodging and Transportation

Telephone support
Canadian Cancer Society

Information resources for prostate cancer patients and their families
Ninon Bourque Patient Resource Library
The Ottawa Hospital Website
Publications by The Ottawa Hospital
Prostate Cancer Resources
Other Resources
The Ottawa Hospital Cancer Assessment Clinic (CAC), 7NE, General Campus

The Ottawa Hospital Cancer Assessment Clinic (CAC) is located at the General Campus, on the 7th floor. This clinic provides care to patients undergoing assessment and diagnosis for colorectal, prostate and lung cancer. The clinic is open Monday to Friday from 8 a.m. to 4 p.m. The reception main phone number is 613-737-8899, ext. 79670.

The CAC is a gateway to cancer care with coordination provided throughout the system. The CAC streamlines referral process to specialists and diagnostic testing. Care is provided by an interdisciplinary team including nurses, clerical staff, surgeons, radiation oncologists, medical oncologists, social workers and dieticians. The team provides disease information and educational material. Nurses provide coordination of care, telephone support and are a primary contact for patients and families. Social workers support and counsel newly diagnosed cancer patients and their families. Your contact with the interdisciplinary team will allow you to be better informed about you medical situation and treatment options. In consultation with the team, you can make the best decision regarding treatment for you.

The Ottawa Hospital Cancer Centre (TOHCC)

TOHCC is the cancer treatment centre for Eastern Ontario. The Centre is open Monday to Friday from 8:00 to 4:00. The main number is 613-737-7700.

For problems or emergencies during Cancer Centre hours, phone the main number and ask for your nurse’s extension. For emergencies that are related to your cancer treatment, after hours or on weekends and holidays, call 613-737-7700 and wait for TOH switchboard. You will be asked to leave a message including your name and phone number, the name of your oncologist, and if you would like to speak to the Oncologist “on call’’. If your concerns are not related to your cancer or treatment, please call your family physician first. In an emergency situation, please go to your nearest Emergency Department or call 911 for assistance.

- The Ottawa Hospital – Cancer Program Online:
  www.ottawahospital.on.ca → Clinical Services → Departments, Programs, Clinics and Services (drop down menu) → Cancer Program
  or: www.ottawahospital.on.ca/wps/portal/CancerProgramEN
• Operates two sites; at the General Campus of The Ottawa Hospital and the Irving Greenberg Family Cancer Centre located at the Queensway Carleton Hospital. As well, there are outreach clinics at a number of regional hospitals.
• Provides comprehensive cancer care and treatment including chemotherapy treatment, radiation therapy treatment, clinical trials, consult and follow-up visits.
• Provides a full range of supportive care programs including counseling and support groups.

Psychosocial Oncology Program

The Psychosocial Oncology Program is an interprofessional service that provides access to support and rehabilitation for cancer patients and their families. You can access information and referral depending on your needs. Services are provided by the following disciplines: Social Work, Psychology, Psychiatry, Nutrition, Occupational Therapy, Physiotherapy, Kinesiology and Speech Language Pathology. A referral can be made by a member of your health-care team to the appropriate professional.

Social workers

Social workers at the Cancer Centre and the Cancer Assessment Clinic are part of The Psychosocial Oncology Program and provide individual and family counseling services and offer several support groups. They can also help you with practical issues such as access to medication coverage, transportation, financial support and work-related issues.

This service is available to all patients with a cancer diagnosis and their families. Your doctor or nurse can make a referral to a social worker on your behalf, or you can call 613-737-7700, ext. 70516. Social workers at the Cancer Assessment Clinic can be accessed at 613-737-8898, ext. 79670.

Champlain Community Care Access Centre

The Oncology service of the Champlain Community Care Access Centre (CCAC) is available to patients at the Cancer Centre. The CCAC provides support services in the home, as well as access to long-term care. If you feel you need a referral to community care, ask your nurse or physician who will make the referral for you. You can also contact the CCAC yourself. A CCAC case manager can meet with you at
the Cancer Centre to talk about what you may need. Your case manager can also advise you about additional services and supports in the community and how to access them. Your case manager will see you if you are admitted to hospital and will reassess your needs before you are discharged.

Information about the Ottawa Community Care Access Centre is also available on the Website at www.ottawa.ccac-ont.ca or phone 613-745-5525 or 1-800-538-0520.

**Spiritual Care Services**

Professional interfaith chaplains are part of the health-care team. The chaplain can help people who are experiencing distress by providing spiritual care and support and by helping to find inner sources of personal spiritual strength. To speak with a chaplain, call 613-798-5555, extension 78126 (General Campus) or extension 14587 (Civic Campus).

**Community resources**

**Canadian Cancer Society**

The Canadian Cancer Society offers a wide range of services to cancer patients. These services include transportation, emotional support, information, wigs, smoking cessation, etc. The Canadian Cancer Society has the following local offices in the Ottawa area:

<table>
<thead>
<tr>
<th>Canadian Cancer Society Unit Office</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ottawa Unit</td>
<td>613-723-1744</td>
</tr>
<tr>
<td>Lanark, Leeds and Grenville Unit</td>
<td>1-800-367-2913 or 613-267-1058</td>
</tr>
<tr>
<td>(Brockville, Carleton Place, Gananoque, Perth and Smith Falls)</td>
<td></td>
</tr>
<tr>
<td>Renfrew County Unit</td>
<td>1-800-255-8873 or 613-735-2571</td>
</tr>
<tr>
<td>(Arnprior, Deep River, Eganville, Pembroke, Petawawa and Renfrew)</td>
<td></td>
</tr>
</tbody>
</table>
Stormont, Dundas, Glengarry and Prescott Russell Unit
(Cornwall, Hawkesbury and Russell)  1-800-669-4181 or 613-932-1283

You can also find out about resources in your community on the Ontario Division section of the Canadian Cancer Society’s Website at www.ontario.cancer.ca.

**Prostate Cancer Canada Network (PCCN) Ottawa**

Information and support group for men with prostate cancer, 613-828-0762. Meets 3rd Thursday of each month at St. Stephen’s Anglican Church, 930 Watson St., Ottawa; www.pccnottawa.ca.

**Gay buddies with prostate cancer**

Information and support group for gay men with prostate cancer. Contact: bruce@bursey.ca.

**Finding a family doctor**

If you do not have a family physician, you can call The College of Physicians and Surgeons of Ontario to find out who is taking new patients. Call 1-800-268-7096, ext. 626 or visit the Website at: www.cpso.on.ca/docsearch.

**Financial information**

If you have financial concerns related to your prostate cancer and treatment, you can contact the social workers at the Cancer Centre or the Cancer Assessment Centre. The following organizations can also provide you with information:

- **Ontario Works**  1-800-268-1154 or 416-314-5518
  www.mcss.gov.on.ca/mcss/english/pillars/social/contacts/owcontract.htm
  Contact your local Ontario Works office listed in the blue pages of your phone directory.

- **Ontario Trillium Drug Program**  1-800 575-5386 or 416-326-1558
Ontario Disability Support Program ............... 1-888-789-4199

Employment Insurance Benefits ............... 1-800-206-7218 or
Contact your local Human Resources and Skills Development Canada office,
listed in the federal government services pages of your phone directory
www.hrsdc.gc.ca/en/gateways/nav/top_nav/program/ei.shtml

Canada Pension Plan – Disability Benefits ........... 1-800 277-9914

The Canadian Cancer Society does not provide financial assistance, but does have
information in the Website at www.onotario.cancer.ca. (Select “service directory” from
the “get support” section and then “where will my money come from” from the menu
on the left. (www.onotario.cancer.ca/ccs/internet/standard/0,3182,3543_316353__
langId-en,00.html).

You can also phone any of the Canadian Cancer Society offices listed above for
information.

Lodging and transportation

The Maurice J. Grimes Lodge, located at 200 Melrose Avenue, Ottawa, provides
accommodation for cancer patients who live more than 40 kilometers from the
Cancer Centre and who are coming to the Centre for tests or treatment. The Lodge
is open from Monday to Friday. For more information, call 613-725-6328,
ext. 10355.

The Ottawa Hospital Intern’s Residence, 751 Parkdale Avenue, Ottawa, rents
apartments for short stays for out-of-town families of Ottawa Hospital patients. For
more information, call 613-761-5400.

If you need transportation to medical appointments, the following are some options:

Canadian Cancer Society volunteers may be able to provide transportation. Call
your local Cancer Society unit office (see page 74). Social workers can also help
you to make transportation arrangements.
The Hospice at May Court

The Hospice at May Court is a community-based organization committed to providing support and practical help for people and their families who are facing a life threatening illness, regardless of age, religion or culture. Its objectives are:

• to ensure the patient’s pain, discomfort and anguish are alleviated as far as possible
• to ensure that the needs of the patients and their loved ones are addressed in all aspects, including physical, emotional, social, psychological and spiritual
• to help the patient remain alert and in control in a sympathetic environment, ideally in their own home
• to help the patients and their loved ones find answers to their questions, and advocate on their behalf
• to assist the bereaved in dealing with their grief.

For more information: 613-260-2906.

Telephone support

Canadian Cancer Society

Cancer Information Service – 1-888-939-3333
Provides information on all aspects of cancer treatment, risk reduction and community support. The service is available Monday to Friday, from 9 a.m. to 6 p.m.

Cancer Connection Ontario – 1-800-263-6750
Peer support to cancer patients and their families provided by volunteers who have had cancer themselves or been caregivers to cancer patients.
Legal issues

Every adult, regardless of age or health, should complete a Power of Attorney and make a will.

Power of attorney

A Power of Attorney is valid only when you are living. There are two types of Power of Attorney:

1. Continuing Power of Attorney for Property allows you to name a person(s) to manage your financial affairs on your behalf, under specified conditions.

2. Power of Attorney for Personal Care allows you to name a person(s) to make decisions about your personal care, should you become mentally incapable. Personal care includes decisions about health-care, living arrangements, food, clothing, and safety. You can give verbal or written instructions, conditions, and restrictions to the person you have named. The most common type of instructions is to decline artificial life support in the event of a terminal disease. Your healthcare wishes, as expressed in this document, make it easier for both your family and your physician(s).

When you are planning to do a Power of Attorney, make sure you ask the person you want to manage your affairs or make decisions on your behalf, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where it is kept.

To do a Power of Attorney

1. Contact a lawyer

2. Go to the Ministry of the Attorney General Website at www.attorneygeneral.jus.gov.on.ca/html/PGT/powkit.htm, or contact a Hospital/Cancer Centre social worker, to obtain the “Ontario Ministry of the Attorney General” booklet which has information and the Power of Attorney forms. Using this booklet, you can do both the Power of Attorney for Property and Power of Attorney for Personal Care, at no expense.
**Will**

A will takes effect only upon a person’s death. The purpose of a will is twofold. It states your wishes for the distribution of your assets, and it names the person (the executor) to carry out this distribution. There are two types of wills: “formal wills” and “holographic wills”.

1. A formal will is usually prepared by a lawyer, but a will form can be purchased from a stationary store. For this type of will, the client signs it in the presence of two witnesses (beneficiaries and their spouses should not be witnesses).

2. A holographic will is prepared without a lawyer’s help. To be binding, a holograph will must be entirely in the person’s handwriting, with no printing or typewriting anywhere on the document and must end with the signature of the testator (the person making the will). This type of will does not need to be witnessed, but a witness is a good idea.

When you are planning to write a will, make sure you ask the person you want to be your executor, to make sure they are willing to take on this responsibility. When you have done the paperwork, let this person know, and tell them where it is kept.

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**Information resources for prostate cancer patients and their families**

**Ninon Bourque Patient Resource Library**

The Ninon Bourque Patient Resource library is dedicated to providing up-to-date, reliable cancer information to patients and their families. The Library has over 1,500 books, video and audiocassettes, CDs and CD-ROMs about cancer and related topics. Most of these items can be borrowed for three weeks. There are also two computers, which you can use to search for medical information on the Internet.

Library staff will help you to find information and can suggest reliable Websites and other resources for cancer information.

The Library is located at The Ottawa Hospital Cancer Centre General Campus on the main floor between the chemotherapy waiting room and Module A and is open Monday to Friday from 8:30 a.m. to 12:30 p.m. and from 1:00 p.m. to 3:30 p.m.

Phone: 613-737-7700, extension 70107
E-mail: patientlibrary@toh.on.ca.
The Ottawa Hospital Website

www.ottawahospital.on.ca

The Website provides information about the programs and services offered at The Ottawa Hospital. The Patient Services section tells you what you need to know if you are admitted to the hospital or coming for an appointment and includes maps, parking information and bus schedules. The Cancer Centre section contains information specifically for people having treatment for cancer.

Publications by The Ottawa Hospital

The Ottawa Hospital Cancer Centre has produced several booklets, which you may find helpful while having treatment at the Centre.

The following booklets are also available on The Ottawa Hospital’s Website at www.ottawahospital.on.ca.

The Ottawa Hospital Cancer Centre Patient Information Booklet. This guide prepares you for your first visit to the Cancer Centre by giving an overview of treatment, support services at the Centre and in the community, transportation, financial considerations, etc.

Chemotherapy Patient Information Booklet has general information about what chemotherapy is and how it is given, possible side effects, and frequently asked questions about chemotherapy.

Radiation Therapy Patient Information Booklet has general information about radiation treatment, how radiation treatment is given, coping with possible side effects, etc.

Prostate Cancer Resources

Resources are provided for your information only and are not intended as a substitute for medical care. If you have any questions about your cancer treatment, you should talk to your doctor or other health-care provider. The inclusion of a resource in this list does not necessarily imply endorsement by The Ottawa Hospital. Many of the following resources are available for loan from the Ninon Bourque Patient Resource Library at the General Campus of The Ottawa Hospital Cancer Centre. Library staff can also help you to find information on any cancer-related topic.
Books


American Cancer society’s complete guide to prostate cancer, David G. Bostwick, 2005.

Eat to beat prostate cancer cookbook: everyday food for men battling prostate cancer, and for their families and friends. David Rickett, 2006.


Eating well, staying well during and after cancer. Abby S. Bloch. American Cancer Society, 2004 (ISBN 0944235514)

Goes down easy! Recipes to help you cope with the challenge of eating during cancer treatment. Elise Mecklinger, 2006.


Pamphlets


**Clinical trials**

**Ontario Cancer Trials** – www.ontariocancertrials.ca

New cancer therapies are tested in clinical trials. You may wish to consider participation in a clinical trial when deciding on the best option for your treatment. You can search a database of all clinical trials taking place in Ontario and find out more about what clinical trials are.

**Websites**

**Prostate:**

Canadian Prostate Cancer Network – www.cpcn.org

Prostate Cancer Canada Network (PCCN) Ottawa – www.pccnottawa.ca

Canadian Cancer Society – www.cancer.ca

Princess Margaret Hospital – www.prostatecentre.ca

Prostate Cancer Foundation – www.prostatecancerfoundation.org

ProCure – www.procure.ca

Prostate Cancer Research Foundation of Canada – www.prostatecancer.ca

Prostate Cancer and Gay Men – http://health.groups.yahoo.com/group/prostatecancerandgaymen

Male Care – www.malecare.com

Mayo Clinic – www.mayoclinic.com
A Dance with Cancer – 5 Gay Men Confront Prostate Cancer – film is available at www.cancer.ca/LGBTQ

The Ottawa Hospital Website – information for patients and visitors/cancer program information – www.ottawahospital.on.ca

Our Voice – Living with Prostate Disease in Canada – www.ourvoiceinprostatecancer.com

Other resources:

The Patient Information Website of the American Society of Clinical Oncology (ASCO) – www.plwc.org
This Website is designed to help patients and families make informed health-care decisions about their cancer and its treatment. This site provides information on more than 85 types of cancer, clinical trials, coping, side effects, etc. The cancer information in this Website has been approved by American oncologists (cancer specialists).

The National Cancer Institute coordinates the U.S. federal government’s cancer research program. The Website has information for patients and health-care professionals on all aspects of cancer prevention, treatment, coping, etc. and includes information on cancer clinical trials taking place around the world.

MedlinePlus – www.medlineplus.gov
A service of the U.S. National Library of Medicine, this site provides a portal to health information. Some of the information is provided in the form of videos and slide shows and there is also “easy to read” information.

U.S. National Centre for Complementary and Alternative Medicine – nccam.nih.gov/

Unconventional Therapies
Terminology/Glossary
<table>
<thead>
<tr>
<th><strong>Adenocarcinoma</strong></th>
<th>A form of cancer that involves cells from the lining of the walls of many different organs of the body. Almost all prostate cancers are adenocarcinomas.</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjuvant</strong></td>
<td>An additional treatment used to increase the effectiveness of the primary therapy; radiation therapy and hormonal therapy are often used as adjuvant treatments following a radical prostatectomy.</td>
</tr>
<tr>
<td><strong>Benign</strong></td>
<td>Not cancerous. Benign tumours do not spread to tissues around them or to other parts of the body.</td>
</tr>
<tr>
<td><strong>Benign Prostatic Hyperplasia (or hypertrophy) (BPH)</strong></td>
<td>Benign (non-cancerous) condition in which an overgrowth of prostate tissue pushes against the urethra and the bladder, blocking the flow of urine.</td>
</tr>
<tr>
<td><strong>Bilateral</strong></td>
<td>Affecting both the right and left sides of the body.</td>
</tr>
<tr>
<td><strong>Biopsy</strong></td>
<td>The removal of cells or tissues for examination under a microscope. When only a sample of tissue is removed, the procedure is called an incisional biopsy or core biopsy. When an entire lump or suspicious area is removed, the procedure is called an excisional biopsy. When a sample of tissue or fluid is removed with a needle, the procedure is called a needle biopsy or fine-needle aspiration.</td>
</tr>
<tr>
<td><strong>Bladder</strong></td>
<td>A hollow muscular balloon shaped organ that stores urine until urination occurs.</td>
</tr>
<tr>
<td><strong>Bone scan</strong></td>
<td>A picture of the bones using a radioactive dye that shows any injury, disease or healing. This test helps to determine if cancer has spread to the bones.</td>
</tr>
<tr>
<td><strong>BPH</strong></td>
<td>See benign prostatic hyperplasia.</td>
</tr>
<tr>
<td><strong>Brachytherapy</strong></td>
<td>A procedure in which radioactive material sealed in needles, seeds, wires, or catheters is placed directly into or near a tumour. Also called internal radiation, implant radiation, or interstitial radiation therapy.</td>
</tr>
<tr>
<td><strong>Cancer</strong></td>
<td>The abnormal and uncontrolled growth of cells that may invade and destroy surrounding tissues (tumour).</td>
</tr>
<tr>
<td><strong>Chemotherapy</strong></td>
<td>The treatment of cancer involving the use of drugs to kill the cancer cells.</td>
</tr>
<tr>
<td><strong>Clinical trial</strong></td>
<td>Research experiment designed to evaluate a treatment or medication.</td>
</tr>
<tr>
<td><strong>Complementary Therapy</strong></td>
<td>The use of various practices to supplement or enhance conventional medical treatment, e.g. acupuncture, massage, herbs, energy forces and biologic treatments.</td>
</tr>
<tr>
<td><strong>Differentiation</strong></td>
<td>Refers to how mature (developed) the cancer cells are in a tumour. Differentiated tumour cells resemble normal cells and tend to grow and spread at a slower rate than undifferentiated or poorly differentiated tumour cells, which lack the structure and function of normal cells and grow uncontrollably.</td>
</tr>
<tr>
<td><strong>Digital Rectal Examination (DRE)</strong></td>
<td>An examination in which a doctor inserts a lubricated, gloved finger into the rectum to feel for abnormalities.</td>
</tr>
<tr>
<td><strong>Double-Blind, Double-Blinded</strong></td>
<td>A clinical trial in which neither the medical staff nor the person knows which of several possible therapies the person is receiving.</td>
</tr>
<tr>
<td><strong>Downsizing, Downstaging</strong></td>
<td>The use of hormonal or other forms of management to reduce the volume of prostate cancer in and/or around the prostate prior to other attempted curative treatment.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>-------------------------------------------</td>
<td>---------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>DRE</strong></td>
<td>See digital rectal examination.</td>
</tr>
<tr>
<td><strong>Duct</strong></td>
<td>In medicine, a tube or vessel of the body through which fluids pass.</td>
</tr>
<tr>
<td><strong>Dysplasia</strong></td>
<td>Cells that look abnormal under a microscope but are not cancer.</td>
</tr>
<tr>
<td><strong>EBR, EBRT</strong></td>
<td>External beam radiation (therapy).</td>
</tr>
<tr>
<td><strong>Ejaculation</strong></td>
<td>The release of semen through the penis during orgasm.</td>
</tr>
<tr>
<td><strong>Endorectal</strong></td>
<td>Through the rectum; there are endorectal MRIs as well as ultrasound to visualize the area. See transrectal ultrasound (TRUS).</td>
</tr>
<tr>
<td><strong>Endorectal Ultrasound (ERUS)</strong></td>
<td>A procedure in which a probe that sends out high-energy sound waves is inserted into the rectum. The sound waves are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissue called a sonogram. ERUS is used to look for abnormalities in the rectum and nearby structures, including the prostate. Also called transrectal ultrasound.</td>
</tr>
<tr>
<td><strong>Erectile Dysfunction (ED)</strong></td>
<td>An inability to have an erection of the penis adequate for sexual intercourse. Also called impotence.</td>
</tr>
<tr>
<td><strong>EXBT, EXRT</strong></td>
<td>External beam therapy; external radiation therapy.</td>
</tr>
<tr>
<td><strong>External beam radiation</strong></td>
<td>A form of radiation therapy in which the radiation is delivered by a machine pointed at the area to be radiated. May be known as external beam radiation (EBR, XBR), external beam radiation therapy (EBRT, XBRT).</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<tr>
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</tr>
<tr>
<td><strong>External Sphincter</strong></td>
<td>Muscular structure that constricts the urethra below the prostate, retaining urine until the sphincter is relaxed.</td>
</tr>
<tr>
<td><strong>Fine-needle aspiration</strong></td>
<td>The removal of tissue or fluid with a needle for examination under a microscope. Also called needle biopsy.</td>
</tr>
<tr>
<td><strong>Free PSA (fPSA)</strong></td>
<td>PSA exists in two forms in the blood, either bound to protein or unbound (“free”).</td>
</tr>
<tr>
<td><strong>Gene Therapy</strong></td>
<td>A new form of treatment where defective genes are replaced with normal genes.</td>
</tr>
<tr>
<td><strong>Gland</strong></td>
<td>An organ that makes one or more substances, such as hormones, digestive juices, sweat, tears, saliva, or milk. Endocrine glands release the substances directly into the bloodstream. Exocrine glands release the substances into a duct or opening to the inside or outside of the body.</td>
</tr>
<tr>
<td><strong>Glandular</strong></td>
<td>Pertaining to a gland.</td>
</tr>
<tr>
<td><strong>Gleason Score (GS)</strong></td>
<td>A system of grading prostate cancer cells based on how they look under a microscope. Gleason scores range from 2 to 10 and indicate how likely it is that a tumour will spread. A low Gleason score means the cancer cells are similar to normal prostate cells and are less likely to spread; a high Gleason score means the cancer cells are very different from normal and are more likely to spread.</td>
</tr>
<tr>
<td><strong>Gleason Grade</strong></td>
<td>The grade of a tumour depends on how abnormal the cancer cells look under a microscope and how quickly the tumour is likely to grow and spread. Grading systems are different for each type of cancer.</td>
</tr>
<tr>
<td><strong>Gonads</strong></td>
<td>The part of the reproductive system that produces and releases eggs (ovary) or sperm (testicle/testis).</td>
</tr>
<tr>
<td><strong>Grade</strong></td>
<td></td>
</tr>
</tbody>
</table>
**Grading**
A system for classifying cancer cells in terms of how abnormal they appear when examined under a microscope. The objective of a grading system is to provide information about the probable growth rate of the tumour and its tendency to spread. The systems used to grade tumours vary with each type of cancer. Grading plays a role in treatment decisions.

**Histology**
The study of tissues and cells under a microscope.

**Hormone**
A chemical made by glands in the body. Hormones circulate in the bloodstream and control the actions of certain cells or organs. Some hormones can also be made in a laboratory.

**Hormone Refractory Prostate Cancer**
Prostate cancer that has become refractory, and no longer responds to hormone therapy.

**Hormone Therapy (HT)**
Treatment that adds, blocks, or removes hormones. For certain conditions (such as diabetes or menopause), hormones are given to adjust low hormone levels. To slow or stop the growth of certain cancers (such as prostate and breast cancer), synthetic hormones or other drugs may be given to block the body’s natural hormones. Sometimes surgery is needed to remove the gland that makes hormones. Also called hormonal therapy, hormone treatment, or endocrine therapy.

**HRPC**
Hormone refractory prostate cancer; prostate cancer that resists hormone therapy.

**Hyperplasia**
An abnormal increase in the number of cells in an organ or tissue.
<table>
<thead>
<tr>
<th><strong>Hypertrophy</strong></th>
<th>The enlargement or overgrowth of an organ or part due to an increase in size of its constituent cells. Compare to hyperplasia; see benign prostatic hyperplasia (BPH).</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Impotency</strong></td>
<td>Refers to the inability to have an erection of the penis adequate for sexual intercourse. Also called erectile dysfunction.</td>
</tr>
<tr>
<td><strong>Incontinence</strong></td>
<td>Inability to control the flow of urine from the bladder (urinary incontinence) or the escape of stool from the rectum (fecal incontinence).</td>
</tr>
<tr>
<td><strong>Infertility</strong></td>
<td>The inability to conceive children. Infertility may be a side effect of treatment in men with prostate cancer.</td>
</tr>
<tr>
<td><strong>Interstitial Radiation Therapy (IRT)</strong></td>
<td>A procedure in which radioactive material sealed in needles, seeds, wires, or catheters is placed directly into or near a tumour. Also called brachytherapy, internal radiation, or implant radiation.</td>
</tr>
<tr>
<td><strong>Kegel Exercises</strong></td>
<td>Repetitive exercise designed to strengthen the muscles of the pelvic floor to improve urinary control and prevent leakage.</td>
</tr>
<tr>
<td><strong>Laparoscopy</strong></td>
<td>The insertion of a thin, lighted tube (called a laparoscope) through the abdominal wall to inspect the inside of the abdomen and remove tissue samples.</td>
</tr>
<tr>
<td><strong>Libido</strong></td>
<td>Interest in sexual activity.</td>
</tr>
<tr>
<td><strong>Lupron</strong></td>
<td>A U.S. trade or brand name of leuprolide acetate; an LHRH (Luteinizing hormone releasing hormone).</td>
</tr>
<tr>
<td><strong>Luteinizing Hormone Release Hormone (LHRH)</strong></td>
<td>A naturally occurring hormone that controls sex hormones. It is responsible for stimulating the production of testosterone in the body.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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<td>-----------------------------</td>
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</tr>
<tr>
<td>Lymph</td>
<td>The clear fluid that travels through the lymphatic system and carries cells that help fight infections and other diseases. Also called lymphatic fluid.</td>
</tr>
<tr>
<td>Lymph Nodes</td>
<td>A rounded mass of lymphatic tissue that is surrounded by a capsule of connective tissue. Lymph nodes filter lymph (lymphatic fluid), and they store lymphocytes (white blood cells). They are located along lymphatic vessels. Also called a lymph gland.</td>
</tr>
<tr>
<td>Lymphatic System</td>
<td>The tissues and organs that produce, store, and carry white blood cells that fight infections and other diseases. This system includes the bone marrow, spleen, thymus, lymph nodes, and lymphatic vessels (a network of thin tubes that carry lymph and white blood cells). Lymphatic vessels branch, like blood vessels, into all the tissues of the body.</td>
</tr>
<tr>
<td>Lymphocyte</td>
<td>A type of white blood cell. Lymphocytes have a number of roles in the immune system, including the production of antibodies and other substances that fight infection and diseases.</td>
</tr>
<tr>
<td>Magnetic Resonance Imaging (MRI)</td>
<td>A procedure in which radio waves and a powerful magnet linked to a computer are used to create detailed pictures of areas inside the body. These pictures can show the difference between normal and diseased tissue. MRI is especially useful for imaging the brain, spine, the soft tissue of joints, and the inside of bones. Also called nuclear magnetic resonance imaging.</td>
</tr>
<tr>
<td>Malignant</td>
<td>Cancerous. Malignant tumours can invade and destroy nearby tissue and spread to other parts of the body.</td>
</tr>
<tr>
<td>Medical Oncologist</td>
<td>A doctor who specializes in the treatment of cancer using chemotherapy.</td>
</tr>
<tr>
<td><strong>Metastasis</strong></td>
<td>The spread of cancer from one part of the body to another. A tumour formed by cells that have spread is called a “metastatic tumour” or a “metastasis”. The metastatic tumour contains cells that are like those in the original (primary) tumour. The plural form of metastasis is metastases (meh-TAS-ta-seez).</td>
</tr>
<tr>
<td><strong>Neoadjuvant</strong></td>
<td>Treatment given before the primary treatment; for example, neoadjuvant hormone therapy could be given prior to another form of treatment such as a radical prostatectomy.</td>
</tr>
<tr>
<td><strong>Neoplasia</strong></td>
<td>Abnormal and uncontrolled cell growth.</td>
</tr>
<tr>
<td><strong>Nerve Sparing</strong></td>
<td>A surgical technique during a prostatectomy where one or both of the neurovascular bundles controlling erections are spared. The utilization of this procedure is governed by the extent of the cancer and the skill of the surgeon.</td>
</tr>
<tr>
<td><strong>Oncologist</strong></td>
<td>A doctor who specializes in treating cancer. Some oncologists specialize in a particular type of cancer treatment.</td>
</tr>
<tr>
<td><strong>Orchiectomy</strong></td>
<td>Surgery to remove one or both testicles.</td>
</tr>
<tr>
<td><strong>Osteoporosis</strong></td>
<td>A condition that is characterized by a decrease in bone mass and density, causing bones to become fragile.</td>
</tr>
<tr>
<td><strong>Palliative Care</strong></td>
<td>Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of palliative care is to prevent or treat as early as possible the symptoms of the disease, side effects caused by treatment of the disease, and psychological, social, and spiritual problems related to the disease or its treatment. Also called comfort care, supportive care, and symptom management.</td>
</tr>
<tr>
<td><strong>Palpable</strong></td>
<td>Capable of being felt during a physical examination by a physician; e.g., when the prostate can be felt during a digital rectal examination.</td>
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</tr>
<tr>
<td><strong>Palpable Disease</strong></td>
<td>A term used to describe cancer that can be felt by touch, usually present in lymph nodes, skin, or other organs of the body such as the liver or colon.</td>
</tr>
<tr>
<td><strong>Partin Tables</strong></td>
<td>These are tables constructed on the basis of the PSA, stage, grade and surgical findings of over 4,000 men. The tables are used to predict the probability that the prostate cancer has spread to the lymph nodes and/or seminal vesicles, penetrated the capsule, or remains confined to the prostate. They were initially developed by a group of urologists at the Brady Institute for Urology at Johns Hopkins University. They are called “Partin tables” after one of the original contributors to this research.</td>
</tr>
<tr>
<td><strong>Pathologist</strong></td>
<td>A doctor who identifies diseases by studying cells and tissues under a microscope.</td>
</tr>
<tr>
<td><strong>Patient-Controlled Analgesia (PCA)</strong></td>
<td>A method in which the patient controls the amount of pain medicine that is used. When pain relief is needed, the person can receive a preset dose of pain medicine by pressing a button on a computerized pump that is connected to a small tube in the body.</td>
</tr>
<tr>
<td><strong>PCA</strong></td>
<td>Abbreviation for prostate cancer; CaP is also used.</td>
</tr>
<tr>
<td><strong>Penis</strong></td>
<td>An external male reproductive organ. It contains a tube called the urethra, which carries semen and urine to the outside of the body.</td>
</tr>
<tr>
<td>Trial Type</td>
<td>Description</td>
</tr>
<tr>
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</tr>
<tr>
<td>Phase I Trial</td>
<td>The first step in testing a new treatment in humans. These studies test the best way to give a new treatment (for example, by mouth, intravenous infusion, or injection) and the best dose. The dose is usually increased a little at a time in order to find the highest dose that does not cause harmful side effects. Because little is known about the possible risks and benefits of the treatments being tested, phase I trials usually include only a small number of patients who have not been helped by other treatments.</td>
</tr>
<tr>
<td>Phase II Trial</td>
<td>A study to test whether a new treatment has an anticancer effect (for example, whether it shrinks a tumour or improves blood test results) and whether it works against a certain type of cancer.</td>
</tr>
<tr>
<td>Phase III Trial</td>
<td>A study to compare the results of people taking a new treatment with the results of people taking the standard treatment (for example, which group has better survival rates or fewer side effects). In most cases, studies move into phase III only after a treatment seems to work in phases I and II. Phase III trials may include hundreds of people.</td>
</tr>
<tr>
<td>Phase IV Trial</td>
<td>After a treatment has been approved and is being marketed, it is studied in a phase IV trial to evaluate side effects that were not apparent in the phase III trial. Thousands of people are involved in a phase IV trial.</td>
</tr>
<tr>
<td>Placebo</td>
<td>An inactive substance or treatment that looks the same as, and is given the same way as, an active drug or treatment being tested. The effects of the active drug or treatment are compared to the effects of the placebo.</td>
</tr>
<tr>
<td><strong>Positron Emission Tomography Scan (PET Scan)</strong></td>
<td>A procedure in which a small amount of radioactive glucose (sugar) is injected into a vein, and a scanner is used to make detailed, computerized pictures of areas inside the body where the glucose is used. Because cancer cells often use more glucose than normal cells, the pictures can be used to find cancer cells in the body.</td>
</tr>
<tr>
<td><strong>Proctitis</strong></td>
<td>Inflammation of the mucous membrane that lines the rectum.</td>
</tr>
<tr>
<td><strong>Prognosis</strong></td>
<td>The likely outcome or course of a disease; the chance of recovery or recurrence.</td>
</tr>
<tr>
<td><strong>Progression</strong></td>
<td>Increase in the size of a tumour or spread of cancer in the body.</td>
</tr>
<tr>
<td><strong>Prostate Gland</strong></td>
<td>A gland in the male reproductive system just below the bladder. The prostate surrounds part of the urethra, the canal that empties the bladder, and produces a fluid that forms part of semen.</td>
</tr>
<tr>
<td><strong>Prostatectomy</strong></td>
<td>An operation to remove part or all of the prostate. Radical (or total) prostatectomy is the removal of the entire prostate and some of the tissue around it.</td>
</tr>
<tr>
<td><strong>Prostate Specific Antigen (PSA)</strong></td>
<td>A substance produced by the prostate that may be found in an increased amount in the blood of men who have prostate cancer, benign prostatic hyperplasia, or infection or inflammation of the prostate.</td>
</tr>
<tr>
<td><strong>Prostatic</strong></td>
<td>Of or pertaining to the prostate gland.</td>
</tr>
<tr>
<td><strong>Prostatic Acid Phosphatase (PAP)</strong></td>
<td>An enzyme produced by the prostate. It may be found in increased amounts in men who have prostate cancer.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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</tr>
<tr>
<td>Radical Prostatectomy</td>
<td>Surgery to remove the entire prostate. The two types of radical prostatectomy are retropubic prostatectomy and perineal prostatectomy.</td>
</tr>
<tr>
<td>Radiography</td>
<td>Producing an image by radiation other than visible light, (e.g., x-rays of one's teeth is done by radiography).</td>
</tr>
<tr>
<td>Radiolabeled</td>
<td>Any compound that has been joined with a radioactive substance.</td>
</tr>
<tr>
<td>Radical Prostatectomy</td>
<td>Surgery to remove the entire prostate, seminal vesicles and surrounding tissues. This surgery can be performed through an open incision or through laparoscopic approach (removal of the entire prostate and seminal vesicles through tiny incisions using a piece of surgical equipment called a laparoscope).</td>
</tr>
<tr>
<td>Radiation Therapy</td>
<td>The use of high-energy radiation to kill cancer cells and shrink tumours. Radiation may come from a machine outside the body (external beam radiation therapy), or it may come from radioactive material placed in the body near cancer cells (internal radiation therapy, implant radiation, or brachytherapy).</td>
</tr>
<tr>
<td>Rectum</td>
<td>The last several inches of the large intestine that ends at the anus.</td>
</tr>
<tr>
<td>Red Blood Cell (RBC)</td>
<td>A cell that carries oxygen to all parts of the body. Also called an erythrocyte.</td>
</tr>
<tr>
<td>Refractory</td>
<td>In medicine, describes a disease or condition that does not respond to treatment.</td>
</tr>
<tr>
<td><strong>Regression</strong></td>
<td>A decrease in the size of a tumour or in the extent of cancer in the body.</td>
</tr>
<tr>
<td><strong>Relapse</strong></td>
<td>The return of signs and symptoms of cancer after a period of improvement.</td>
</tr>
<tr>
<td><strong>Remission</strong></td>
<td>A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.</td>
</tr>
<tr>
<td><strong>Resection</strong></td>
<td>Surgical removal of part or all of an organ.</td>
</tr>
<tr>
<td><strong>Retention of Urine</strong></td>
<td>Difficulty in urinating fully or the inability to completely empty the bladder.</td>
</tr>
<tr>
<td><strong>Screening</strong></td>
<td>Checking for disease when there are no symptoms.</td>
</tr>
<tr>
<td><strong>Seed, Seeding</strong></td>
<td>Brachytherapy, the implantation of radioactive seeds or pellets (may also be called “capsules”) which emit low energy radiation in order to kill surrounding tissue, e.g., the prostate, including prostate cancer cells. Also known as “seed implantation” or “SI”.</td>
</tr>
<tr>
<td><strong>Semen</strong></td>
<td>The fluid that is released through the penis during orgasm. Semen is made up of sperm from the testicles and fluid from the prostate and other sex glands.</td>
</tr>
<tr>
<td><strong>Seminal vesicles</strong></td>
<td>Two glands at the base of the bladder, connected to the prostate that add nutrients to the semen.</td>
</tr>
<tr>
<td><strong>Side effect</strong></td>
<td>A problem that occurs when treatment affects tissues or organs other than the ones being treated. Some common side effects of cancer treatment are fatigue, pain, nausea, vomiting, decreased blood cell counts, hair loss, and mouth sores.</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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</tr>
<tr>
<td><strong>Spinal anesthesia</strong></td>
<td>Injection of an anaesthetic into the area around the spinal cord to block pain sensation during surgery.</td>
</tr>
<tr>
<td><strong>Stage, Staging</strong></td>
<td>The extent of a cancer within the body. If the cancer has spread, the stage describes how far it has spread from the original site to other parts of the body.</td>
</tr>
<tr>
<td><strong>Steroid</strong></td>
<td>A type of drug used to relieve swelling and inflammation.</td>
</tr>
<tr>
<td><strong>Testicle</strong></td>
<td>One of two egg-shaped glands found inside the scrotum behind and below the penis that produce sperm and are the primary source of the male hormone testosterone. Also called a testis, plural testes.</td>
</tr>
<tr>
<td><strong>Testosterone</strong></td>
<td>A hormone that promotes the development and maintenance of male sex characteristics.</td>
</tr>
<tr>
<td><strong>TNM Classification System</strong></td>
<td>A system for describing the extent of cancer in a patient’s body. T describes the size of the tumour and whether it has invaded nearby tissue, N describes any lymph nodes that are involved, and M describes metastasis (spread of cancer from one body part to another).</td>
</tr>
<tr>
<td><strong>Tomography</strong></td>
<td>A series of detailed pictures of areas inside the body; the pictures are created by a computer linked to an x-ray machine.</td>
</tr>
<tr>
<td><strong>Transrectal Ultrasound (TRUS)</strong></td>
<td>A procedure in which a probe that sends out high-energy sound waves is inserted into the rectum. The sound waves are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissue called a sonogram. TRUS is used to look for abnormalities in the rectum and nearby structures, including the prostate. Also called endorectal ultrasound.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
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<td>-------------------------------------------</td>
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</tr>
<tr>
<td>Transurethral Prostatectomy</td>
<td>Also called a transurethral resection of the prostate or TURP.</td>
</tr>
<tr>
<td>Transurethral Resection Of The Prostate (TURP)</td>
<td>Surgical procedure to remove tissue from the prostate using an instrument inserted through the urethra.</td>
</tr>
<tr>
<td>Tumour</td>
<td>A mass of excess tissue that results from abnormal cell division. Tumours perform no useful body function. They may be benign (not cancerous) or malignant (cancerous).</td>
</tr>
<tr>
<td>Ultrasound (US)</td>
<td>A procedure in which high-frequency sound waves (ultrasound) are bounced off internal tissues or organs and make echoes. The echoes form a picture of body tissues called a sonogram. Also called ultrasonography.</td>
</tr>
<tr>
<td>Ureter</td>
<td>The tube that carries urine from the kidney to the bladder.</td>
</tr>
<tr>
<td>Urethra</td>
<td>The tube through which urine leaves the body. It empties urine from the bladder.</td>
</tr>
<tr>
<td>Urologist</td>
<td>A doctor first trained as a surgeon, who specializes in disorders of the genitourinary system.</td>
</tr>
<tr>
<td>Whitmore-Jewett Staging System</td>
<td>A staging system for prostate cancer that uses ABCD. “A” and “B” refer to cancer that is confined to the prostate. “C” refers to cancer that has grown out of the prostate but has not spread to lymph nodes or other places in the body. “D” refers to cancer that has spread to lymph nodes or to other places in the body. Also called the ABCD rating or the Jewett staging system.</td>
</tr>
</tbody>
</table>
Guide feedback

1. How helpful was the guide to you in understanding prostate cancer and its treatment?
   - Extremely helpful
   - Very helpful
   - Helpful
   - Somewhat helpful
   - Not at all helpful

2. How helpful was the guide in helping you to “navigate” the system?
   - Extremely helpful
   - Very helpful
   - Helpful
   - Somewhat helpful
   - Not at all helpful

3. How helpful was the guide to you in sharing information with others; i.e., care providers, family?
   - Extremely helpful
   - Very helpful
   - Helpful
   - Somewhat helpful
   - Not at all helpful

4. What did you like most about the guide?

5. What would you change about the guide?

6. Please feel free to share any additional comments or suggestions:

Thank you for taking time to complete this survey about the guide.
This survey may be returned to The Ottawa Hospital Cancer Assessment Clinic.

Your feedback is important!
This guide was originally made possible by an educational grant from the Ottawa Regional Cancer Foundation. Based on comments from individuals who had used the guide, we have made the guide available to any individual in Champlain District newly diagnosed with prostate cancer.

If you would like to contribute to “Prostate Cancer Information Guide and Personal Record”’s ongoing distribution throughout the region and the surrounding counties, you can send a donation to The Ottawa Hospital Foundation with this completed form.