

Prost**AIDE**

Patient Resource Kit





ProstAIDE Patient Resource Kit

The **ProstAIDE Patient Resource Kit** is a collection of information made available to the patient by the physician. The information focuses on advanced prostate cancer and its treatment and includes information designed to help patients manage their life with cancer.

Table of Contents

Disease Information 4 Disease Continuum Schematic 7 Treatment Information 8 Questions for Caregivers and Patients 13 Frequently Asked Questions (FAQ) 14 Patient Booklet 16 Section 1 - Treatment Plan 17 Section 2 - Preparing for Appointments 20 Section 3 - Personal Goals and Notes 22 Section 4 - 'Who's Who & What Do They Do?' 23 Additional Resources 25	Definitions Associated With Advanced Prostate Cancer	2
Treatment Information 8 Questions for Caregivers and Patients 13 Frequently Asked Questions (FAQ) 14 Patient Booklet 16 Section 1 - Treatment Plan 17 Section 2 - Preparing for Appointments 20 Section 3 - Personal Goals and Notes 22 Section 4 - 'Who's Who & What Do They Do?' 23	Disease Information	4
Questions for Caregivers and Patients 13 Frequently Asked Questions (FAQ) 14 Patient Booklet 16 Section 1 - Treatment Plan 17 Section 2 - Preparing for Appointments 20 Section 3 - Personal Goals and Notes 22 Section 4 - 'Who's Who & What Do They Do?' 23	Disease Continuum Schematic	7
Frequently Asked Questions (FAQ) 14 Patient Booklet 16 Section 1 - Treatment Plan 17 Section 2 - Preparing for Appointments 20 Section 3 - Personal Goals and Notes 22 Section 4 - 'Who's Who & What Do They Do?' 23	Treatment Information	8
Patient Booklet 16 Section 1 - Treatment Plan 17 Section 2 - Preparing for Appointments 20 Section 3 - Personal Goals and Notes 22 Section 4 - 'Who's Who & What Do They Do?' 23	Questions for Caregivers and Patients	13
Section 1 - Treatment Plan17Section 2 - Preparing for Appointments20Section 3 - Personal Goals and Notes22Section 4 - 'Who's Who & What Do They Do?'23	Frequently Asked Questions (FAQ)	14
Section 2 - Preparing for Appointments	Patient Booklet	16
Section 3 - Personal Goals and Notes	Section 1 - Treatment Plan	17
Section 4 - 'Who's Who & What Do They Do?'	Section 2 - Preparing for Appointments	20
•	Section 3 - Personal Goals and Notes	22
Additional Resources	Section 4 - 'Who's Who & What Do They Do?'	23
	Additional Resources	25



Definitions Associated With Advanced Prostate Cancer

Androgen Deprivation Therapy (ADT): A treatment (medication or surgical removal of the testicles) to stop the body from producing the male hormones called androgens. The main androgen is testosterone. ADT is also called hormone therapy (see below).

Biochemical Recurrence: After your prostate cancer treatment, your doctor monitors the PSA level (see below) in your blood. If the PSA level goes up without any other signs or symptoms that the prostate cancer is progressing, this is called biochemical recurrence.

Castration-Resistant Prostate Cancer (CRPC): CRPC is usually defined when androgen deprivation therapy is no longer controlling the PSA level and/or the cancer-associated symptoms, or when tests show that the cancer has spread. If there is spread to the bones or other parts of the body, this is called metastatic CRPC or mCRPC.

Chemotherapy: Medication used to kill or slow down the growth of cancer cells. Chemotherapy is given in cycles of treatment days followed by days of no treatment. The length of the cycle depends on the medication, but is typically 21 days long. Chemotherapy cycles are often repeated over a three (3) to six (6) month period. Chemotherapy is usually given as a liquid injected into a vein in your arm.

Clinical Trials: Research carried out to study new treatments and to find out if a new treatment is better than an existing treatment. As a patient with advanced prostate cancer, you may be asked if you would like to take part in a clinical trial. Your doctor is in the best position to explain what you need to know about taking part in a clinical trial.

Hormone Resistant: Prostate cancer is considered to be hormone resistant when it continues to grow after hormone therapy. When prostate cancer stops responding to hormone therapy, the PSA level rises and the cancer grows.

Hormone Therapy: In order to grow, prostate cancer cells need male hormones called androgens. The main androgen is testosterone. Hormone therapy either stops the effects of testosterone or stops the body from making testosterone. A common abbreviation that doctors use for hormone therapy is ADT, meaning androgen deprivation therapy (see above).

Luteinizing Hormone-Releasing Hormone (LHRH) Analogue: LHRH analogue is a type of hormone therapy used to treat patients with localized prostate cancer with a high risk of recurrence, patients whose prostate cancer has come back, or patients who have metastatic prostate cancer.

Metastasis: Refers to cancer that has spread outside the prostate gland. Often healthcare providers refer to it as "mets."

Metastatic Prostate Cancer: This is advanced prostate cancer that has spread outside the prostate gland. It is treated with hormone therapy, usually with a good response. However, the effect of hormone therapy decreases over time. If prostate cancer metastasizes or spreads, it is most commonly to the lymph nodes or the bones, but may also spread to other organs.

Metastatic CRPC (mCRPC): Defined when hormone therapy is no longer controlling the disease and there is evidence that the disease has spread to other organs (usually seen with a bone scan or CT scan). Treatment options for CRPC include palliative chemotherapy, palliative radiotherapy, radio-isotopes, bisphosphonates to protect the bones from fracture, and supportive care.



Prostate-Specific Antigen (PSA): A protein made by the prostate gland. PSA levels can be measured in a blood sample. It rises in most patients with prostate cancer. However, a high PSA level does not always mean you have cancer and a low PSA level does not always mean there is no cancer.

Radiotherapy: Radiotherapy is a treatment using high-energy rays to kill cancer cells. Radiotherapy may be used as a primary treatment for prostate cancer. It may also be used as an additional treatment after surgery and as supportive treatment to lessen pain or other symptoms caused by cancer metastases.

References

National Comprehensive Cancer Network. NCCN Guidelines for Patients™l Prostate Cancer. Accessed at <u>www.nccn.com/files/cancer-guidelines/prostate</u> February 27, 2012.

Prostate Cancer Canada. Glossary. Accessed at <u>http://www.prostatecancer.ca/Prostate-Cancer/Prostate-Cancer/Glossary</u> February 27, 2012.

Additional Resources

Canadian Cancer Encyclopedia. Canadian Cancer Society. Accessed at <u>http://info.cancer.ca/ttp://info.cancer.ca/cce-ecc</u> July 3, 2012.



Disease Information

"My cancer is back? I thought it was gone!"

Hearing the news that you have cancer is overwhelming, to say the least. Similarly, patients who are told their cancer is back after initial therapy are often shocked to hear the news again. In fact, most patients with advanced disease have been through prostate surgery or radiation therapy in the past, and thought they were cured. And often, patients who are told that the prostate cancer has come back or has spread to other parts of their body do not necessarily have symptoms. In all cases, hearing this news is always difficult.

The goal of this patient resource kit is to help you understand advanced prostate cancer. We believe that education will help you to understand what is happening in your body and will also help you to make decisions about your treatment. We want to help you live as fully and comfortably as possible.

"What happens when prostate cancer 'progresses'?"

Localized prostate cancer and locally advanced prostate cancer are potentially curable. If the prostate cancer progresses such that it is no longer considered localized disease or locally advanced disease, then it is considered to be advanced disease. Prostate cancer sometimes spreads into the seminal vesicles (the glands where semen is made) or into the bladder (where urine collects before urinating). Sometimes the cancer can enter the lymph nodes near the prostate. The lymph nodes are part of the lymph system, which carries body fluids other than blood around the body. In more advanced disease, the cancer can spread to the bones or other organs in the body. Usually, prostate cancer cells are slow growing compared to other cancers. However, prostate cancer cells may grow faster when they enter the bones.

Local Disea	se:	Locally Adv	anced Disease:	Advanced	d Disease:
Colon Tumor cannot be felt by doctor:		Tumor has spread to seminal vesicl		Tumor has spread to bladder	
Tumor can be felt by doctor on digital rectal exam: gland with tumor Tumor has spread to lymph nodes					
National Comprehensive Cancer Network NCCN Guidelines for Patients™I Prostate Cancer. Accessed at <u>www.nccn.com/files/cancer-guidelines/prostate</u> February 27, 2012					

"When is chemotherapy used for prostate cancer?"

Chemotherapy is used for the treatment of advanced prostate cancer when the cancer has become resistant to hormone therapy and has spread to other parts of the body. In using chemotherapy, oncologists hope to slow the growth of the cancer cells. Not all patients are eligible for chemotherapy, and decisions to start this treatment should be made in consultation with your medical oncologist.



"What is meant by a 'cancer care team'?"

Even a high-performance athlete does not face his or her challenges alone. They always have a great team around them. It's the same for you! You have a team with you to help you with the challenges ahead. Have a look at the cancer care team below. You are in the center and the team is around you.



"What does my team expect from me?"

Your cancer care team can best help you if they know your concerns, fears, and worries. They have a lot of information and experience to share. So talk with your team. Share your concerns. Ask your questions. That way your cancer care team can help you better.

"What can I expect to happen to my body?"

This is different for everyone. The symptoms you experience depend on many factors, including factors related to the cancer, factors related to the treatment, and factors related to your own body. With advanced prostate cancer, the cancer may have spread to your bones or other organs and cause you to have new symptoms, such as bone pain. Pain is the symptom most feared by many patients with cancer. Treatments are available to slow the cancer growth and delay the onset of cancer-associated bone pain. In addition, your cancer care team will always do their best to keep you comfortable.



Many men experience feelings of anxiety and depression and are hesitant to talk about their emotional concerns. Many men also struggle with a change in their sexual relationship. Fatigue is often a common problem for patients with cancer and can affect quality of life. Again, there are treatments for these challenges and difficulties. Talk with your cancer care team so that they can offer the best treatment for you.

"What can I do to help myself?"

You can do your best to take good care of yourself. Good nutrition, in the form of a balanced diet with adequate calories and plenty of fluids, is important when you are facing the challenges of cancer and its treatment. Also, not smoking and limiting the use of alcohol are positive steps. Moderate exercise may help you to maintain muscle tone and lower stress. You should talk with your cancer care team to understand what exercise program is suitable to your situation.

Also think of ways to treat yourself well, do hobbies you enjoy, visit with friends, and see new places. Live your life as best as you are able.



Reference

National Comprehensive Cancer Network. NCCN Guidelines for Patients™l Prostate Cancer. Accessed at www.nccn.com/files/cancer-guidelines/prostate February 27, 2012.



Disease Continuum Schematic



References

National Comprehensive Cancer Network. NCCN Guidelines for Patients™l Prostate Cancer. Accessed at www.nccn.com/files/cancer-guidelines/prostate February 27, 2012.

Saad F, McCormack M. Understanding Prostate Cancer. 3rd ed. Montreal, Canada: Annika Parance; 2012.



Treatment Information

Systemic Prostate Cancer Treatment

If cancer has spread beyond the prostate gland into other parts of your body, your doctor will probably recommend systemic therapy. The specific systemic therapy prescribed will depend on the extent of disease and the medicines that were used previously in your treatment plan. In general, the types of systemic therapy are:

- 1. Hormone therapy¹
 - a. LHRH Analogues (agonists) and Antagonists
 - b. Antiandrogens
- 2. First-line chemotherapy¹
- 3. Second-line therapy¹

1. Hormone Therapy

Hormone therapy is used to treat men who are at *high risk* of having the prostate cancer come back after surgery or radiation or men who have actually had a recurrence of prostate cancer after initial treatment. Hormone therapy works by starving prostate cancer cells of male hormones (androgens) that they need to grow. Two main categories of hormone medicines are used to treat prostate cancer – LHRH analogue therapy and antiandrogen therapy.² Reduction in male hormones can also be achieved by the surgical removal of the testicles.

a) LHRH Analogues

LHRH analogues (sometimes also referred to as LHRH agonists) are given by injection (into the skin on the abdomen or the buttock muscles) at regular intervals, every month or every two (2), three (3), four (4) or six (6) months.

When you first start an LHRH analogue, your testosterone levels may increase temporarily and as a result, you may have a temporary increase in symptoms. Your doctor may prescribe an antiandrogen on a short-term basis to counter this effect.¹



Side Effects³

Metabolic Side Effects: Weight gain, cholesterol problems, and an early form of diabetes due to a reduced sensitivity of cells to insulin (called insulin insensitivity) may all be side effects of LHRH analogue therapy. Your doctor may recommend other medicines to counter these effects. These metabolic side effects can lead to heart or circulation problems.

Bone Side Effects: The density of bone may decrease over time while taking an LHRH analogue. You can help the general health of your bones by not smoking and avoiding excessive alcohol use. Your doctor may prescribe calcium, vitamin D, and other medicines to protect the density of your bones.

Sexual Side Effects: Because these medicines decrease the production of the male sex hormone, you will probably experience a decrease in the desire for sex, and have difficulty achieving and maintaining erections. While these side



effects are difficult for many men to deal with, many resources are available to you to help you deal with these effects psychologically and physically. Every man is unique with regards to these effects and how he chooses to cope. Talk to your doctor about your options.

Other Side Effects: You may experience hot flashes, increased sweating, loss of muscle mass, and/or breast tenderness. Also, you may find that you have a loss of interest in doing things and you may feel depressed or anxious. These effects can be upsetting. You may wish to speak with a cancer psychologist who can evaluate with you the best way to cope with the changes to your body.

b) Antiandrogens³

Antiandrogens are taken as a pill. Sometimes an antiandrogen is combined with LHRH analogues for a short time to decrease the initial testosterone flare. In other situations, antiandrogens are combined with LHRH analogues for a longer period of time to strengthen the activity of the LHRH analogue.

Side Effects: The main side effects of antiandrogen therapy alone are gynecomastia (breast growth and tenderness) and digestive problems.

Expectations of Treatment

Benefits

- Hormone therapy is expected to slow the growth of your prostate cancer. Some men take hormone therapy for many years (sometimes more than 10 years), while others have relief from symptoms of their disease after taking hormone therapy for shorter periods of time.
- Hormone therapy is one of the best available therapies to decrease the growth of prostate cancer, and to decrease cancer-associated complications and pain.
- The side effects are sometimes difficult, yet tolerable when compared with the possible effects of advanced prostate cancer. There are various strategies available to you to help manage these side effects.

Limitations

- Hormone therapy given for advanced prostate cancer is meant to slow the progression of the disease.
- The treatments are expected to be effective for a period of time (sometimes more than 10 years) until the prostate cancer cells become resistant to the hormone therapy.

2. First-Line Chemotherapy¹

Chemotherapy is a treatment option your doctor may recommend when the cancer cells become resistant to hormone therapy and have spread to other parts of your body including your bones. At this point, the PSA level usually rises and the cancer grows.

Chemotherapy is given systemically (meaning system-wide in the body) in cycles. Usually, a cycle consists of a treatment day followed by a time period with no treatment. Chemotherapy is given to destroy cancer cells. It can also destroy healthy cells, especially cells that multiply quickly, like blood cells. The healthy cells have the ability to regenerate between chemotherapy cycles. Your cancer care team will monitor things like your blood cell count before starting a chemotherapy cycle.



Generally, chemotherapy is given when other systemic treatments have stopped controlling the cancer. However, there is ongoing research into using chemotherapy earlier in the disease process. Your doctor may approach you about being a participant in such a clinical trial.

Expectations of Treatment

Benefits

- Chemotherapy is expected to slow down the progress of prostate cancer and prolong life for a short while.
- Chemotherapy can lessen or prevent some of the pain caused when cancer spreads

Side Effects

- Balancing the benefits and risks of chemotherapy depends on the individual. Some patients are willing to put up with unfavorable side effects to get any possible improvement in their condition. For other patients, the side effects interfere too much with their quality of life.
- Chemotherapy causes a decrease in the following blood cells:
 - Red blood cells with low red blood cells you may have varying degrees of fatigue
 - White blood cells with low white blood cells you are more vulnerable to infections
 - o Platelets with low platelets you are prone to bruising and even bleeding
- Chemotherapy may cause nausea, vomiting, and diarrhea. Medication is usually given to decrease these side effects. It is not unusual that food may taste differently.
- "Chemo-brain" is a term used to refer to the effects that chemotherapy may have on your ability to think clearly, concentrate, stay focused, be organized, and remember things. Sometimes just being aware of this effect helps patients to deal with the effects. You are not crazy; it's the chemo!

3. Second-Line Therapy¹

Until recently, there were few options for patients whose disease progressed during first-line chemotherapy. Recently, some new medicines have become available in the form of second-line chemotherapy and second-line hormone therapy.

Supportive Treatment

1. Bone-Targeted Therapy¹

Bone metastases occur in many patients with advanced prostate cancer and can cause pain, fractures, and other complications. There are medicines that your doctor may prescribe to prevent such complications. Two such medicines are now available in Canada.



2. Pain Therapy¹

In general, cancer centres have a pain protocol that your cancer care team will follow to be sure that you are not living in pain. Be sure to let your cancer care team know if you have pain. Ask your cancer care team about the pain protocol at your centre to learn more.



3. Supportive Care Measures

Here are some tips that may help to control symptoms of prostate cancer and its treatment¹:

- Taking calcium and vitamin D daily may help prevent or control osteoporosis (softening of the bones).
- Your doctor may suggest certain medicines to help strengthen bones when you are taking hormone therapy.
- Medicines are available that can improve erections by increasing blood flow to the penis.
- Stool softeners or laxatives can ease the constipation associated with some pain medications.
- Exercise may help to reduce fatigue.
- Continuing to do pleasant activities, maintaining your social activities, and doing things that enrich your life are all positive steps you can take.

4. Emotional Support

Your cancer care team may have a psychologist who has expertise in cancer. This professional can be a tremendous resource to offer support to you, your caregiver, and your family. A cancer psychologist can help you figure out if emotional challenges you may have are because of the cancer treatment or brought on by the challenge of living with cancer. He or she has many tips and tools to help you cope with these challenges and promote the best quality of life.

5. Suggestions for Taking Care of Yourself¹

- Let others help you. Now is a good time to accept offers for rides, meals, going for a walk, or an offer from a friend for some company.
- Be as healthy as you can by eating well, getting your rest, and exercising. If you smoke, stop smoking now.
- Talk with your friends and family about what is worrying you and what you feel you need to best cope with the situation. Let them know what is important to you, including your feelings about end-of-life decisions.



 Do the things you've wanted to do like keeping a journal, playing music, taking a trip, or reconnecting with a friend or loved one. You might even wish to try a new activity, like taking an art course or taking up bird watching.



- Be open to talking with your cancer care team about taking medications that can help your emotional and physical symptoms. Also please make sure your cancer care team is aware of any medicine you are taking, including natural remedies. Your cancer care team can help you decide on the best medicines to take.
- Talk with your cancer care team about what you are going through. They are there for you and they can best help you if they understand your concerns and needs.
- Know the resources that are available to you and use them.
- Help yourself by asking questions, taking notes, and participating in your treatment as much as possible.

References

1. National Comprehensive Cancer Network. NCCN Guidelines for Patients™l Prostate Cancer. Accessed at <u>www.nccn.com/files/cancer-guidelines/prostate</u> February 27, 2012.

2. Prostate Cancer Canada. Treatment. Accessed at <u>http://www.prostatecancer.ca/Prostate-Cancer/Prostate-Cancer/Treatment</u> February 27, 2012.

3. Canadian Pharmacists Association. *Compendium of Pharmaceuticals and Specialties (CPS)*. Ottawa, Canada: Canadian Pharmacists Association; 2012.

4. Canadian Urological Association. CUA patient information. Accessed at <u>http://www.cua.org/patient_information_e.asp</u> February 27, 2012.

5. PROCURE. Hormone therapy. Accessed at <u>http://www.procure.ca/en/hormone-therapy.html</u> July 3, 2012.

6.Saad F, McCormack M. Understanding Prostate Cancer. 3rd ed. Montreal, Canada: Annika Parance; 2012.



Questions for Caregivers and Patients

- What are the treatment options available for me?
- What are the risks and benefits of each treatment?
- How will my age, general health, stage of prostate cancer, and other medical conditions affect my treatment choices?
- Do I have to be treated?
- What can I expect from treatment both positive and negative?
- What if I try treatment and decide to stop because of side effects?



- What are the worst side effects of treatment? And what are the options to help deal with side effects?
- Will I be able to do my daily activities during treatment?
- What is the chance that the cancer will continue to spread?
- Are there support groups for patients like me?

Reference

Adapted from: National Comprehensive Cancer Network. NCCN Guidelines for Patients™I Prostate Cancer. Accessed at <u>www.nccn.com/files/cancer-guidelines/prostate</u> February 27, 2012.



Frequently Asked Questions (FAQ)

Cancer Treatment Options

Q. My doctor said I would get hormone treatment for my prostate cancer. What does he/she mean by this?

A. Hormone therapy is used most often to treat advanced prostate cancer. Hormone therapy is not a cure for advanced prostate cancer, but rather controls the growth of cancer cells, usually for many months or even years. For more information – <u>http://www.cua.org/patient_information_e.asp</u>

Q. My doctor tells me that my cancer is now hormone therapy resistant, often referred to as castration resistant. Should I go on chemotherapy? What if I decide not to go on chemotherapy?

A. Choosing a treatment option may be hard. You may not want the side effects of treatment; however, choosing not to have treatment means that the cancer is more likely to progress and cause symptoms. Also, other medical problems may affect the decision of how aggressively to pursue treatment options.

For more information - www.nccn.com/files/cancer-guidelines/prostate



Supportive Treatment – Treatment of Pain

Q. Will I be in pain?

A. We will always have something we can do to help ease your pain. Talk with your cancer care team about any discomfort you are having. That way they can offer the right treatment to relieve your symptoms. For more information – www.nccn.com/files/cancer-guidelines/prostate

Q. I've heard that meditation might help. Is that true?

A. Meditation is one of several relaxation methods evaluated and found to be of possible benefit by an independent panel convened by the US National Institutes of Health (NIH) as a complementary therapy for treating chronic pain and insomnia. Scientific evidence does not suggest that meditation is effective in treating cancer; however, it may help to improve the quality of life for people with cancer.

For more information -

http://www.cancer.org/Treatment/TreatmentsandSideEffects/ComplementaryandAlternativeMedicine

Organization Issues – Finding Your Way Around the Healthcare System

Q. Who's in charge of my care?

A. Many types of healthcare workers manage the care of patients with prostate cancer. They work in a coordinated manner. The person in charge may change depending on your cancer stage. In advanced disease, often the medical oncologist or urologist is in charge of your treatment. They may work together in deciding the best treatment for you. The oncology nurse or the clinic nurse usually administers your treatment and can help with any questions you may



have. Your family doctor is also always able to help with your care. To help you understand who's involved in your care, refer to the 'Who's Who & What Do They Do?' information leaflet in this kit.

Activities

Q. What activities am I allowed to do? Do I have restrictions on the activities I can do?

A. You are allowed to live your life. You are living with cancer, which is not easy. Yet you are allowed to be as active as your body and energy level will allow. Sometimes the effects of your treatment may decrease your energy. If there are activities you wish to do but lack the energy, speak with your doctor. There may be ways to address your reduced energy level. Keeping as physically active as you can is the best way to keep your energy level up.

Death and Dying

Q. When will I die?

A. We will answer this question with another question. How do you want to live with cancer? Is it important for you to live your life as best as you can?

We have guidelines about survival times, but every patient is unique and every patient responds differently. We only know the future once it happens. In the meantime, try to live your life the way you want, as much as you are able. If there are things you want to do, share this information with your cancer care team. They may be able to help you.



Patient Booklet

The purpose of this booklet is simple – it will help your doctor and your cancer care team to help you. There are four sections to this booklet.

Section 1 - Treatment Plan

There is a space for you to write down the medications you are taking, the tests you have to have done and any other treatment information you are given during your clinic visit. You can add nutritional information, if you see the dietician, or exercises that may have been recommended by the physiotherapist.

Section 2 - Preparing for Appointments

This section is where you can really help your doctor and your cancer care team to help you. Your doctor will ask that you keep track of certain symptoms between appointments such as the amount of pain you have or the amount of pain medications taken. There is also a space to keep a note if you need prescription renewals so you can remember to ask during your appointment. Finally, there is a section where you can note the questions you have for your doctor so that you can get all the answers you need during your visit to the clinic. (See the FAQ and the Q&A in this toolkit.)

By using this section to prepare, you help your doctor and thus he/she will have more time to talk with you.

Section 3 - Personal Goals and Notes

This is where you can jot things down when you think of them, in the waiting room, in the car, in the coffee shop. If there is something you want to do and you're not sure of your physical limitations, note it here and talk about it with your doctor.

Section 4 - 'Who's Who & What Do They Do?'

In this section there is a brief description of the members of your cancer care team. The list of personnel below will help you understand who's who and what they do.

Section 1 Treatment Plan



There is a space for you to write down the medications you are taking, the tests you have to have done and any other treatment information you are given during your clinic visit. You can add nutritional information, if you see the dietician, or exercises that may have been recommended by the physiotherapist.

A: Medication (other than chemotherapy and hormone therapy)

Date	Medication Name	Goal of Medication	Your Comments / Questions





B: Chemotherapy or Hormone Therapy

Date	Chemotherapy Received	Cycle Number	Your Comments / Questions





C: Nutrition, Exercise, Supportive Care

Date	Specific Treatment - Nutrition, Exercise, Supportive Care	Goal	Your Comments / Questions

Section 2 **Preparing for Appointments**



This section is where you can really help your doctor and your cancer care team to help you. Your doctor will ask that you keep track of certain symptoms between appointments such as the amount of pain you have or the amount of pain medications taken. There is also a space to keep a note if you need prescription renewals so you can remember to ask during your appointment. Finally, there is a section where you can note the questions you have for your doctor so that you can get all the answers you need during your visit to the clinic. (See the FAQ and the Q&A in this toolkit.)

By using this section to prepare, you help your doctor and thus he/she will have more time to talk with you.

Answer:
Information received during your clinic visit: Symptoms and side effects
Other:
Next Appointment Date:

Section 2 **Preparing for Appointments**



ProstAIDE Patient Resource Kit

B: Your Symptom / Side Effect Tracker¹

Date	Symptom / Side Effect Example: Pain, fatigue, nausea, etc.	How bad was it? Circle a number 1 = least bad 10 = most severe	What you did to make it better.	Did it help?	Comments / Question
		1 2 3 4 5 6 7 8 9 10	Medication: Other:		
		1 2 3 4 5 6 7 8 9 10	Medication: Other:		
		1 2 3 4 5 6 7 8 9 10	Medication: Other:		
		1 2 3 4 5 6 7 8 9 10	Medication: Other:		
		1 2 3 4 5 6 7 8 9 10	Medication: Other:		

¹ Adapted from The Ottawa Hospital: Prostate Cancer Information Guide and Personal Record

Section 3 Personal Goals and Notes



This is where you can jot things down when you think of them, in the waiting room, in the car, in the coffee shop. If there is something you want to do and you're not sure of your physical limitations, note it here and talk about it with your doctor.

Date	Personal goals / notes	What do I need to be able to do it

Section 4 'Who's Who & What Do They Do?'



In this section there is a brief description of the members of your cancer care team. The list of personnel below will help you understand who's who and what they do.

Cancer care team member:	What they do:
Medical oncologist: Name: Contact:	A doctor who specializes in chemotherapy and other forms of systemic cancer treatment.
Radiation oncologist: Name: Contact:	A doctor who specializes in the treatment of cancer with radiation.
Urologist: Name: Contact:	A doctor and surgeon who specializes in the urinary system of men and women and in male sex organs.
Cancer care nurse: Name: Contact:	The nurse in the cancer clinic has many functions and can help you to get answers to your questions. Often times the doctor's time with you is short so any concerns you have you can mention to the nurse. He/she can help to clarify things so that your time with the doctor is productive. The nurse also may administer the treatments and medications when you come to the clinic.
Pharmacist: Name: Contact:	The pharmacist may be located in the cancer clinic or in the drug store. In either place, the pharmacist can help you to understand the medications you are taking.

Section 4 'Who's Who & What Do They Do?'



ProstAIDE Patient Resource Kit

Cancer care team member:	What they do:
Social worker: Name: Contact:	Your social worker can assist you to cope with and solve issues in your everyday life ranging from obtaining additional support at home to dealing with difficult relationships.
Dietician: Name: Contact:	The dietician can help you to understand your body's nutritional requirements and can offer meal plans to best meet those nutritional needs.
Family doctor: Name: Contact:	Your family doctor is an important member of your cancer care team. He or she offers you the continued care outside of the cancer treatment centre.
Palliative care doctor: Name: Contact:	A palliative care doctor specializes in preventing and relieving suffering in patients who are terminally ill.
Psychologist in oncology: Name: Contact:	People with cancer are under stress and often can feel strong emotions. A psychologist can help you to deal with these emotional challenges. The psychologist can help to distinguish if your emotional challenges are secondary to treatment or induced by the challenge of living with cancer. Addressing the psychological aspects of your cancer and its treatment may help you to best cope with all the issues you are facing.
Psychiatrist: Name: Contact:	Like the psychologist, a psychiatrist can help you to deal with the emotional challenges of living with cancer. He/she can offer pharmacological treatments to help you cope with your disease and treatment.



Additional Resources

The Ottawa Hospital. Prostate Cancer: Information Guide and Personal Record. http://www.ottawahospital.on.ca

Saad F, McCormack M. Understanding Prostate Cancer. 3rd ed. Montreal, Canada: Annika Parance; 2012.

Canadian Urological Association <u>http://www.uroinfo.ca</u>

Prostate Cancer Canada http://www.prostatecancer.ca

PROCURE http://www.procure.ca

Les mots et les gestes qui soignent http://www.lesmotsetlesgestes.org