

**PROSTATE CANCER CANADA NETWORK
SUPPORT GROUP HANDBOOK**



prostatecancernetwork.ca

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Table of Contents

1. Introduction
2. In the Beginning
3. Programs & Activities
4. The Meeting
5. Awareness
6. Resource Materials

Table of Contents

Page

Chapter 1: Introduction

1.0	A Short History of PCCN Support Groups	1
	A. Working Together from Strength to Strength	
	B. The Need	
1.1	What is a Prostate Cancer Support Group?	2
1.2	Why do People Join a Support Group?	3
1.3	Mission Statement, Purpose, Goals, and Objectives	4
	A. Mission Statement	
	B. Purpose	

Chapter 2: In the Beginning

2.0	Support Groups - How and Where to Start	7
	A. Reasons for Starting a Support Group	
	B. Getting Organized	
	C. Building a Leadership Team	
	D. Leadership Team Meetings	
2.1	Effective Leadership	9
2.2	How do Prostate Cancer Support Groups Function?	11
	A. Structure	
	B. Open and Closed Support Groups	
2.3	Support Group Meetings	12
	A. Meeting Locations	
	B. Format	

	C.	Agenda	
	D.	Beyond the Agenda	
2.4		Ground Rules	16
Chapter 3: Programs and Activities			
3.0	A.	Guest Speakers	17
	B.	Mentoring Sessions	
	C.	Special Interest or Breakout Groups	
	D.	Newsletters	
	E.	Awareness Activities	
	F.	Fundraising	
	G.	Advocacy Initiatives	
Chapter 4: The meeting			
4.0		Support Group Humour	20
4.1		Involving Spouses	21
4.2		Recruiting Volunteers	22
4.3		Training and Leadership Development	23
4.4		Maintaining and Encouraging Membership	24
4.5		Group Sustainability	26
4.6		Program Evaluation	27
4.7		Administrative Activities	28
4.8		Group Directories and Mailing Lists	29

Chapter 5: Awareness

5.0	Reaching Out	30
A.	Community Forums	
B.	Going Forward with Your Community Forum	
	1. Developing a Theme	
	2. Preparation	
	3. Prepare an Agenda	
	4. Select a Chairperson	
	5. Arrange for a Guest Speaker	
	6. Volunteers	
	7. Display Board and Handout Material	
	8. Advertising	
	9. Budget	
	10. Acknowledgements and Follow-up	
C.	Beyond the Community Forum	
5.1	Support Group Benefits	34
	1. Friendship	

Chapter 6: Resource Material

6.0	PCCN and Other Recommended Resources	36
	Canadian and International Cancer Sites, Clinical Trials, Directories, & Information Services	

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“The Canadian Cancer Action Network (CCAN) is dedicated to ensuring patient interests remain an integral part of the emerging pan-Canadian cancer control strategy. CCAN unites cancer-site patient organizations and population organizations from across Canada in a coordinated and focused effort to ensure the patient voice is heard in all areas of the cancer control continuum.”

Prostate Cancer Canada wishes to acknowledge the contribution of Dr. John Oliffe, Associate Professor, Nursing, University of British Columbia and the Prostate Cancer Foundation, BC.

1.0: A Short History of PCCN Support Groups

A. Working Together from Strength to Strength

The establishment of Prostate Cancer Canada Network (PCCN) in 2009 heralded a new era for prostate cancer support groups in Canada.

The Prostate Cancer Canada Network (PCCN) has moved forward and grown in strength and stature from its inception, Remembrance Day, November 11, 1995, as the Canadian Prostate Cancer Network (CPCN).

In the early 1990s there were only a handful of prostate cancer support groups in Canada. Since then, the number has grown to more than 120, located coast to coast, from St. John's, Newfoundland and Labrador, to Victoria, British Columbia.

PCCN now speaks for the thousands of Canadian men who, each year, are diagnosed with prostate cancer. This growth, in part, reflects the value prostate cancer support groups provide, not only to men, their spouses, and families who are living with prostate cancer, but also to the countless number of men who have been made more aware of prostate cancer and the importance of early detection and appropriate treatment.

Through its affiliated network of support groups, Prostate Cancer Canada Network is now able to reach out to a greater number of men and their families, across Canada, and provide support and up-to-date medical information to those affected by prostate cancer. PCCN also conducts public campaigns promoting prostate cancer awareness, early detection, and advocates for increased funding to combat prostate cancer through research, improved diagnosis and treatment, educational programs and public awareness.

When PCCN was established, Bob Shiell, the Managing Director, stated; "By working together we will be able to go from strength to strength, to benefit Canadian men and their families during their journey with prostate cancer. The ultimate benefit will be a coast-to-coast network of strengthened support groups that will have more and better tools and training to support those affected by prostate cancer".

This Prostate Cancer Canada Network Support Group Handbook is intended for the use of its support groups and those who may have an interest in establishing a support group.

B. The Need

Prostate cancer is the most common male cancer and the third highest cause of cancer deaths in Canadian men. One in 6 men will develop prostate cancer during his lifetime (the risk is highest after age 60) and one in 27 will die of it. In 2009, an estimated 25,500 men were diagnosed with prostate cancer and 4,400 died. On average, 490 Canadian men will be diagnosed and 85 will die of prostate cancer every week.

1.1 What is a Prostate Cancer Support Group?

A prostate cancer support group is a group of two or more people with a common interest who come together to deal with a shared concern or problem, prostate cancer.

Studies of men's health practices have demonstrated that men do not typically engage with self-health or acknowledge illness, let alone openly discuss their health concerns with other men. The emergence of prostate cancer support groups as a community based resource; to assist men and their families dealing with the challenges of living with prostate cancer appears to run contrary to such practices.

Most prostate cancer support groups are led by a prostate cancer survivor(s) and the majority of members are men with prostate cancer. Some groups include spouses, family members, caregivers, and people from the community at large with an interest in learning more about prostate cancer. One of the significant features of a prostate cancer support group is that they exist and are run by and for the mutual benefit of their members, many of whom are prostate cancer 'experts' themselves.

Prostate cancer support groups can range in size from relatively small groups of 5 or 6 men in smaller more rural communities. Those in urban centres tend to be larger, some having over 300 members. These larger groups usually meet on a regular basis and their membership includes spouses, family members, in addition to men with prostate cancer. On average, most prostate cancer support groups have a core membership somewhere between 20 and 60 members. However, what is important to remember is that the success of a support group is not measured in terms of its size, but rather by the benefits and support it provides to its members.

Members are encouraged to attend formal presentations, often by medical professional, ask questions, share information and resources, and help one another to better understand their diagnosis, treatment options and their potential side effects. They discuss the type of questions they should be asking their health care providers to ensure they have the information they require to make informed decisions.

The most common and usually the best attended activity of most prostate cancer support groups are the regular members' meetings. These meetings provide an unparalleled opportunity for the members to come together, on a regular basis, to talk, share experiences, and provide support and encouragement to one another. Some groups invite guest speakers from the medical community to their meetings on a regular basis, others do so from time to time. This allows members to ask questions and learn about recent developments or advancements for treating and dealing with prostate cancer and managing their health.

1.2 Why Do People Join a Support Group?

Prostate cancer support groups offer a unique opportunity for men and their families to meet and talk with other prostate cancer survivors who may have already dealt with some of the same questions, issues, and concerns they are experiencing. They can also provide information and direct members to educational or medical resources that can help them make informed decisions concerning their health and treatment.

Sharing or exchanging information with a prostate cancer survivor can provide an element of hope and encouragement to newly diagnosed individuals and their families, and help to restore a sense of control and confidence as they work through the process of dealing with their disease and deciding upon a course of action and treatment.

There is evidence that people who attend support group meetings have a better understanding of the disease and their treatment choices. They also tend to experience less anxiety, develop a more positive outlook, and a better ability to cope and adapt to life during and after treatment for prostate cancer.

That said it is important to remember that support groups are not for everyone. Everyone does not have the same needs, concerns, or reasons for attending or belonging to a support group and the benefits they obtain from attending a support group vary from one person to another. Some men choose to attend a support group because they are looking for information to help them deal with the uncertainties of a diagnosis of prostate cancer and to find answers to their questions. Others are simply looking for practical solutions to help them cope with their diagnosis and minimize any side-effects related to their treatment.

Some men find that after attending one or two meetings, they have obtained all the information they want and that their needs have been met. Others will find that talking or sharing information about their condition makes them uncomfortable and is something they would rather not do.

There will also be men who 'join' a support group, but may not attend meetings on a regular basis, choosing instead to attend sporadically when a topic of specific interest to them is being discussed, or when their needs or situation changes. You will often find these individuals are more than willing to stay in touch and appreciate being on the group's mailing list.

1.3 Mission Statement, Purpose, Goals and Objectives

A. Mission Statement

Some support groups find it helpful to develop a mission statement. A mission statement is simply a short, written statement which defines the purpose, objectives, and priorities of a group.

Some groups choose to limit their mandate or involvement to providing support to members and raising prostate cancer awareness, in which case the mission statement would simply be:

- To increase prostate cancer awareness and provide support to men with prostate cancer.

Other groups may choose to expand the scope of their mandate to include outreach, advocacy, fundraising, and activities in addition to support for its members and raising prostate cancer awareness. A more detailed mission statement might be:

- To provide support and information to the men and their families who are affected by prostate cancer.
- To raise awareness of prostate cancer by speaking at public forums and participating in community events.
- To advocate for adoption of prostate specific antigen (PSA) testing and digital rectal examination (DRE) screening programs to enhance early detection of prostate cancer.
- To raise funds for prostate cancer research and treatment facilities.

In either case, the main advantage of having a mission statement is to establish and more clearly define the scope and range of the group's goals and objectives and provides the group with a sense of direction to ensure decision-making. Providing a copy of the mission statement to each support group member is an easy way to make sure everyone is familiar with purpose and objectives of the group and helps keep the group focused and cohesive.

B. Purpose

The primary purpose of a prostate cancer support group is to create an opportunity for men, both newly diagnosed, and those living with prostate cancer, to meet and talk with others who are in a similar situation who are willing to share their personal experiences with prostate cancer and provide encouragement and support.

A diagnosis of prostate cancer is most often unexpected and almost always traumatic. As a result, it is not uncommon for newly diagnosed men to experience a wide range of emotions including, confusion, bewilderment, anger, fear, panic, and denial.

Many people find that just having an opportunity to talk with another person, who has experienced the same situation, helps alleviate some of the anxiety and distress they commonly experience.

Some men experience minimal or no adverse consequences as a result of being diagnosed and treated for prostate cancer, while others experience devastating side effects, which may include urinary incontinence, erectile dysfunction or bowel disorders. The process of accepting, coping, and incorporating these conditions into one's lifestyle can be very difficult and making the adjustment required to switch from what was one's 'old normal' lifestyle to what has become the 'new normal' lifestyle is a transition, and it takes time.

It is important to recognize, that everyone does not have the same needs, concerns, or reasons for attending a support group. Some men choose to attend a support group because they are looking for scientific or medical information to help them deal with the uncertainties of a diagnosis of prostate cancer and to find answers to their questions. Others are simply looking for practical solutions to help them cope with their diagnosis and minimize any side-effects related to their treatment.

Regardless of the reason for being part of a support group, no one should be pressured or made to feel threatened, but rather, be allowed to participate and engage in group activities only when they are comfortable doing so.

The specific goals and objectives of individual prostate cancer support groups vary, but they generally include;

- promoting awareness of prostate cancer risk factors, including, race, family history, diet, and lifestyle
- providing support to men with prostate cancer and their families living with prostate cancer
- helping newly diagnosed men understand and deal with prostate cancer
- sharing the latest prostate cancer treatment and health information
- helping men regain a sense of control and cope with the side effects of prostate cancer
- creating and providing a non-threatening, confidential environment where prostate cancer survivors and their spouses can meet, socialize, and share their experiences, and learn from one another
- providing a strong community voice in matters relating to prostate cancer
- advocating for more effective test procedures and early detection programs
- raising awareness of prostate cancer
- advocating for no-cost baseline PSA tests for men at age 40
- advocating for equitable access to optimal prostate cancer treatments
- advocating for increased funding for prostate cancer research

Chapter 2 - Support Groups - How and Where to Start

A. Reasons for Starting a Support Group

A common reason for wanting to start a support group is that you or a small group of individuals in your community have identified the need and share a common interest in helping men diagnosed and living with prostate cancer. This often relates back to a situation where someone, at some time, helped you and you are now in a position to help others.

Regardless of the motivation for establishing a support group, the most important thing is that someone takes the initiative and accepts the responsibility of leading the process.

When faced with a diagnosis, recurrence or progression of prostate cancer, it is not uncommon for men to seek out information and try to find someone who can provide answers to all those questions that flood the mind, in an effort to deal with it and try to regain a sense of control.

Support groups can help meet this need by providing an opportunity to meet and talk to someone who has experienced a similar situation. Often there is a unique strength in group settings which helps people mobilize the energy required to navigate their way through what at times can be a complex disease, and a confusing and frightening medical system.

Many times it is the person who has experienced and dealt with this type of trauma that is best suited to be of help.

The ability of a support group to accept the continual challenges of meeting and adjusting to the changing needs and circumstances of its members truly reflects its potential for success.

B. Getting Organized

The leadership team plays a crucial role both in the establishment and the ongoing success, maintenance, and growth of a support group.

The most important role of the leadership team is to build consensus, develop a clear understanding of the group's goals and objectives, and mandate.

Key functions of the leadership team include developing and implementing an action plan, identifying what needs to be done, who will be responsible for doing it, and when the various tasks are to be completed. The team also plans meetings, selects topics for discussion, makes arrangements for speakers, plans group activities, and conducts the general business of the group.

C. Building a Leadership Team

It may seem that support groups start quite spontaneously and keep going without much planning. This may happen, but, it is not usually the case. It takes time and effort to establish and maintain a viable and effective support group. A team approach usually works best. Think mutual help from the beginning.

One of the first steps in organizing a support group is to establish a leadership team. This can be as few as two people but seems to work best with four or five once the group starts to grow.

There are several ways you can recruit a leadership team. But one of the most effective ways to involve people who share your interest in taking on a leadership role as well as belonging to the support group.

In the case of a new group, discussing the idea that you are planning to establish a support group with family, friends, neighbours, business associates and social contacts is a good idea and may identify potential committee members. Your family doctor, urologist, oncologist or pharmacist may also be in a position to identify or refer individuals to you who may be interested in becoming involved.

You may also want to contact existing prostate cancer support groups to help advertise and promote the creation of your group. It may be that they have members who would be willing to provide assistance or get involved in a new group.

It is important to involve as many enthusiastic people as possible right from the beginning of the planning and building process. You will often find that these are the individuals who eventually form the backbone of the group and are willing to take on additional tasks and assume more responsibility as the group grows. Working with a group of people helps to distribute the work load and reduces the likelihood of getting bogged down.

D. Leadership Team Meetings

Meetings once a month help keep your leadership team engaged and motivated. They also provide an opportunity for members to check on progress and timelines for upcoming meetings, discuss and resolve any outstanding issues, review and evaluate recent meetings, report and provide updates on current activities and events, and conduct the routine business of the group. Preparing and circulating an agenda and the minutes of the previous meeting prior to the meeting will help keep members informed and focused. All members should have the opportunity to participate in the meetings and add items to the agenda.

As the leadership team and committee members work through the planning and implementation stages, it is important to keep a written record of the team's decisions and action items. In the case of new groups, these records often prove to be useful and help keep the group on track. The information will also provide an historical record of how and when group was established, who was involved, the decisions that were made, and the actions that were taken and will of interest to the membership in the future.

2.1 Effective Leadership

Prostate cancer support groups are most effective when there is mutual respect, a shared sense of purpose, tolerance for conflict and a strong feeling of cohesiveness within the group.

Discussions in a support group often involve highly personal and emotional issues and a single insensitive action or remark can undermine and damage the cohesiveness and trust that is so important in a group.

It is important for the group leaders to recognize the potential for conflict and disagreements exist when individuals are dealing and trying to cope with stressful situations, such as a diagnosis of prostate cancer, or dealing with the side effects. Having to cope and adjust to a 'new' lifestyle is a transition, it takes time, and it can be very stressful. Or it could simply be a situation where members disagree on an issue or someone monopolizes discussions makes inappropriate or offensive remarks, or whose behaviour is otherwise unacceptable.

There are two essential characteristics that define good leadership within a prostate cancer support group.

The first is an ability to listen and care about the feelings of others. Active listening is very important in creating and maintaining a respectful atmosphere within a group. It involves being attentive listening carefully without interruption until the person speaking has explained the entire situation, and being aware of the speaker's body language and tone of voice. And then confirming that you have understood what was said.

The second is a willingness to delegate and share responsibilities with others. As you will see later in this handbook, there are many tasks that need to be shared. You must be willing to ask for volunteers and rely on others to perform some of the tasks. This will enhance effectiveness of the group and result in a greater overall level of satisfaction for the members.

In other words, don't try to do everything yourself. Taking on too much responsibility deters others from getting involved and increases the risk of burn-out.

Additional leadership qualities include;

- welcoming and introducing newcomers to the group
- tactfully engaging others in group discussions and activities
- validating other people's feelings
- talking about your own experiences, only, when it is relevant to the discussion
- good organizational and facilitation skills
- providing an equal opportunity to participate in discussions and ask questions
- dealing with conflict, in an objective, tactful, non-judgemental manner

- not interrupting or attempting to finish someone else's comments
- ensuring everyone has an equal opportunity to participate and ask questions
- reinforcing member's positive experiences and self-management strategies
- maintaining a positive attitude and sense of humour
- admitting you don't know when asked a question you can't answer
- directing people to sources of relevant information
- explaining and enforcing the ground rules for group meetings and discussions

In summary, it is important that leaders encourage all members to share the responsibilities and get involved in group functions, but at the same time, individuals must be allowed to decide for themselves when they are comfortable and ready to get more involved in group functions or accept a leadership role.

2.2 How Do Prostate Cancer Support Groups Function?

A. Structure

The structure of support groups generally depends on a number of factors, such as the size and location of the group, where the meetings are held, the goals and objectives of the group, the scope of activities, the needs and health status of its members, and the leadership style of the individuals in charge of the group.

There are large structured groups that have leadership teams or steering committees with 6 -12 members, and committees to plan, organize and conduct outreach activities, awareness events, advocacy initiatives, and fundraising events. Meetings are held monthly and include formal presentations, usually by medical professionals. Members and guests sign in, wear name tags and member's attendance is recorded.

The other end of the spectrum are the small non-structured groups, with a handful of members, that get together only occasionally at the call of the chairperson, or as the need arises, and meet informally at a local restaurant or someone's home.

In some cases problems can arise when a group tries too hard to be 'the same' as another group when in fact it is 'different'. The most effective structure is the one that works for your group. It usually becomes clear over time and may in fact change from time to time as the needs of the members change and the group evolves.

B. Open and Closed Support Groups

Prostate cancer support group meetings may be open or closed depending on the needs and wishes of the members.

Open groups do not usually limit or restrict membership or participation in the group. In addition to men with prostate cancer and their families, and individuals from the local community are welcome and encouraged to attend. Open groups normally publicize and circulate the time, date, and location of their meetings, and the speakers and topics being presented at upcoming meetings. This information is placed in their newsletter, the local media, radio or television station, and posted on the website to encourage attendance at their meetings.

Closed groups, on the other hand, are generally attended only by men with prostate cancer, and in some cases spouses or family members. Meetings are not usually advertised or open to the general public.

There are, however, situations where a combination of these approaches works well. For example, some open groups choose to hold separate meetings or breakout sessions during their regular meetings for individuals with unique needs or different interests. This may include men who are newly diagnosed or attending the support group for the first time, men who have had the same type of treatment(s), individuals dealing with side effects, men experiencing a recurrence or progression of their cancer or couples living with prostate cancer.

2.3 Support Group Meetings

A. Meeting Locations

Support groups hold their meetings in a variety of locations such as schools, churches, public libraries, community centres, local hospitals, arenas, or service clubs. Some facilities donate space for non-profit community groups or events. The facility should be large enough to accommodate the size of the group.

It is important to have quality audio/visual equipment for your speakers and people wanting to ask questions, especially, if you are expecting a large number of people, meeting in a large facility or one which has poor acoustics. A portable microphone that can be passed around is also very useful as it allows people to ask questions without having to come to the front of the room, or requiring them or someone else to repeat their questions. Some facilities will provide equipment, in other instances it may be necessary to borrow or rent it.

Few locations are perfect but a meeting location should have comfortable chairs, quiet surroundings, good acoustics, audio/visual equipment, lighting, temperature regulation and clean, easily accessible washrooms. Long term availability, adequate parking, accessible public transportation and an area to prepare refreshments are also important considerations.

Before you commit to a location, confirm that it will be available for the dates and times you have set for your meetings, whether or not you are responsible for setting-up tables and chairs before and after each meeting, the arrangements for gaining access to the facility and determine who is responsible for opening, closing and locking up after the meetings. Know how much time you will have for each meeting, when you must be finished, and how much flexibility there will be for members who want to stay and chat. If possible, arrange to have keys prepared and distributed to leadership team members. Also be aware of who has a key and where it is kept.

B. Format

It is important to ensure the meetings are well organized. In the case of a new group, you may want to invite the chairman and/or other members from another support group to give you some guidance.

Most prostate cancer support groups meet monthly. The general meetings provide an opportunity for members to meet and socialize with other prostate cancer survivors and their spouses, share information, attend presentations and participate in discussions about prostate cancer related topics.

The format and program content will vary from one group to another. For the most part, they follow a similar format which normally includes time for social interaction, personal discussions and refreshments, a 'business' section to update members on group activities and future plans, and a 'formal' presentation or guest speaker with a question and answer period.

Although it is not always possible, it is ideal if you can arrange to have a medical person available to answer member's questions.

Try to encourage members to participate and get involved in the meetings. Using 'open ended' questions during the meetings and asking them to let you know what they like or don't like are ways to keep members engaged and helps to evaluate the effectiveness and relevancy of your programs to the members.

C. Agenda

It can be helpful to have a written agenda for the meetings. They help keep the meeting on track and over a period of time, provide a permanent record of speakers and topics that were discussed at your meetings, as well as a written record of the work your support group has done.

The following is offered for consideration,

- Welcome all those present and ask members and guests to sign the attendance registry.
- The chairman opens the meeting, introduces visitors and guests, reviews the agenda, ground rules, provides a brief overview of the group's purpose, goals and objectives, mentions the housekeeping provisions (location of washrooms and availability of refreshments, etc.) and responds to any questions.
- Provide members and guests an opportunity to introduce themselves and if comfortable doing so, to briefly state what they hope to gain or learn by their attendance. However, use your judgement as it may not be practical to introduce everyone if there are a large number of people.
- Provide time for a short coffee break.
- Introduce guest speaker(s) followed by a question period.
- At the end of the meeting, the chairperson thanks the speakers and all those who attended, reminds everyone of the date, time and location of the next meeting.
- Allow some time at the end of the meeting for people to talk with the guest speaker, members of the leadership team, or to simply chat with one another. It also provides an opportunity to find out what members thought about the meeting and to ask them to suggest possible speakers or topics for future meetings.

A sample agenda:

Doors Open, Pre-Meeting Social Time/ Refreshments	30 minutes
Welcome by Chair & Opening of Meeting	5 minutes
Review Agenda/Updates/ Announcements	5 minutes
Introduction of New Members/ Visitors	5 - 10 minutes
Program/ Speaker	40 minutes
Speaker Q & As/Feedback from Breakout Groups	15 - 20 minutes
Thank Speakers/ Close Meeting	5 minutes
Social Time	Open
Total time:	Approx. 2 hrs

D. Beyond the Agenda

An effective prostate cancer support group requires some big-picture thinking about things like purpose and direction. But you cannot overlook the much smaller logistical details as well.

Planning and organization plays a huge role in determining the success of your group meetings. As well as planning the agenda, you want to ensure your meetings run smoothly, hold the interest of the members, and are a comfortable experience for everyone. The following is a list of suggestions that have worked well for others;

- post directions to the meeting room near the entrance of building
- set up the meeting area well in advance of the first arrivals: tables, chairs, refreshments, printed agendas, paper, pens, sign-up sheets
- be aware of the temperature/comfort level in the room
- prepare the agenda in advance
- welcome newcomers, guests and members as they arrive for the meeting
- ask guest to complete name tags
- start the meeting on time; it encourages people to arrive on time

- if the room is large encourage people to speak loudly or, if possible, provide a microphone so that everyone can hear
- review the ground rules (i.e. raise hand so the chairperson can acknowledge them, no side conversations) and location of washrooms
- encourage everyone to participate and provide an equal opportunity to ask questions or speak to points raised during speaker's presentation
- if there is a large crowd, to limit the number of questions, e.g. one per person, until everyone who wishes to speak has an opportunity to do so
- be flexible with time and content but remain clear on your priorities
- remember your role as leader and facilitator, know who is doing what and when

2.4 Ground Rules

Establishing ground rules for the group provides structure and a code of conduct for the benefit of members, leaders and guests alike.

Ground rules help establish and maintain an atmosphere of cordiality, comfort and minimize the likelihood of members being made to feel uncomfortable. They should provide clear guidance on issues such as, talking, asking questions, punctuality, behaviour, confidentiality and the role and responsibilities of the chairperson. They can also help prevent conflicts from occurring and facilitate their resolution if they do, by making sure that everyone is aware of what is expected and what is unacceptable.

Suggestions include,

- meetings will start and end on time
- members should make an effort to be punctual
- comments and conversations of support group members are confidential and should not be discussed outside the group
- personal information that can be used to identify an individual as a member of the support group is confidential
- members do not give medical or recommend specific treatments
- members may relate personal experiences and share information about the treatments they experienced, or advise others where such information can be obtained
- members should direct questions through the chairperson and give their full attention to the person speaking
- only one person talks at a time and everyone will have an opportunity to speak
- individuals should try to speak loudly and clearly, or use a microphone, if available, so questions and comments can be heard by everyone
- no side conversations
- members are encouraged to participate, but not required to do so
- no one should make comments that are likely to offend or make others uncomfortable

Chapter 3: Programs and Activities

Developing and maintaining program services and activities for your group can be an ongoing challenge, however, it is one which can be met in a variety of ways and is often best approached by breaking them down into their component parts.

A. Guest Speakers

Arranging to have a guest speaker at your support group meeting is a great way to provide valuable information. Once you have determined the interests of the membership, try to arrange for an expert to come and speak to your group.

Guest speakers can be recruited from a variety of sources: members of the medical community, urologists, radiation oncologists, family physicians, nutritionists, dieticians, physical therapists and the like are quite popular. It may also be possible to have someone from your support group or a neighbouring support group do an 'informal' presentation on a topic they have a particular interest in or are knowledgeable about. Other options include having someone present book reviews, video presentations, or hold 'town-hall' meetings on various topics of the members' choice.

Some programs and speakers will be more popular than others with your group. The best combination usually becomes evident over time and the topics and focus of discussions may shift in response to the changing needs and interests of the members.

Book your speakers as far in advance as possible. This makes it easier for members to commit to attending meetings and they can help spread the word to others. It also allows your steering committee to publicize the event through typical channels, the group's newsletter, local newspapers, and posting a notice on the group's website. These are all potential resource people who can provide information and may be willing to attend your meetings as a guest speaker.

The Prostate Cancer Canada Network can also be approached to provide or recommend a speaker from their 'speaker's bureau'.

Presenting speaker(s) with a small token of appreciation is always appropriate. Gift certificates, books, Prostate Cancer Canada lapel pins, ties, or scarves all make good gifts.

B. Mentoring Sessions

Some groups hold mentoring sessions for newly diagnosed men and their spouses, and for individuals who are attending the support group for the first time.

The mentors are prostate cancer survivors who have a good knowledge of diagnosis, treatment, potential consequences and long term effects. They are willing and able to share and experiences and respond to questions.

These sessions are usually held apart from the main meeting area or even on separate days or times. The number of mentors is kept to a minimum to make everyone feel as comfortable as possible. It allows men to talk freely about their situation and ask questions in the relative privacy of a small group. It also helps to ensure the mentors have sufficient time to provide all the relevant information, respond fully to any questions, and provide background information about the support group. You may find that some men or couples choose to attend more than one mentoring session.

C. Special Interest or Breakout Groups

Some support groups hold breakout sessions as part of their regular monthly meetings; others hold them separately at a different time or location. Breakout sessions provide a unique opportunity for the members to get together to discuss issues or concerns they have in common.

There are also a number of groups where members get together from time to time for social occasions, or on a regular basis to jog, run or exercise, or just meet and visit at a local watering hole for a 'chin wag'. There are no limits to the options for members getting together informally to support and encourage one another.

D. Newsletters

Many support groups prepare and distribute newsletters to their members, professional associates, and other interested parties. A newsletter is an excellent way to keep members informed of current activities, announce topics and speakers for upcoming monthly meetings advertise and promote local and national awareness activities and fundraising events. Most groups circulate their newsletter by e-mail, but, mail is also appropriate. If your group does not have a newsletter, the Prostate Cancer Canada Network can help you set one up.

E. Awareness Activities

Some groups choose to get involved in local community events promoting awareness and the importance of early detection and treatment of prostate cancer. These events can range from setting up an exhibit or information booth at locations as diverse as, fall fairs, farmer's markets, antique car shows, health fairs, and sporting events. It could also involve making public presentations to service clubs, submitting articles to community newspapers or writing and submitting letters to the editor of local or national newspapers.

There will also be opportunities for your support group to get involved and participate, at a local level, in Prostate Cancer Canada (PCC) fundraising events, such as the Father's Day Walk/Run, Movember, Wake Up Call Breakfast and 40 community events. This is often an effective way to gain public exposure and recognition and bring your support group and services you provide to the attention the community.

F. Fundraising

No group can function without operating funds. Even a volunteer-run support group needs to pay for operating items such as paper, pens, stamps, printing or copying, name tags, refreshments, small gifts for speakers, fees for meeting rooms, renting or purchasing audio/visual equipment, etc.

Maintaining accurate financial records, and being accountable for money collected and spent by the group is essential to the group's credibility. This requires accurate record keeping. The chairman may want to assign this role to a volunteer who is willing to act as the bookkeeper and/or treasurer. It is also a good idea to establish a separate bank account for the group.

There are several ways to generate revenue and it is often helpful to approach other support groups for ideas. Possibilities include;

- a prominently displayed donation box near the refreshments at meetings
- member donations

- tag days
- 50/50 draws at monthly meetings

All support groups are encouraged to get involved at the local level with Prostate Cancer Canada sponsored programs and events which promote prostate cancer awareness and raise funds for prostate cancer research. See section 3.0 E – Awareness Activities.

G. Advocacy Initiatives

Some support groups choose to take their community involvement to the next level and advocate locally, provincially and/or nationally for increased funding for prostate cancer research, development of more effective diagnostic procedures, enhanced testing for early detection, diagnosis, treatment, and long term support of prostate cancer issues, and the promotion of men's health and wellness issues.

In the future, Prostate Cancer Canada hopes to provide advocacy training and expertise in this area for support groups interested in getting more involved.

Chapter 4 – The meeting

4.0 Support Group Humour

Humour is frequently a component of prostate cancer support group interactions.

A study of Australian-based support groups found that after giving a person enough time to talk and welcoming new members into the group, incorporating humour was the third most important characteristic identified for successful support group leaders.

It has also been shown that humour plays an important role in men's social interactions and provides a strategy to self-disclose and vent feelings. In cancer survivors where there is a positive correlation between humour and comfort level, humour is frequently used as a coping mechanism to improve immune system functioning, to promote general wellness, and to release tension.

Men also use humour to distance themselves from specific illness events, burdensome situations and to reduce their anxiety.

A Canadian study by John Oliffe (UBC) reported that group cohesion was fostered by humour directed at reducing men's anxiety about their cancer, as well as the uncomfortable uncertainty of being in the company of strangers during what was often a challenging and potentially vulnerable time.

Some group leaders regularly share a joke at the beginning of the meeting to help break the ice and promote group inclusiveness. However, it is equally important that group leaders be able to differentiate and recognize whether the humour is facilitative or restrictive. In the latter, the leader must learn how to confront/challenge the resistance in a way that is helpful and does not deter the overall use of humour.

4.1 Involving Spouses

Some members encourage their spouses to attend regular monthly meetings. They share the same concerns and have the same need for information and support as their husbands and want to be able to help them cope.

At the same time, however, it is important to be aware of the fact that some people may be reluctant to discuss personal issues, such as incontinence or erectile dysfunction, or sexual intimacy in the presence of strangers or members of the opposite sex. In these situations, you must be sensitive, exercise good judgement, and provide an environment that is comfortable for everyone.

Some groups provide a separate room where the spouses can hold 'break-out' sessions as part of the regular meetings. Others meet at a separate time and location. Another combination is meetings attended by 'couples only'. Combined, these options provide an opportunity for everyone to have the confidential environment they need to share and discuss their concerns and provide encouragement and support for one another.

Whenever possible, spouses should be encouraged to volunteer and become members of group committees or the leadership team.

Some spouses who choose not to attend support group meetings may be interested in attending social functions and interacting socially with other members.

4.2 Recruiting Volunteers

To prevent leadership team members from suffering an overload or 'burn out,' always be on the lookout for new volunteers. It is important to identify and involve as many enthusiastic people as possible right from the beginning. You may find that these are individuals who will eventually form the backbone of the group and assume more responsibility as time goes on.

Information contained in the member's database can also be used to identify those who have expressed an interest in volunteering. Some members, however, may require some encouragement and respond better to a personal invitation, particularly new members who may not feel comfortable enough to step forward.

Getting to know members during the informal chat/refreshment time will help make you aware of their particular skills or interests. They, in turn, will get to know you better and may be more inclined to step forward. Making notes at the end of every meeting, recording names, people's interests, and skills you have discovered will serve you well when trying to fill your future volunteer needs.

4.3 Training and Leadership Development

Providing training on leadership development and facilitation skills for team leaders is something most support groups find beneficial.

Prostate Cancer Canada Network is exploring the possibility of training and workshops on a variety of topics at the annual PCCN conference.

Many communities have access to local agencies through United Way, the Canadian Cancer Society, or community services that provide or are willing to make such training available to volunteer/ non-profit organizations. Check for resources that may be available in your community.

Another option for consideration is Toastmasters International which also provides training in public speaking.

4.4 Maintaining and Encouraging Membership

The main reason most men go to a prostate cancer support group is to get information and talk to someone who may be able to help them decide what to do in terms of treatment. In most cases it is a question of talking with others and learning more about the advantages and disadvantages of the various treatments - for some, it may be a question of finding information that will help them cope and adjust to living with prostate cancer.

Regardless of why men come to a support group, the best way to maintain and encourage attendance is to give members positive messages and worthwhile information that meets their needs. If you can do that on a consistent basis, members will come regularly and the group will be successful.

These are some suggestions,

- Don't reinvent the wheel. Take advantage of the experience and advice of other support groups, or contact Prostate Cancer Canada Network at info@prostatecancernetwork.ca.
- Hold meetings at a time and location that is convenient and readily accessible.
- Set up a hospitality committee; greet everyone who attends the meeting.
- Welcome new members and guests at each meeting and provide an opportunity for them to introduce themselves and share their situation with the group, if they wish.
- Provide interesting programs, be responsive to the member's needs, and encourage members to identify topics for discussion and speakers.
- Vary the activities and provide time for members to socialize and always serve refreshments.
- Encourage members to work together and get involved in group activities.
- Keep members informed, have leaders and committee members report on their activities.
- Record attendance and maintain an up to date membership directory with contact addresses and phone numbers
- Encourage discussion and promote social and/or special events or activities.
- Stay in touch with members through a phone committee so they are aware of current activities and have the opportunity to talk to someone
- Create and maintain an inclusive, non-judgemental, welcoming environment.

4.5 Group Sustainability

Most groups need time to evolve and develop into a cohesive self-sustaining unit. Over time, as the group continues to meet on a regular basis and members get to know and become more comfortable with one another, groups tend to take on a life of their own.

Even after a prostate cancer support group is up and running, it still takes time and energy to keep it together and running smoothly. It is not unusual for the structure and focus of a support group to shift over time as the needs and circumstances of its members change. Expect “ups and downs” in attendance and enthusiasm.

It is recommended that support group leaders review and assess the general member’s meetings, speakers, and other group activities and periodically solicit input from their membership at the team meetings or at least on an annual basis.

4.6 Program Evaluation

Making and maintaining notes on the content of each meeting, coupled with member comments, provide valuable information when planning future meetings. Including the members in the process of planning and organizing future meetings is encouraged.

This can be done informally at the end of the regular monthly meeting by simply asking members to share their thoughts and impressions of the meeting, or by means of an evaluation form or questionnaire that members can complete as they leave via e-mail.

Sample Evaluation Questionnaire

Your response to these questions would be greatly appreciated

1. Did the meetings meet your expectations?
2. Please comment on the content, presentation and relevancy to your situation.
3. What suggestions do you have to improve the meetings?
4. Please indicate topics or speakers you would be interested in having discussed at future meetings.
5. Please comment on the meeting space and facilities.

It is best to follow up with members on a regular basis, otherwise it becomes more difficult for them distinguish the details of one meeting from another.

An annual review provides an opportunity for the leadership team to identify and assess the changing profile of the group and interests of the members. After reviewing the feedback and suggestions from the membership, the leadership team should consider whether it is necessary or desirable to search out new speakers or modify the program format or content to address the changing needs.

A decision to move in a new direction must be made carefully and consideration given to the impact it could have on membership and the ability to attract new members.

4.7 Administrative Activities

In addition to group leaders, most prostate cancer support groups rely on volunteers to perform ongoing administrative duties, such as,

- informing members of the time, date, and speakers at upcoming meetings
- setting up and dismantling tables and chairs at meetings
- preparing and distributing newsletters
- welcoming and greeting members and guests
- inviting and scheduling guest speakers
- providing and serving refreshments at meetings
- obtaining and maintaining membership information
- collecting and distributing mail
- responding to correspondence, telephone and e-mail messages
- recording and distributing minutes of meetings
- chairing general members meetings
- introducing and thanking guest speakers
- managing the group website

4.8 Group Directories and Mailing Lists

Collecting and maintaining membership information can be useful for matching newly diagnosed patients with 'mentors' or other members, and can be used for recruiting volunteers for group activities and special events.

It is important for support groups to be fully aware of the requirement and need to respect and protect a member's identity and confidentiality at all times. Personal information should not appear in telephone or mailing list directories unless the individual has given permission in writing.

Once compiled, its distribution should be restricted only to those whose names and information are included in the directory. It should not be used for purposes other than those related to the support group, nor should names be sold or otherwise provided to a third party.

The following is a sample of some questions some groups use to collect information.

1. Provide name, address, phone, fax, or email addresses and indicate how you wish to be contacted
2. Identify skills or expertise (work-related or other) that could be shared with the group.
3. What type of treatment have you had and when did you have it?
4. What areas or topics you would like to learn more about?
5. Indicate area of interest in volunteering
 - at meetings
 - outreach activities
 - leadership team
 - fundraising
 - speaking engagements
 - mentoring newcomers
 - other (please specify): _____

Name: _____ Date: _____

*Note: All members must be advised that the completion of any questionnaire is voluntary and all information provided will be held in strict confidence.

Chapter 5: Awareness

Reaching Out

Getting to know members of other prostate cancer support groups in your area and the strategies they use to run meetings can be a valuable resource. Similarly, they could profit from your experiences.

By knowing you can contact them for advice and direction, members of other groups can be important sources of motivational support. Contact the Prostate Cancer Canada Network to obtain a contact list for prostate cancer support groups.

Many new prostate cancer support groups have been launched by means of a community forum.

A. Community Forums

Good planning is the key to a successful community forum, so be sure to allow sufficient time.

Community forums provide information and answer questions about support groups and can generate enthusiasm for a support group; raise public awareness of prostate cancer and help locate people interested in joining a support group. In addition to providing information promoting the establishment of a new group and raising public awareness of prostate cancer, forums provide an effective way to assess interest and demand for regular group meetings.

At the forum, displaying posters and distribute handout material, available from the PCCN, outline the purpose, goals, objectives and benefits of prostate cancer support groups and invite everyone to attend future meetings. Forums are a good way to recruit new members.

B. Going Forward with Your Community Forum

Once you decide to go ahead there are still decisions to make.

1. Developing a Theme

The theme could be something as simple as; “What Every Man and his Family Needs to Know About Prostate Cancer”.

2. Preparation

Establish a date, time and location for the meeting. It is important to have as many of the details pertaining to the support group in place before holding the forum. Pick a location that is convenient, readily accessible and one that people are comfortable attending.

3. Prepare an Agenda

Preparing and circulating an agenda lets people know what to expect and helps keep the meeting focussed and on time. Allow time at the beginning for people to sign in, pick up and read information sheets, socialize and have some refreshments. It also provides a buffer for those who arrive late.

The chairperson should 'officially' start the meeting by welcoming and thanking everyone for coming, review the agenda, introduce guests and members of the organizing committee, and invite the attendees to introduce themselves.

Depending on the number of people attending the meeting, you may want to proceed with the program, guest speaker, or take a short break.

Following the question period, the chairperson should formally close the meeting and thank everyone for their interest and participation.

The following is a sample of an agenda:

Pre-meeting Social Time	30 minutes
Opening Remarks	5 minutes
Program/Introductions/ Speaker(s)	45 minutes
Question & Answer Period	20 minutes
Closing comments & announcements	5 minutes
Total time:	Approx. 1.5 - 2 hrs

4. Select a Chairperson

Ideally this should be someone who is comfortable speaking in front of large groups. The opening remarks will establish the tone of the meeting. They should be designed to put people at ease and make them feel comfortable, particularly those who have had little or no involvement with support groups.

5. Arrange for a Guest Speaker

The guest speaker will also help to set the tone for the meeting and provide those attending the forum an example of the content, type, and quality of information that is provided at prostate cancer support group meetings. You may want to consider a family physician or urologist who could talk about prostate cancer, the importance of early diagnosis and appropriate treatment, and the role and significance of the prostate specific antigen (PSA) test and digital rectal examination (DRE) in diagnosing prostate cancer, someone from an established support group or the Prostate Cancer Canada Network to talk about prostate cancer support groups, or a prostate cancer patient/survivor to talk about his personal story.

6. Volunteers

An event such as a forum requires a team of volunteers to help set up tables, chairs, install and test the A/V equipment, staff the registration and information tables, distribute information packages, provide water glasses for the speakers, prepare and serve refreshments, and clean up after the meeting.

It is also important to arrange for volunteers to greet attendees as they arrive and provide time for them to pick up and read information sheets and brochures from the display table, and to meet and talk with members of the organizing committee before the official start of the meeting.

7. Display Board and Handout Material

Setting up an eye catching display board and information table near the entrance to the meeting room is an effective way to attract attention and educate people attending the forum.

Suggested materials include the goals and objectives of prostate cancer support groups, information booklets and brochures, the names, telephone numbers and/or email addresses of support group members who can be contacted to recommend reading material and internet sites, and the names of sponsors. Be sure you have enough handouts for everyone.

You may want to contact existing prostate cancer support groups to help you hand out materials and answer questions at the information table. The Prostate Cancer Canada Network can also provide information and brochures.

Set up a registration table where people can sign in - name, telephone number, and email address. This will provide a record of who attended the meeting and makes it easier to contact them after the meeting.

8. Advertising

It helps to publicize your forum as far in advance as possible. A lead time of several weeks is not unreasonable. The following examples have been used effectively by groups in the past; inserting a notice in 'up-coming events columns' of local newspapers, radio/ television public service announcements, distributing 'save the date' announcements to service clubs, placing posters at doctor's offices, hospitals, cancer clinics, libraries, lunch rooms of local businesses, churches/temples bulletins, and storefront windows. Getting established prostate cancer support groups to post a notice on their website or distribute the information in their newsletters is also an effective way to promote your event.

9. Budget

There will be some costs associated with holding a community forum, so you may want to develop a budget and identify the potential costs associated with printing posters, pamphlets or information sheets, the use or rental of a facility and audio/visual equipment, refreshments, and an honorarium or gift for a guest speaker.

If necessary, it may be possible to obtain donations or sponsorships to help cover your costs. Possible sources of assistance include the Prostate Cancer Canada Network, local businesses, service clubs, drug stores, health food stores, and established prostate cancer support groups.

10. Acknowledgements and Follow-up

In recognition of all the work that goes into organizing and holding the event, it is important to acknowledge and thank everyone for their participation and assistance, the volunteers, the organizing committee, any sponsors or other support groups, and most importantly everyone who attended the meeting.

The chairperson should thank the presenters at the conclusion of the forum and may want present a small gift of appreciation. It is also a good practice to once again express appreciation to all those who were acknowledged in the opening remarks.

Lastly, after the forum, call a meeting of the organizers to debrief and note what went well, any changes you would make the next time and determine your future course of action.

It is always a good idea to contact attendees shortly after the meeting to ask whether or not they found the meeting helpful, answer any questions they might have, remind them of the date, time and location of the next meeting, and determine their level of interest and whether they would consider being part of the leadership team.

Finalize the payment of outstanding accounts and send thank you letters to the sponsors, speakers and volunteers.

Thank you letters can make a tremendously positive impression on recipients. But getting around to writing them after an event can be a difficult task. If possible, have all of your thank you letters written before the event. Then afterwards, you can add a few sentences relating to each person's participation. With this approach, the recipients will receive your letter promptly and it will leave a more lasting impression.

C. Beyond the Community Forum

In addition to having increased awareness of prostate cancer in your area, the forum will have served one of two other functions.

It will have provided an opportunity to follow up and talk with the attendees and confirm the level of interest in establishing and holding ongoing support group meetings. Regardless of the number of people who attended the community forum, it will not be unusual for some of them to accept an invitation to become more involved with the support group.

5.1 Support Group Benefits

More reasons for being part of a support group

- members become part of a collective voice
- support groups are non-judgemental and provide a safe environment to openly discuss common issues and concerns
- members become more informed and knowledgeable about their condition
- allows members to develop and improve coping skills by drawing on the experiences of others
- sharing one's situation and experiences helps relieve and reduce the anxiety and feelings of isolation that men experience
- acquiring new knowledge and skills can foster and enhance self confidence, and increase one's ability to live with cancer and develop coping strategies to manage and deal with issues that may arise
- allows those who are newly diagnosed to learn about prostate cancer and its therapies so they can make informed decisions about treatment
- helps individuals regain a sense of control and empowers them to take an active role and get involved and make decisions affecting their health and treatment
- allows participants to give and receive information and support to help adjust and deal with the uncertainty a prostate cancer diagnosis can cause
- creates a sense of cohesion and motivation that helps sustain the group and the individual
- support groups provide a type of friendship that meets the needs people have at a specific point in time
- friendships strengthen coping skills and fuel support for patients and their families
- the friendships that develop are the life blood of a group and their importance cannot be overstated
- helps establish a greater understanding of the disease among the general population and the need for early detection

Many individuals find that they benefit not only from the support they receive, but also from the sense of well-being they gain from helping others. It has been said 'support is not something you do for others but rather something you do *with* others'.

Friendship

When we honestly ask ourselves
which persons in our lives mean the most to us,
we often find that it is those who,
instead of giving much advice, solutions, or cures
have chosen rather to share our pain
and touch our wounds with a gentle and tender hand.

The friend who can be silent with us in a moment of confusion,
who can stay with us in an hour of grief and bereavement,
who can tolerate not knowing, not curing, not healing
and face with us the reality of our powerlessness,
that is the friend who cares.

Henri Nouwen, Out of Solitude

Chapter 6: Resource Material

PCCN and Other Recommended Resources

Prostate Cancer: A Booklet for Patients for the Newly Diagnosed. This booklet is fast becoming the current information watchword on the disease. Concise and written in layman's language, the booklet has been distributed in limited quantities to all Canadian prostate cancer support groups. Individuals, support groups and other interested organizations may order this booklet via email. Individuals may also pick up copies at their local support group meetings. Individuals, support groups and other interested organizations may order these booklets via the email address on this website. Individuals may also pick up copies at their local support group meetings.

Our Voice, a magazine for men with prostate cancer is published four times yearly. Along with updates on the latest medical and research information, Our Voice draws upon reader input for some of its editorial content. Readers, including men and their partners, are encouraged to submit personal stories or questions. Support groups will be sent 10 copies of each new issue, upon request.

Books available from your library or bookstore

Prostate Cancer 3rd edition by S. Larry Goldenberg, MD FRCSC

Dr. Goldenberg is a world renowned, urologist, and researcher located in Vancouver BC. His book is easily read, and he tells it like it is.

Living with Prostate Cancer by Mark Moyad MD

A Primer on Prostate Cancer by Dr. Stephen Strum and Donna Pogliano

An in-depth look at prostate cancer from all angles. Profusely illustrated, many in colour, this is the book if you want to delve deeply into the disease. Dr. Strum has devoted most of his career to prostate cancer. He is a world authority on the subject.

Peter Scardino's Prostate Book by Peter Scardino MD and Judith Kelman.

Dr. Scardino is the Chairman of the Department of Urology at Sloan Kettering in the USA and has written a book that deals with the diseases of the prostate. 2/3 of the book is devoted to prostate cancer and it is written in a very understandable manner.

Saving Your Sex Life by John P. Mulhall, MD

Dr. Mulhall is currently Director of the Sexual and Reproductive Medicine Program in the Division of Urology at the Memorial Sloan-Kettering Cancer Center of New York. He is widely acknowledged as a world authority on sexual rehabilitation following treatment for prostate cancer. The book gives state-of-the-art, up-to-date, comprehensive information on the impact of prostate cancer treatments on your sexual function and what options are available to you for the treatment of such sexual problems.

Anti Cancer - A New Way Of Life by David Servan-Schreiber, MD

Dr. Servan is a clinical professor of psychiatry at the University of Pittsburgh School of Medicine and a co-founder the Center for Integrative Medicine. This is an easy to read guide for cancer patients and anyone who wants to adopt healthy lifestyle habits in order to control and prevent cancer.

Web Links

<http://Prostate Cancer Canada www.prostatecancer.ca> and Prostate Cancer Canada Network www.cpcn.org

Prostate cancer Canada and The Prostate Cancer Canada Network are committed to finding a cure for prostate cancer and providing support to Canadian men and their families who are affected by prostate cancer. Information is available in both English and French.

Canadian Cancer Action Network www.cccanceraction.ca

CCAN represents the interests of all Canadians affected by cancer and its vision is to have the best cancer care system in place for Canadians – a system that is comprehensive, accessible, sustainable, affordable, universal and equitable

Cancer View Canada - www.cancerview.ca

Linking Canadians to cancer services, information and resources including Clinical Cancer Trials in Canada This site was created by the Canadian Partnership Against Cancer and Daily Cancer News a service that provides cancer news information and items from various international news sources.

1. Canadian Sites

[Active Surveillance \(ASURE.ca\)](http://Active Surveillance (ASURE.ca))

Dr. Laurence Klotz and Dr. Andrew Loblaw began this website in conjunction with their work at Sunnybrook Hospital in the area of active surveillance as an option for men diagnosed with favourable-risk, localized prostate cancer. The website provides information on active surveillance and very useful PSA assessment tools. These tools calculate PSA kinetics over time, including PSA doubling time and velocity, and compare PSA results in an individual patient (corrected for baseline PSA, Gleason score, and age) to the large cohort of patients on active surveillance at Sunnybrook.

Canadian Prostate Health Council http://www.canadian-prostate.com/

This is an excellent source for online pamphlets on prostate cancer and prostate health.

Canadian Partnership Against Cancer http://www.partnershipagainstcancer.ca

CPAC PSA Screening Toolkit intends to provide a synopsis of the main issues relating to PSA (prostate specific antigen) screening in Canada

ProCure http://www.procure.ca/

ProCure is dedicated to giving information on the prevention, diagnosis, treatment, and eventual cure of prostate cancer. Headquartered in Montreal, Canada, it provides both French and English resources. Excellent web site.

The Prostate Centre at Princess Margaret Hospital, Toronto http://www.prostatecentre.ca/

This Centre provides excellent online information about the prostate and prostate cancer.

The Prostate Centre at Vancouver General Hospital, British Columbia http://www.prostatecentre.com/

The website offers information on prostate cancer treatment and research.

The Prostate Centre, Victoria, British Columbia http://www.theprostatecentre.org/

The efforts of prostate cancer survivors did much to make this facility happen.

British Columbia Foundation for Prostate Disease <http://www.prostatecancerbc.ca/home/>
This organization's goal is to improve knowledge, prevention, and treatment of prostate cancer.

Calgary Prostate Cancer Institute <http://www.prostatecalgary.com/default.aspx>
The Institute provides current information about prostate disease, research findings and treatment options as well as diagnostic services, confidential counselling and support.

Early Prostate Diagnosis Ontario
EPCDO's goals are to tell people about the value of early diagnosis of prostate cancer through the PSA blood test (combined with physical tests), and to convince OHIP to cover the cost of these tests when carried out in a doctor's office or at a testing lab.

Vancouver Island Prostate Cancer Foundation
The site provides information for the recently diagnosed, including information about support and advocacy.

2. International, Non-Canadian, Commercial, or Private Sites

Blue Torch Medical Technologies Inc. www.bluetorchmed.com
This US company specializes in nerve sparing technology. It has information on nerve-sparing surgery for prostate cancer/

Bostwick Laboratories www.bostwicklaboratories.com
This is a commercial American laboratory specializing in prostate cancer.

Cryocare www.cryocarepca.org
This site on a treatment that freezes prostate cancer is sponsored by Endocare, Inc.

HealthTalk: Prostate Cancer www.healthtalk.com
This site is an information resource for people living with serious diseases and health conditions. It makes available audio programs and transcripts on the latest research and treatment advances.

His Prostate Cancer (hisprostatecancer.com)
This site, written by the wife of a prostate cancer survivor who was diagnosed at age 49, aims to provide practical information that specifically addresses the needs of the wives and partners of men with prostate cancer. It provides sections on sex after cancer, incontinence, managing stress, and communication.

Hypertext Guide to Prostate Cancer www.hypertext.org
Written by Bill Dyckes, this guide gives an overview of prostate cancer, with hypertext links to detailed information on more than 250 medical websites.

Krongrad Institute www.laprp.com
This is a commercial American prostate cancer treatment centre specializing in laparoscopic radical prostatectomy.

James Buchanan Brady Urological Institute—Prostate Cancer <http://urology.jhu.edu/prostate/cancer.php>

This institute is part of Johns Hopkins Medicine.

Med Broadcast—Men's Health www.medbroadcast.com

MedBroadcast.com is a Canadian commercial site offering health information.

Male Care www.malecare.com

This non-profit corporation is concerned with cancers that effect men: prostate, testicular, and male breast cancer. It is an up-to-date site with a wealth of current information on these cancers.

Mayo Clinic—Prostate Cancer www.mayoclinic.com

National Prostate Cancer Coalition www.fightprostatecancer.org

This American advocacy group supports education and awareness programs and provides information to patients and their families.

New Prostate Cancer Infolink <http://prostatecancerinfolink.net>

This site was founded and is managed by Dr. Arnon Krongrad, director of The Krongrad Institute and Mike Scott, original founder of the National Prostate Cancer Coalition. It offers men information on prostate cancer risk, prevention, diagnosis, and management, as well as the opportunity to ask questions and share stories.

Prostate Cancer Foundation www.prostatecancerfoundation.org

This is the world's largest source of funding for prostate cancer research. It provides a great deal of current information on research, prevention, diagnosis, treatment, and support.

Prostate Cancer Helpline www.prostate-cancer.org.uk

This is the website of Britain's prostate cancer charity.

Prostate Cancer Research and Education Foundation (PC-REF) www.pcref.org

This is a non-profit organization dedicated to identifying and supporting innovative prostate cancer research projects.

Prostate Cancer Research Institute (PCRI) www.prostate-cancer.org

The objective of PCRI is to educate patients and their families about prostate cancer. The site provides excellent current information on the disease and its treatment and includes a "Decision Aide" section and access to prediction tools (both in print and in the form of software).

Prostate Cancer Resource Center (from Healing Well) www.healingwell.com/prostatecancer

This site about prostate cancer is made available by HealingWell.com, an American corporation that provides information on diseases, disorders, and chronic illness.

Prostate Info www.prostateinfo.com

This corporate site provides information on prostate cancer for patients and professionals. Patient information includes material on male hormone therapy, anti-androgens, and PSA tests. The site also features a Prostate Cancer Screening Reminder feature where, with a simple e-mail, you can encourage someone who may be at "high-risk" for prostate cancer to get a check-up.

PSA Rising www.psarisng.com

This site provides information for the support and education of prostate cancer survivors. Its index of online news is particularly good.

Sloan-Kettering Cancer Center www.mskcc.org

This website provides access to excellent nomograms on prostate cancer.

Us TOO International www.ustoo.org

This is a prostate cancer education and support network started in 1990 by prostate cancer survivors.

Virgil's Prostate On-line www.prostate-online.org

This is American Virgil Simon's on-line guide to fighting prostate cancer.

Web MD Men's Health Center www.webmd.com

This is a corporate site providing health information to consumers.

3. Cancer Sites

American Cancer Society www.cancer.org

Canadian Cancer Society www.cancer.ca

Cancer Care Ontario www.cancercare.on.ca

This is an umbrella organization that steers and coordinates Ontario's cancer services and prevention efforts so that fewer people get cancer and patients receive the highest possible quality of care.

Gilda's Club—Greater Toronto www.gildasclubtoronto.org

This is an organization offering emotional support to those with cancer.

Health Canada—Cancer www.hc-sc.gc.ca

National Cancer Institute (U.S.) www.cancer.gov

Of particular use are the Physician Directed Queries (PDQs) which summarize information on the treatment of prostate cancer, on screening for prostate cancer, and on the prevention of prostate cancer.

National Cancer Institute of Canada

Online Cancer Guide www.onlinecancerguide.com

RT Answers www.rtanswers.org

This website is sponsored by the American Society for Therapeutic Radiology and Oncology, and it offers answers to radiation therapy (RT) questions. A special page gives information about prostate cancer and radiation.

Steve Dunn's Cancer Guide <http://cancerguide.org>

University of Michigan Comprehensive Cancer Center www.cancer.med.umich.edu

4. Clinical Trials

Center Watch Clinical Trials Listing Service www.centerwatch.com
Canadian trials are listed.

Clinical Trails <http://clinicaltrials.gov>
ClinicalTrials.gov is a service of the U.S. National Institutes of Health, but it lists Canadian and international trials.

Ontario Cancer Trials www.cancertrials.ca

5. Directories

Alberta Cancer from Alberta HQ <http://albertahq.com>
This is a directory of cancer sites and cancer-related organizations in Alberta.

Healthopedia—Prostate Cancer www.healthopedia.com
This site provides some basic information on prostate cancer, but it acts as an excellent directory to other sites.

Prostate Health Center www.prostatehealthcenter.com
This is an American-based human edited prostate health directory of online information.

6. Information Services (reviews, news services, online journals, etc.)

Canada News Wire www.newswire.ca
You can search for print and broadcast news releases by organization name or date of release.

Canadian Urological Association Journal (CUAJ) www.cua.org
This journal is owned, operated, and endorsed by the Canadian Urological Association. It encourages leading academic urologists and other clinicians to submit their highest quality research.

Cancer News on the Net www.cancernews.com
For prostate cancer news, select the category "prostate cancer."

Current Oncology www.current-oncology.com
The Current Oncology website is a portal through which health professionals of all levels and interested laypeople can gain access to articles and information covering the broad field of oncology. Established in 1994, Current Oncology is a Canadian based and internationally distributed multidisciplinary journal, whose aim is to report upon and to review progress in the field of cancer therapy and management. The website also provides links to patient support groups and associated organizations.

Johns Hopkins Prostate Disorders Health Alerts and Bulletins www.johnhopkinshealthalerts.com

If you register for this free service, information on dealing with prostate cancer, BPH, or prostatitis will be sent directly to your e-mail address, to read other bulletins, you must subscribe.

Med Line Plus Prostate Cancer—Latest News www.nlm.nih.gov

A wealth of information is available from this page.

Prostate Cancer News <http://patient.cancerconsultants.com>

This site is provided by CancerConsultants.com, a developer of cancer-related websites and a marketing consultant.

Senior Health Report—Prostate Cancer www.seniorhealthweek.org

This provides current prostate cancer news.

Message Boards, Personal Stories, and support information

M.D. Anderson Prostate Cancer Online Message Board www.manderson.org

The M.D. Anderson Cancer Centre of the University of Texas provides this peer discussion forum in which PCa survivors serve one another as an online support mechanism.

Prostate Cancer Meets Proton Beam: A Patient's Experiences www.protons.com

Shared Experience Cancer Support www.sharedexperience.org

You can search a library of cancer experiences.

UNC Article “Anatomy of a Support Group” www.outriderpromotions.com/unc/publications/pipelines.php?id=11

This excellent article was published in the 1998 issue of Pipeline, the Urological Nurses of Canada's newsletter.

Other Sites (General Health, Side Effects of Treatment)

Canadian Continence Foundation www.continence-fdn.ca

Canadian Erectile Difficulties Resource Centre www.edhelp.ca

Chemotherapy and Beyond www.chemocare.ca

Scott Hamilton's chemotherapy site offers current chemo information for cancer patients and their families, caregivers, and friends, as well as access to a message board and to descriptions of survivors' experiences.

Pfizer Canada—Erectile Dysfunction www.pfizer.ca

Urology Channel www.urologychannel.com

This website provides information on issues such as prostate cancer, incontinence, erectile dysfunction, and BPH. Individuals can download video, ask questions, and get free anonymous answers from a board certified urologist.

Urology Nurses of Canada www.outriderpromotions.com/unc/index.php

Vitamins and Nutrition Center www.vitamins-nutrition.org

Wellspring Cancer Support

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