e-IMPAQc

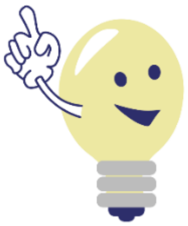
Communicating with your healthcare team

This tool has been excerpted from the TEMPO (Tailored, wEb-based, self-Management PrOgram) and/or the Coping Together symptom self-management program. The content of this document has been reviewed and approved by healthcare professionals.

Knowing what to expect after a cancer diagnosis and/or treatment

> *"Well, what to expect was probably the main thing, because I didn't know what I was heading into and didn't know anyone that had the treatment or had gone through what I was just about to go through."*
>
> **Mateo, diagnosed with prostate cancer**

Suggestions for knowing what to expect:



1. **Learn about what typically happens** after a cancer diagnosis
2. **Know which questions to ask,** and when to ask them
3. **Know which members of your health care team** to turn t
4. **Know what kind of information** you need and where to get it
5. Manage feelings of anxiety by doing **regular physical activity**

We will now explain how these suggestions can help you and provide step-by-step guidance on how to use these suggestions.

TOP TIP: Use the suggestion right for you:

✓ Read the description of each suggestion that follows

✓ Choose the strategy or strategies that you prefer

✓ Make an action plan to help you fit your preferred suggestion into your daily life

✓ Set rewards for the progress you make toward achieving your goal.

How can these suggestions help?

Knowing what to expect after a cancer diagnosis and getting answers to questions helps people feel more in control, and can reduce worry and distress. It is important that people give themselves some time to come to terms with what is happening and to consider what lies ahead. Finding out about cancer and what typically happens is important. Always remember to discuss your new knowledge with your health care professionals, as they will be able to make sure you have an accurate understanding and can relate what you are learning to your situation. Talking with them is the best way to understand what the diagnosis means, how treatment will work, and how this will impact on you.

Suggestion 1: Learn about what typically happens

Everyone has unique circumstances, medical histories and resources that make **every journey different**. Cancer is a complex disease and no two experiences are the same. However, understanding what is likely to happen can provide a general road map or timeline you may find yourself following.

It may be useful to think of your cancer experience as having four stages:

1. Newly diagnosed
2. Preparing for treatment
3. During treatment
4. After treatment

TOP TIP: Always ask "what happens next"

It doesn't matter what stage you are at– always ask your health care professionals **"what happens next?"**

This will help you understand what is going on in your immediate future, what the outcomes might be, and what plans you need to put into place. For example, if the doctor has suggested a test, ask them when the results will be back, what the possible outcomes will be, and what those outcomes will mean for YOU.

The table below lists common issues and concerns that might emerge at each stage and suggestions of what you can do.

1. Newly diagnosed: Learning about the diagnosis and coping with the diagnosis

You might be thinking:	**What you can do:**
• How can we find out more about the cancer diagnosis? • What is the cancer stage? • What questions do we need to ask the doctor? • How do we deal with the diagnosis? • How do we tell family and friends? • What tests are needed? • What can be done while waiting for the results? • Is the diagnosis life-threatening?	• Reach out to others and support organisations for advice/guidance • Get information • Arrange for someone to attend appointments with you • Discuss your concerns with your health care team and try to obtain information about the prognosis **All of these are discussed in the subsequent sections of this factsheet.**

2. Preparing for treatment: Learning about and choosing treatment and getting to know your treatment plan

You might be thinking:	**What you can do:**
• What are the treatment options? • What is the treatment goal? • What impact will treatment have on me? • What are the side effects? • Who is on the health care team? • Can I still work? • Should clinical trial be considered? • Should complementary therapies be considered?	• Learn about treatment options • Find out information about the health care system • Investigate and make use of support options in your area • Negotiate with the doctor your involvement in making your treatment decision The **Making Treatment Decisions** factsheet might be helpful during this stage.

3. During treatment: Coping with treatment and side effects

You might be thinking:

- How long will treatment take?
- How can I deal with the side effects?
- What will be the impact on my work?
- How do we know the best care is received?
- What are signs that treatment is working?
- How can we get care at home?
- What is the cancer stage?
- What can be done to improve my recovery?
- What should we do if one/both of us isn’t/aren’t coping?
- Should complementary therapies be considered?

What you can do:

- Find out what test results mean
- Investigate and make use of support options
- Begin/resume an appropriate exercise regimen
- Talk to the health care team about managing side effects
- Join a support group

4. After treatment: Planning follow-up and adjusting to life after treatment

You might be thinking:

- What are the treatment options?
- What impact will treatment have on me?
- What are the side effects?
- Who is on the health care team?
- Can I still work?
- Should complementary therapies be considered?
- What are the long-term effects of the cancer and its treatment?
- What was the meaning of cancer to me?
- How can we get a copy of my medical records for the future?

What you can do:

- Discuss and address physical and emotional changes as well as your ongoing needs with your family and health care team
- Develop a follow-up plan with the health care team
- Learn about and schedule follow-up tests (e.g. annual mammograms or colonoscopies)
- Join or continue to attend a support group
- The Dealing with Stress and Worry and Supporting Each Other factsheets might be helpful during this stage.

Exercise: Our cancer timeline. In the next table, identify your main concerns and what you can do to address these.

1. Newly diagnosed	
Our main concerns/issues:	**What we can do to address them:**
2. Preparing for treatment	
Our main concerns/issues:	**What we can do to address them:**
3. During treatment	
Our main concerns/issues:	**What we can do to address them:**
4. After treatment	
Our main concerns/issues:	**What we can do to address them:**

Suggestion 2: Know which questions to ask, and when to ask them

The best way to find out what happens next is to know which questions to ask, and when to ask them. You may find that you have a lot of questions, or that some of your questions have not been properly answered. This is quite common, but with some planning you can get the answers you need.

Although you will want to know the answers to all of your questions, some will be more relevant at certain stages than at others. The diagram below highlights issues and concerns you might have questions about at various points. You can find more specific question checklists in the **'Asking questions to the health care team'** section of this fact sheet.

Newly Diagnosed
- What type of cancer?
- What tests are needed?
- What is the prognosis (probable course and outcome)?
- Who is on the treating team?

Preparing for Treatment
- What are the treatment options?
- Which treatment options are best/available?
- What is chemotherapy? Radiotherapy?
- Who can I/we speak to if I am/we are not coping?
- What should be done to prepare for treatment?

During Treatment
- What are the medications?
- How long will the treatment/recovery take?
- Who can I/we speak to if I am/we are not coping?
- How do I/we deal with side effects?
- Where can I find help for our financial worries and things we need help with at home?

After Treatment
- Will the cancer come back?
- What are the long-term consequences of the treatments?
- What rehabilitation services will be needed/are available?
- When do we need to see the doctor again?
- What tests will be needed/when?

Suggestion 3: Know which members of your health care team to turn to

You might have noticed that since the diagnosis, a health care team is being built around you. Each health care professional has a different role and provides specialized help. Knowing who to ask which questions will ensure you get the best and most accurate advice. To help you know which questions are most suited to each health care professional, see the '**we don't know who to ask'** section of the fact sheet.

TOP TIP: Know how to contact your health care team

Know how to contact the members of your health care team after hours. You also need to know who to contact and where you need to go if your team can't be contacted directly.

Suggestion 4: Know what kind of information you need and where to get it

Getting the right type of information can help you feel more in control and prepared for what is happening.

STEP 1: Identify what you need to know

The table on the next page identifies topics you would like to know more about. After the table, we have listed other potential sources of information.

Exercise: Identifying your educational needs

Stage	Common information needs	Do I need this ✓ =Yes
Newly diagnosed	• Type of cancer • Symptoms of cancer • Recurrence or spread of cancer • Effect on life plan • Outcome of no treatment or delayed treatment • Coping with diagnosis • Communicating with others about cancer	
Preparing for treatment	• Available treatment options • Side effects • Getting second opinion • Alternative and complementary therapies • How treatment works and who is involved • Treatment success • Physical limitations • Clinical trials	

	• Treatment cost, insurance, other financial issues • Typical duration of leave from work	
During treatment	• Coping with side effects of treatment and risks/benefits of treatment • Emotional reactions • Alternative and complementary therapies • Counseling • Practical support (e.g. home care) • Support groups or support from other patients/caregivers • Effect on family, friends, caregivers, and relationships • Effect on social activities • Risk of disease to family • Effect on work	
After treatment	• Self-care issues • Nutrition during recovery • Immediate post-treatment follow-up care	

STEP 2: Find the right information source

The Internet
Public, non-profit and/or officially sanctioned agencies organizations such as the **Canadian Partnership Against Cancer** and **Canadian Cancer Society** are good places to start. For more information on searching the Internet, see the **“we need more information”** section in the **Getting the Support You Need** factsheet.

Cancer organizations

Canada has a host of government and community-funded organizations offering a variety of valuable resources for patients and their families. We've compiled a list for you in the **"we need more information"** section in the **Getting the Support You Need** fact sheet.

Government

Government-run agencies with consumer information on specific cancers:
Public Health Agency of Canada, http://www.phac-aspc.gc.ca/

Community and not-for-profit

The **Canadian Cancer Society** (www.cancer.ca) works in partnership with many national and provincial organizations and corporations and provide access to fact sheets, brochures, publications and information on new technology and research. If you need support or have any questions, you can contact the Canadian Cancer Society at 1-888-939-3333 or TTY 1-866-786-3934.

TOP TIP: Be cautious with Internet searches

Given the vast amount of information available on the Internet, and the fact that just about anybody can post it there, you need to be cautious of what your searches produce. Always try to discuss and clarify information you find on the Internet with your health care team.

Bookstores and libraries

Libraries are good sources of research-based texts on cancer. Your health care professionals can also advise you about where you can buy books with the information you need. Cancer support groups may have a good selection of books and information resources that they lend to members. The Canadian Cancer Society has recommended reading lists, produce their own **free booklets**. Follow this link for the one on prostate cancer: http://www.cancer.ca/en/cancer-information/cancer-type/prostate/prostate-cancer/?region=on

Other people and their caregivers

It’s often helpful to share thoughts, concerns, tips and ideas with people who are, or have been, in a similar situation. Here are a few areas to consider:

One-on-one support

The **Canadian Cancer Society** offers one-to-one support by telephone or in person. To find out more, call 1-888-939-3333 or visit www.cancer.ca

Support groups

The best way to find a support group in your region is to ask your health care professionals (perhaps your nurse or social worker) or to contact the Canadian Cancer Society.

Some cancer-specific organisations help people locate convenient support groups. Examples include:

- Prostate Cancer Canada http://www.prostatecancer.ca/Supporting-You/Services/Support-Groups
- Canadian Breast Cancer Foundation http://support.cbcf.org/get-support/find-a-support-group/

Health care professionals

Your health care team may know patients and caregivers you can talk to about their experiences, or who are eager to make contact with other people going through a similar experience.

The Internet

You can interact with others via blogs, online forums, chat rooms and social networks. See the **“we need more emotional support”** section of the **Getting the Support You Need** fact sheet for a list of blogs, forums, chat rooms and social networks.

TOP TIP: Free coping program

The American Cancer Society has a free interactive program called ‘I Can Cope – Online.’ Go to: www.cancer.org/Treatment/SupportProgramsServices/OnlineCommunities/ParticipateinaCancerEducationClass/ICanCopeOnline/index.

Suggestion 5: Manage feelings of anxiety by doing regular physical activity

Remember to talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

What others say about using these strategies

“Having a list of questions and prompts is very important, because there are things that did not even occur to me and now I think that would have been really good to have asked those questions…the same goes for all the websites that you can follow-up on.”

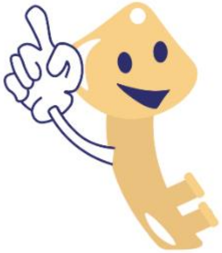
Raymond, diagnosed with prostate cancer.

“Mainly I needed to know about the radiotherapy my husband was about to have – what it involved, what the side effects could be, what I could expect to feel. I read up on that just before I started so that I knew what to expect.”

Daniela, wife of Raymond diagnosed with prostate cancer.

Key Points: Knowing what to expect

1. Although cancer experiences are unique to each individual, they usually share common features.
2. Finding information is key to help you understand what might come next.
3. This information is available from various sources, including health care professionals, the Internet, other couples facing cancer and printed resources.



Knowing the role of the different health care professionals involved

"*There's the actual issue of having so many doctors. You never know who to talk to about what. One's for radiotherapy and then you've got the surgeon. It's quite confusing, as there doesn't seem to be one person overseeing everything. Then, if I have other issues not related to cancer, I see my family doctor. So it's hard to know who to ask about all of the different health issues."*

Jim, diagnosed with prostate cancer.

"I know a psychologist is there to help you cope with things mentally and emotionally…I think the woman that came to see me after my surgery was a psychologist and she did say I could also see a social worker, but I am not sure what a social worker does. I guess they would…I'm not really sure…Maybe I should ask my doctor."

Elliott, diagnosed with prostate cancer

As your health care team is built around you, understanding the role of each member, and who the best person to answer your questions is, can be confusing. Each health care professional has a specialized role and different information and expertise to offer you. Knowing who to ask is key to ensuring you get the information and support you need.

The information we've included in this section will help you work out who to go to with your questions; however, **remember** that any member of your health care team will be able to steer you in the right direction if you ask them.

Suggestion for knowing who to ask

1. **Match your question to the right health care professional –** know who on your health care team to direct your question to.
2. Manage feelings of anxiety that occur by doing **regular physical activity**

We will explain how these suggestions can help and provide step-by-step guidance on how to use suggestions

TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.

Why these suggestions can help?

Health care professionals each have their own levels of expertise, so each one might not have satisfactory answers to *all* of your questions. For instance, the oncologist might be concerned, but won't have the specific expertise to help you when you ask about keeping your household running while you are on treatment. Rather, the oncology social worker at the hospital might have a more in-depth and practical response to your needs. But the oncologist or the nurse can tell you who the social worker is.

Suggestion 1: Match your question to the right health care professional

Your health care team might consist of any or all of the health care professionals listed in the table below. Use this table to help identify who you should ask your questions to.

Health care professional	Questions you might ask
Family Doctor	
Their role: Your primary health care provider, who may have been the first port of call with cancer and who will probably continue to monitor progress **What they can provide:** Listen to concerns; discuss treatment, side effects or referrals; maintain a supportive relationship; help with authorising leave and other appropriate benefits	✓ How can I best manage fatigue or nausea? ✓ What should I do about my diabetes now I am on treatment? ✓ I am worried about how my husband is coping – can you help him?
Surgeon	
Their role: Usually a specialist who operates on cancer **What they can provide:** Guidance on procedures; listen to concerns; follow up care	✓ How successful is this type of surgery? ✓ How much time will I need to take off work? ✓ What can I expect to happen after my surgery?
Medical Oncologist	
Their role: Doctor who specializes in treating cancer, including prescribing/administering chemotherapy **What they can provide:** Information about prognosis and treatment options; help make decisions and/or discuss options; listen to concerns; manage effects of treatment	✓ What is the most successful treatment for this type of cancer? ✓ Will I lose my hair? ✓ How will chemotherapy interact with my other medication?

Radiation oncologist	
Their role: Doctor who specializes in prescribing/administering radiation therapy **What they can provide:** Guidance on procedures; listen to concerns.	✓ How effective is this treatment? ✓ What should I do if I develop skin redness during radiotherapy?
Nurse	
Their role: Administer cancer treatments, such as chemotherapy, and help to manage symptoms. Coordinates care, assists patients and caregivers in navigating health services and provides a point of contact for information and support. Provide emotional support and information about medical and support care needs **What they can provide:** Information and access to resources, emotional support, listen to concerns, guidance on procedures, discuss options, liaises with other members of the medical team, a central contact point	✓ I'm feeling really stressed by everything, is this how other people feel? ✓ What happens after I finish my radiation treatment? ✓ I don't understand why I have to have this test done. Can you please explain?
Community health or home care nurse	
Their role: May visit you at home, if necessary, to help with care and treatment **What they can provide:** Listen to needs and concerns; instruct on procedures; consult with other health care professionals	✓ Is there anything that might help me manage at home?

<table>
<tr><th colspan="2">Palliative care specialist</th></tr>
<tr><td>Their role: Involved in pain management, helping you to feel more comfortable and helping you and your family with emotional and other support needs. Can help at any stage of cancer, not just at end-of-life stage
What they can provide: Listen to needs; inform about options; discuss preferences; consult with other health care professionals</td><td>✓ What forms of pain therapy work best for my condition?
✓ What should I do if my symptoms get worse over the weekend?</td></tr>
<tr><th colspan="2">Physical therapist</th></tr>
<tr><td>Their role: Help with the physical recovery from cancer. Can help maintain and improve overall fitness and health.
What they can provide: Guidance on procedures; develop an exercise plan to aid recovery; listen to concerns; encouragement and advice</td><td>✓ What exercises will help me recover from surgery?
✓ When should I start pelvic floor exercises?</td></tr>
<tr><th colspan="2">Occupational therapist</th></tr>
<tr><td>Their role: Help you manage daily activities. Design and provide devices to help you regain independence
What they can provide: Listen to needs and concerns; inform about options; instruct on how things work; provide advice</td><td>✓ What devices are available to help me around the house?</td></tr>
</table>

Dietitian	
Their role: Guide in choosing food to help you feel better or help you with tips to increase appetite **What they can provide:** Discuss needs and concerns; provide advice and encouragement	✓ What food will help ease my nausea? ✓ How can I regulate my weight?
Speech therapist	
Their role: Help with assessing problems with swallowing and speech **What they can provide:** Listen to needs and concerns; discuss foods that are easy to swallow; develop communication skills	✓ What can I eat if I am having trouble with a dry mouth after radiotherapy?
Psychiatrist	
Their role: Can assist you and your family to adjust to the emotional impact of cancer and treatments **What they can provide:** Listen; assess mental and emotional states; discuss options; build a supportive relationship; consult with other health care professionals	✓ How do I know if I have depression? ✓ What are the side effects of antidepressants? ✓ Could the treatment be affecting me emotionally?
Psychologist	
Their role: Can assist you and your family to adjust to the emotional impact of cancer and treatments	✓ Is there anything I can do to cope with being worried all the time? ✓ How do I talk to my children about cancer?

What they can provide: Listen; assess mental and emotional states; discuss options; build a supportive relationship; consult with other health care professionals	
Social worker	
Their role: Counsel people and their family/caregivers who are affected by cancer and help them find practical assistance. Provide information about locating services in your community (e.g. home care, transportation). **What they can provide:** Discuss needs and concerns; build a supportive relationship; encourage; inform about options; help obtain the services needed	✓ How do I find a support group? ✓ Are there support groups for my spouse or my children? ✓ Can you help me with house work?

TOP TIP: Finding the right health care professional to talk to

✓ Speak to your family doctor to find out who the best person is to coordinate your care.

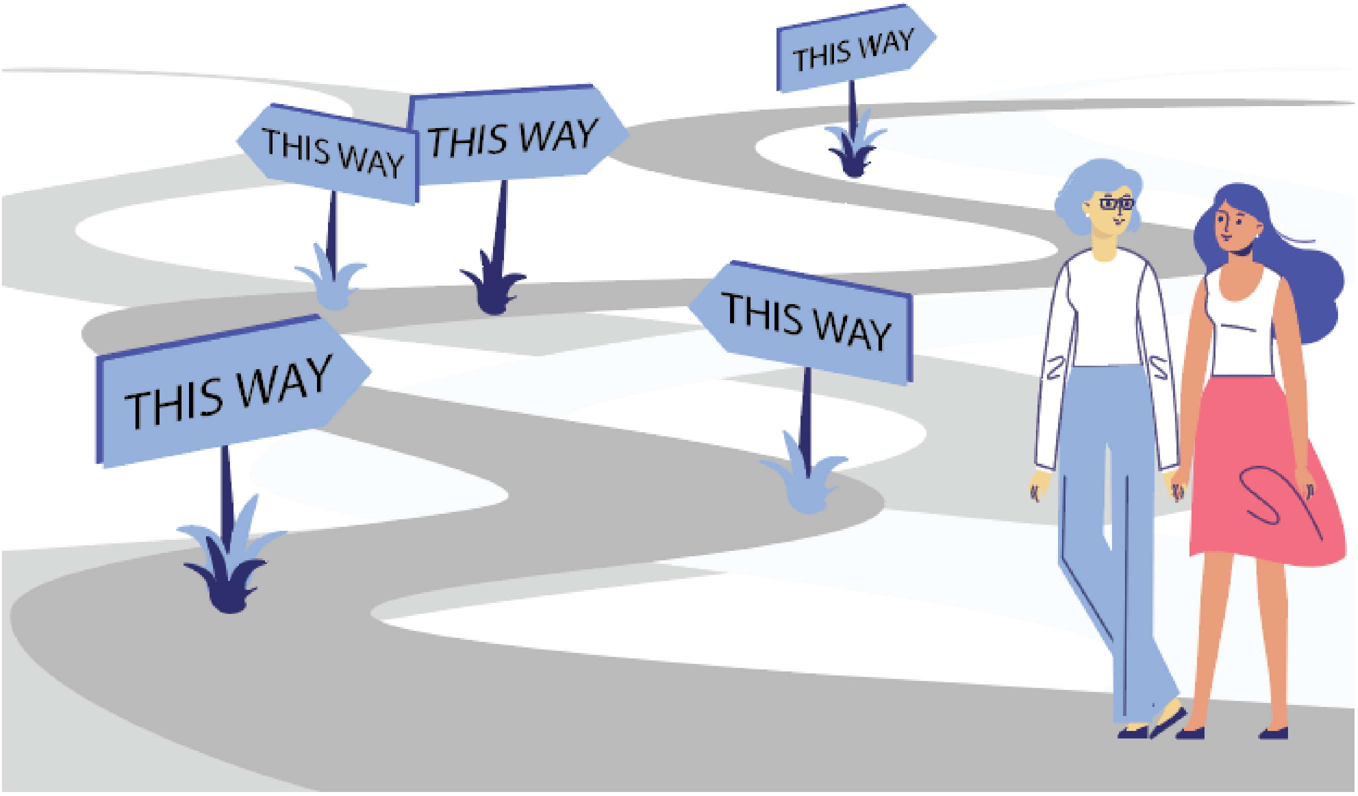
✓ Ask your family doctor or local hospital if you have access to a pivot nurse. Some provinces appoint pivot nurses to manage care plans, act as a contact and support point and help you find the services you need.

Contact your hospital's support care services. Call the hospital's general enquiry number and ask to speak to the oncology social worker or psychologist. Some hospitals have websites listing their services.

The health care system can seem complex and overwhelming. Here are some extra tips to help you find your way.

TOP TIP: Navigating the health care system

- **Take it one step at a time.** If you try to have everything in place and your team all sorted immediately, you are likely to become frustrated. Let one person lead you to the next.
- **Keep asking.** If one piece of advice does not work out, go back to the source and ask for other options, or other people to speak to.
- **Be assertive.** You are entitled to ask for what you need and to be clear about your next step. Be your own advocate. For more information about this, see the ***'Having our main concerns addressed during the appointment'*** factsheet.
- **Recruit help.** Ask the people closest to you for help, they might be able to help with any search, suggest alternatives, make calls or ask questions for you.
- **Keep a record.** Writing down names, contacts, to-do lists and notes from discussions and meetings will help you keep track of where you are up to.
- **When in doubt, ask your Family Doctor or Pivot Nurse.** If you are not sure how your health care team and treatment are coming together, your family doctor or pivot nurse can provide fresh guidance.



Suggestion 2: Manage feelings of anxiety that occur by doing regular physical activity

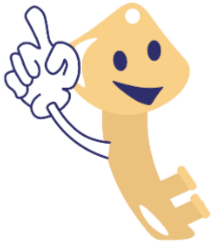
Remember to talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

What others say about using these strategies

“You have to go to the radiotherapist, you have to go to the professors and the doctors who diagnose you and I was just so confused. I read a cancer booklet that told me to go to your local doctor. That’s when we decided to go and talk to him as well, we’re very confused because there’s so many tests and so many doctors and so many things you had to do.”

Martin, diagnosed with prostate cancer

Key Points: Asking the right health care professional



1. Familiarize yourself with the specific roles of your health care team, so that you can direct your questions to the right people.
2. If you are unsure, ask any member of your health care team to help you identify the right person to speak to.

Asking questions to the health care team

"I didn't go to medical school; I have no idea what to ask."

James, diagnosed with prostate cancer.

It's easy to forget the questions you want to ask when you are in front of your health care professional. You might feel there isn't enough time to ask your questions, or you don't want to bother the health professional with your concerns.[1]

Preparing for appointments is key to staying focused and ensuring you come away with all the information you wanted. The following suggestions may help you when asking questions of your health care team.

Suggestions for asking questions to the health care team:

1. Prepare before appointments by using a question checklist
2. Make sure you get the information you need
3. Remember to ask about physical activity during your health professional appointment

Keep reading to find a guide on how to use each of the following suggestions. Each suggestion has been selected for its evidence-based benefits. For further information on suggestions tailored to your individual emotional or physical needs, speak to your health care team.

TOP TIP: The way that we engage with our health care team can differ from person to person, so it is not surprising that your response to these suggestions can differ too. You might need to try more than one suggestion before you find the one that works for you. Practicing more than one suggestion can also help you choose which one to use in response to different situations.

How can these suggestions help?

The questions you ask your health care professionals are just as important as the ones they ask you. But it can be hard to know which questions to ask. Question checklists can help you remember what you want to know and prompt you to ask questions during an appointment. Your health care professional can be a good source of information, asking the right questions may help to get the information that is important to you.

Suggestion 1: Use a question checklist

A question checklist is a list of frequently asked questions or important questions to ask your health care professional. You can find 10 question checklists at the end of this factsheet (see Appendix) covering different aspects of cancer and treatment. At the beginning of each checklist there is a list of which health care professional to ask. You may not want to ask every question on these lists; instead, use them like menus to help choose questions that are important to you.

Steps to using a question checklist

Step One: **Prepare your questions before your appointment.** Rank your questions in order of importance, so your health care professional can deal with the most important ones on the spot and perhaps answer the others later.

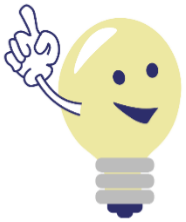
Step Two: **Send your list of questions to your health care professional beforehand.** Ask if you could mail/email them or call and dictate them to the receptionist.

Step Three: **Take your questions to your next appointment** and give a copy to the receptionist when you arrive.

Step Four: **Write down or record the health care professional's answers.** This will make it possible for you to refer back to the answers when necessary.

Step Five: **Caregivers or family members** can also use a checklist, ask some questions, and/or write down the answers.

FACT: People who use checklists remember what they hear, may feel less anxious and are likely to ask more questions to get the information they need to deal with the challenges of cancer.



If I ask all these questions, won't my appointment take more time?

Yes and No. Using question checklists can make consultations shorter or longer, it can depend on many factors.

Why use them? Question checklists help you ask more questions in your appointment, and recall the information you receive. The questions you ask may be more focused and clearer. If you are worried about time, show your health care professional your list of questions and ask how you should go about finding answers.

TOP TIP: Keep asking questions

Don’t worry if you don’t get all your questions answered the first time around. Ask your health professional when you will next see them, and how you can contact them if you have questions between appointments.

Suggestion 2: Make sure you get the information you need

You might use a question checklist to remember to ask questions during the appointment, but how do you make sure you get the information you need?

How do I use this suggestion? Step-by-step guide

Step One: **Before the appointment,** think about which questions on your checklist are most important to you. Be clear about why you are asking the question and what you would like to get out of the appointment.

Step Two: **Find the best person to answer your questions.** Health care professionals each have their own levels of expertise, so each one might not have satisfactory answers to all of your questions.

Step Two: **Ask for clearer information.** Health care professionals work in a world of medical jargon, and even those with the best communication skills can mistakenly assume you understand the information they give you. Use the following phrases to get the information you need in a way you can understand it:

- Could you go over that bit again please?
- When you said that, did you mean…?
- Can you clarify what you mean by that?
- Is it correct that you want me to…?
- Can you draw / write that down for me?

Step Three: **Ask if you can contact them after the appointment.** It can take time to process information, so you may think of more questions after the appointment is over. Ask your health professional how you can contact them or who you can contact if you have questions after the appointment.

Suggestion 3: Remember to ask about physical activity during your health professional appointment

Your health professional appointment is a perfect time to ask about physical activity, what type of exercises you can do, and what intensity is recommended for you. People living with cancer are recommended to do regular physical activity throughout their cancer journey from diagnosis until after treatment, with guidance from their health care team.[3]

What the experts say

Physical activity produces endorphins, which are chemicals in the brain that act as natural painkillers and sometimes referred to as the “feel-good neurotransmitter”. Getting up and being physically active can help you get your mind off the day’s hassles and help you to relax. It can also improve your sleep, which might be disrupted by anxiety and stress.

How do I use this suggestion? Step-by-step guide

After you discuss and confirm with your health care team about incorporating more physical activity your routines, follow the below steps to gradually increase the amount you are currently doing, or to begin a new type of physical activity:

Step One: Choose a physical activity or exercise that you would like to do regularly.
Step Two: Make an action plan to fit your exercise or physical activity into your daily routine
Step Three: Set rewards for the progress you make toward achieving your goal.

What others say about these suggestions

“The question checklist gave us a starting point for the things we might need to know, but we thought it might be a good point of reference when we talked to my doctor. At our next appointment, we took it with us and asked the doctor the questions we wanted answers to. It was such a relief to be able to tick off all our boxes.”

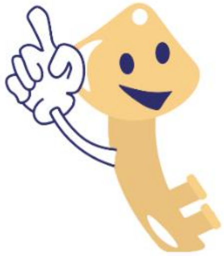
John, diagnosed with prostate cancer.

“The oncologist gave us a lot of information and suggested we go away and consider our options. It wasn’t until hours later that we started thinking of things we needed to know before we could make decisions. I rang the doctor’s office and his assistant suggested I email a list of questions so the doctor could work out the best way to follow up with us.”

Hazel, partner of Dimitri, diagnosed with prostate cancer.

Key Points: Asking questions to the health care team

1. A question checklist helps you prepare and prioritize your questions.
2. Your health care professional can tell you how and when they prefer to receive your question checklist. They might prefer the list to be emailed, sent in advance, or given to them during the appointment.
3. You might be able to contact your health professional between appointments if you have questions. Your health care professional can tell you how they prefer to be contacted, or who you can speak to if they are unavailable.



Resources

Questions to ask

- Canadian Cancer Society. Questions to ask. http://www.cancer.ca/en/cancer-information/cancer-journey/your-healthcare-team/questions-to-ask/?region=on. Last accessed January 24, 2018.
- Canadian Cancer Society. Working with your healthcare team. http://www.cancer.ca/en/cancer-information/cancer-journey/your-healthcare-team/working-with-your-healthcare-team/?region=on. Last accessed January 24, 2018.
- Prostate Cancer Canada. Questions to ask your doctor. http://www.prostatecancer.ca/Prostate-Cancer/Care-and-Support-Post-Treatment/Questions-to-Ask-your-Doctor. Last accessed January 24, 2018.

Physical activity

- Canadian Cancer Society. Physical activity. http://www.cancer.ca/en/prevention-and-screening/live-well/nutrition-and-fitness/physical-activity/?region=on. Last accessed September 14, 2017.
- Canadian Psychological Association. Psychology Works Fact Sheet: Physical Activity (2014). http://www.cpa.ca/docs/File/Publications/FactSheets/PsychologyWorksFactSheet_PhysicalActivity.pdf. Last accessed September 13, 2017.

- Government of Canada. Physical activity (2011). http://www.phac-aspc.gc.ca/hp-ps/hl-mvs/pa-ap/index-eng.php. Last accessed September 14, 2017.

Appendix

Question Checklist about cancer and prognosis

Who to ask: Medical oncologist, Specialist

- What kind of cancer do I have?
- What is the stage of the cancer? What does this mean?
- How common is this type of cancer?
- Which parts of my body are affected?
- Has it spread to other parts of my body?
- Is it slow growing or fast growing?
- How is it treated? What are my treatment options?
- What is the goal of the treatment – to cure, control or manage?
- Where can I find more information about this cancer?
- What is the expected survival for people with this type of cancer?
- Will the treatment improve my chance of survival?

Question Checklist about tests or procedures

Who to ask: Medical oncologist, Specialist, Nurse

- Why is the test/procedure being done?
- How accurate/effective is it?
- What does the test/procedure involve (e.g. how and where is it done)?
- When do I get it done?
- What do I need to do to prepare (e.g. stop eating, drinking, taking medications)?
- How long will the tests take?
- What are the effects or possible complications (e.g. risks, recovery time)?
- Will I be able to drive myself home afterwards?

- Who schedules the test/procedure?
- What will be know after the test (e.g. what do we expect to find out)?
- How long will it take to get the results? How will I get them? May I see them?
- Will these tests need to be repeated?
- What is the next step after the test (e.g. more tests, start treatment)?

Question Checklist about treatment (general)

Who to ask: Medical oncologist, Specialist, Surgeon

- Why should I have treatment right now? What will it do?
- What is the goal of treatment?
- What are some of the benefits and risks of having treatment?
- What is your recommendation? Why?
- What can I expect from this treatment?
- How well established is the treatment you are recommending?
- Are there other treatment options? What clinical trials are available to me?
- How much time do I have to think about this? Should I get a second opinion?
- What is the treatment schedule (how many, how often, how long)?
- What medication do I require?
- What does the treatment involve (how is it done, where)?
- How does it work? How long should it take for the treatment to work?
- Will I need to spend time in the hospital? If so, for how long?
- Will treatment affect my daily life (e.g. sex, work, exercise)?
- What are the common side effects and how can these be controlled?

- Will it affect my ability to have children?
- What happens if I react badly to treatment and need to stop?
- Who should I call if I experience side effects, or have questions?
- How can I expect to feel during treatment?
- What happens if I miss a treatment?
- How often should I be seen for follow-up appointments?
- What other health care professionals will I need to see for treatment?
- How will my condition be monitored after my treatment?
- What should I do to help myself stay healthy?
- Want can I do beforehand to prepare for treatment?C
- C an I go to and from treatment alone? Should someone else go with me?
- How will I know if treatment is working?

Question Checklist about chemotherapy or radiotherapy

Who to ask: Medical and Radiation Oncologists, Nurse

- What is chemotherapy/radiotherapy?
- What is the purpose of chemotherapy/radiotherapy for this type of cancer?
- How any treatments will be needed? How often?
- How long will the therapy last?
- What can I expect from my therapy? What will it feel like?
- What areas of my body will be affected/treated?
- What are the names of the medications that will be used in my treatment?
- How will the treatment be given?

- Will I be able to get to and from the treatment facility alone or should I be accompanied?
- How will it affect my daily life (e.g. work, sex, family)?
- What are the possible side effects of these treatments (e.g. nausea, fatigue, ulcers, hair loss)? How long do they last?
- How can I manage the side effects? Is there anything I can do to lessen the side effects?
- Will chemotherapy/radiotherapy affect what I can eat and drink?
- Will chemotherapy/radiotherapy affect my fertility?
- Will I be radioactive?
- Will I need to take any other medication?
- Will I be able to take multi-vitamins?
- Do I need to take any special precautions during or after treatment (e.g. stay out of the sun, adhere to special diet?
- If I have any problems out of hours, who should I call?
- Is there a possibility of fever or infection? If so, what can I do?
- Is there any further information I can read aboutradiotherapy/chemotherapy?
- Will I need to have blood tests?

Question Checklist about medications

Who to ask: Medical Oncologist, Family Doctor, Specialist, Nurse

- What is the medication called? How do you spell the name?
- Why am I taking it? What does it do?
- When should the medication be taken? How often?
- Should it be taken with food, water?
- What are the common side effects? What can be done about these?
- Will it interfere with other medicines, foods, vitamins, or supplements I am taking?

- Should certain foods or medicines be avoided while taking this medication?
- How will it affect what I eat and drink?
- How will it affect my everyday life (e.g. activities, work)?
- Are there other choices?
- How much does it cost? Is it covered by Medicare?
- Where can I get this medication?
- How long does it take to work?
- How will I know if it has worked?
- What if it doesn't work?
- How long do I need to take it for?
- Can I stop taking my medicine if I feel better?
- What should I do if I forget to take the medication or take the wrong dose?
- What do I do if I need more?
- Is there any written information I can take home with me?

Question Checklist about surgery

Who to ask: Surgeon, Medical Oncologist, Specialist, Nurse

- Why is surgery needed?
- What kind of surgery will be performed? What will be done?
- Is surgery necessary? Are there any alternatives?
- Is surgery the standard treatment for this type of cancer?
- Who will be doing the surgery?
- How long will it take?
- What is the goal of surgery? What are the chances of success?
- What are the benefits and risks of having surgery?
- What kind of pain or discomfort can I expect?

- What are the common complications and what are my chances of developing them?
- What should I do if I develop complications after surgery? Who should I call?
- How should I prepare for the surgery? (e.g. trim nails, eat and drink, medications)
- What is the expected length of stay in the hospital after surgery?
- How long will I take to recover? How can I help my recovery? Dos and don’ts?
- Will I need help afterwards (e.g. at home)? How can I get that help?
- Who will prepare me for surgery? How?
- Will I need a blood transfusion? Can my family donate blood?
- How will the operation affect me in the long-term (e.g. activities, work, sex)?
- What other treatment, if any, will I need after surgery?

Question Checklist about symptoms

Who to ask: Medical Oncologist, Family Doctor, Specialist, Nurse

- Is this a “normal” or expected symptom?
- What is the likely cause (e.g. treatment, the cancer itself)?
- How long is it likely to last? If and when it goes away, is it likely to return?
- Will it change (e.g. get worse or get better)? Will certain activities affect it more?
- Is there an effective treatment for my symptoms?
- What can I do to manage it (e.g. diet, exercise, rest)?
- How might it affect my treatment and recovery?
- What do I do if I notice new symptoms or if existing symptoms worsen?
- When should I contact the doctor? Are there any side effects I should tell the doctor right away?
- In emergency situations, who can I call after hours, on weekends, or on holidays?

Question Checklist about practical and financial support

Who to ask: Social Worker, Community Health Nurse, Family Doctor, Nurse

- Is there a program of activities available through the support services (e.g. physiotherapy, psychologist)?
- What costs will I have (e.g. equipment, medications)? Are less expensive options available?
- What financial assistance is available?
- Is there someone I can talk to about financial matters?
- Can anyone help me with practical things at home?
- What sort of practical help am I likely to need?
- How much will it cost?

Question Checklist about psychosocial concerns

Who to ask: Social Worker, Community Health Nurse, Family Doctor, Nurse

- How am I likely to cope with feelings and pressures during this illness? What have others experiences?
- Who, apart from family and friends, can I talk to about my concerns and feelings?
- How will physical changes affect my mental state?
- What support groups might be worth joining?
- How can I help my family and friends cope? What support is available?
- At what point should my caregiver and I seek help with our concerns?
- Who can help me and my caregiver talk about our feelings

Questions caregivers might want to ask

Who to ask: Social Worker, Community Health Nurse, Family Doctor, Nurse

☐ How can I best support the patient?
☐ What skills do I need? Should I be trained in some techniques?
☐ Where can I get the information I need?

☐ What can I do and who can I speak to if I am not coping?
☐ What support is available to me?
☐ Am I eligible for financial support (especially if I am a primary caregiver)?
☐ Will health care professionals want to discuss things with me that they don’t want to discuss with the patient?

Telling the health care professionals what is going on

> *“I went with him to the next appointment and I didn’t speak up. I just thought ‘if I can put in a statement that might be constructive’ but I noticed that the doctor just stared at Stanley... then Stanley kept talking about this problem that he’s got with the tinnitus in the ears. In the end [the doctor] said ‘Well why don’t you get an iPod?.’ That was the big diagnosis and the remedy. ”*
>
> **Claire, wife of Stanley, diagnosed with prostate cancer.**

It can be daunting to speak up during a consultation with a busy health care professional. Some people worry about wasting the professional’s time with ‘trivial’ or unrelated matters that worry them all the same. And many struggle to describe what and how they are feeling. In reality, health care professionals prefer to know all the things that are worrying you, as this can affect the way you cope with your illness and treatment.

Suggestions for expressing what is going on

1. **Be clear and specific** about your symptoms.
2. **Be honest and frank** about your concerns.
3. Manage your thoughts by doing **regular physical activity**

We will now explain how these suggestions can help you and provide step-by-step guidance on how to use these suggestions.

TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.

Why these suggestions can help?

Good communication with health care professionals helps you feel more satisfied with your care, feel in control and less anxious. The more health care professionals know about you, the better your care is likely to be. People often worry that talking a lot means taking up the health care professional’s time, but research has shown this is not the case. Rather, describing your symptoms concisely will help your health care professional to **better understand what is going and identify** possible solutions. It focuses the appointment on what is most important to you.

Suggestion 1: Be clear and specific about your symptoms

For example, if an oncologist asks you, “How are you going with your treatment?” A vague answer would be “Oh, okay.” Imagine how much more your health care professional would have to work with, if you answered, “I’m feeling okay physically, but I’m feeling a bit anxious about what happens next, so I haven’t been sleeping well.”

Try the following exercise to get things started.

Exercise: Describing your symptoms clearly

Think of a symptom you may have experienced and, using the following questions as prompts, note down the important things you would need to tell a health care professional about that symptom. Try describing the symptom to your caregiver to see if it is clear to them.

Prompt questions:

- When did your symptom begin?
- How often, and when, do you experience the symptom?
- Is it constant, or does it come and go?
- How long does the symptom last (e.g. seconds, minutes, days)?
- What, if any, medications have you taken for the symptom? How much? Have they helped?
- Have you used other therapies for the problem (e.g. vitamins, physical therapy)? What effect have they had?
- Does anything you do help or worsen this symptom (e.g. foods, activities)?
- Is the symptom getting worse or better?
- Have you seen a health care professional before about this symptom? When? Who? How was it treated? Did it help?
- Do you think any of your symptoms are related to events in your life?
- How does the symptom affect your daily activities (e.g. keeping you from doing your usual things)?

Your description:

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Exercise: Describing nausea

PATIENT: “Since I started the chemo, I keep feeling like I want to be sick. Is that normal?”

DOCTOR: “Sounds like nausea, which is pretty common. Tell me more about it.”

PATIENT: “Well, I felt all right after the first session and I thought I was going to be okay. Then when I woke up the next morning and went to sit up, I felt like I was going to throw up. It seems to happen most days now, especially in the mornings and evenings, which is when I tend to throw up. I spoke to the chemist about it and she suggested I try Maxolon, which I’ve been taking only when it feels really bad – maybe every two days or so. That’s been okay but I think it makes me a bit lethargic. My naturopath suggested I try acupuncture but I thought I’d check with you first about whether that might work. I really need to do something about it because it’s affecting how I get through the day and also my appetite – and that’s a problem because not eating seems to make it even worse.”

DOCTOR: “All right, that gives me a good idea of what’s going on. Let’s look at what we might be able to do about it…”

Suggestion 2: Be honest and frank about your concerns

It’s important to be honest with your health care professionals about how you are going.

A three-step way to discuss concerns clearly with your health care professional is:

1. "This is how I am following the treatment..."
2. "What can we do to make it work for me?"
3. "The reason I am doing it this way is..."

Here is an example of how you might express a concern about recovering from surgery:

> "I'm finding that I'm not taking my regular pain tablets, but having my breakthrough pain tablets quite a lot. I do this because I feel they make me tired and constipated. Do you have any suggestions?"

It helps your health care professionals to know how cancer and treatment might be affecting the following:

- Your home life (e.g. disrupted routines, moving house, not having appropriate housing).
- Your job and how much stress or satisfaction it gives you (e.g. change in hours, running out of sick leave).
- Your relationships with others (e.g. ending relationship with partner, friends treating you differently, children behaving differently).
- Your finances (e.g. struggling to pay medical bills).
- Your hobbies and interests (e.g. unable to maintain a treasured hobby).
- Your hopes and goals for the future (e.g. planning to travel or have a family).

Give your health care professional a better picture of how you are coping with cancer by explaining not only what has changed, but also how you feel about it and how you are dealing with it. Follow this formula and try the following exercise to get things started.

Try the following exercise to get things started.

Exercise: Expressing how cancer is affecting your life

Think about something that may have changed in your life since the cancer diagnosis. Note down how you might describe this change, and the way it has affected you, using the three-step formula outlined above. You and your caregiver can each complete this exercise and then discuss what you have written down.

Step 1: What has changed? How and why?

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Step 2: How do you feel about it?

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Step 3: How are you dealing with it, or what help do you need?

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Changes and other events in your life can have an impact on the way you cope with cancer and respond to treatment. This is why the more your health care team knows about you, the better.

Here's an example of how Jane, recently diagnosed with colorectal cancer, expressed a change in her life to her oncologist:

PATIENT: "It might be helpful for you to know that I recently had to sell my home and move in with my daughter. I was struggling to cope by myself and could not afford to live on my own anymore. It hasn't been easy to give up the home I have lived in for 20 years and move into a busy household with young children around. I feel like I am a burden but my daughter says it's not a problem. I think I should talk to someone about getting some help with my care so I can give her a break sometimes. Can you suggest anyone?"

DOCTOR: "It seems your daughter does not mind."

PATIENT: "Even so, I feel we both need support. I heard that a social worker might be able to give me some advice. Can you please tell me who I can contact?"

TOP TIP: Honesty is the best policy

Being honest about what you are experiencing doesn't mean you are complaining. When you tell your story well, it helps your health care professionals make sure you get the care you need.

Suggestion 3: Manage your thoughts by doing regular physical activity

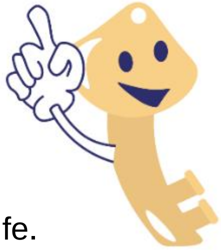
Remember to talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

What others say about discussing symptoms and expressing their concerns

"When I went to see my family doctor with headaches and pains in my chest, he pushed all his 'doctor' tools aside and said we needed to talk. At first I was a bit worried that these new symptoms were bad news. Instead, we talked for about an hour – I felt sorry for the others in the waiting room. He asked me a couple of questions but mainly listened while I raved on about how stressful it was trying to keep up with all the day-to-day stuff while I've been sick."

Greg, diagnosed with prostate cancer.

Key Points: Telling your health care professional what is going on



1. Even small changes to your symptoms and in your life are important to your health care professionals, so they can better understand how you are coping.
2. Be clear and specific when describing symptoms and pain.
3. Be honest and open about your concerns that are happening in your life.

Having our main concerns addressed during appointments

> *"Oncologists only have a limited amount of time to spend with each patient. For instance, if you've only got a 15-minute appointment, by the time they check you all out, that 15 minutes is up. So that's where I think it's important to be prepared for the appointment and to also be aware of other people in your health team that you can contact for the support you need."*
>
> **Andrew, diagnosed with prostate cancer.**

Many couples report that they leave their appointments feeling they did not get what they wanted. Often, it is a case of managing your expectations – that is, deciding what is most important to you and what can realistically be achieved in the available time. It can also mean finding ways to use appointment times more efficiently and being clear with your health care professionals about how much information you need.

Suggestions for getting the most out of your appointments

1. **Prepare for and take an active role** in medical appointments
2. **Be assertive** to help you feel more satisfied with medical appointments
3. **Use other methods to communicate** with your health care professionals
4. **Do regular physical activity** to clear your mind so you will feel more ready for your appointments

We will now explain how these suggestions can help you and provide step-by-step guidance on how to use these suggestions.

TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.

Why these suggestions can help?

Sometimes it seems like there's just not enough time during an appointment to cover everything you want to. It is important to make the most of the time available, and the strategies covered in this section will help you do that. My advice is to be clear about your priorities, the information you want and the questions you want answered. If you have preferences or opinions about your care, feel free to speak up. As a doctor I want you to participate in your own care and I welcome your input. **It's okay to ask for what you need** – whether it's more information, clarification, a chance to express your feelings, or inclusion in any decision making.

Suggestion 1: Prepare for and take an active role in medical appointments

Here are some ways that you can prepare for your medical appointments.

Strategy	Example/Explanation
Keep a file or notebook with the patient's medical information	Keep track of test and procedure dates, results and other records. Take your file or notebook to medical appointments
Know your medication	Some health care professionals suggest that you take all the prescription and non-prescription medicines and supplements to appointments, or at least take a list of them. You might also take contact details

	of other health care professionals you see and, if necessary, your medical records
Think about what you want most to achieve	List your concerns and rank them in order of importance, and discuss your most pressing ones first
Write your questions down	Take a list of questions with you (see the **"Asking questions to the health care professionals"** factsheet)
Make earlier contact	You might want to provide a list of questions or concerns, by phone or email, before the appointment, so the health care professional knows what to expect
Book a longer appointment	If you need to talk with your health care professional for an extended time, let him/her know in advance
Bring a notepad and pen	Writing notes can help you remember important points and will give you a handy reference for later
Bring an audio recorder	It might be difficult to process all the information discussed during an appointment. A simple solution is to make audio record the appointment. Ask your health care professional's permission, explaining that it would help you remember, understand and follow the advice given

Plan to work together with your caregiver, family member, or friend	Your caregivers, family member or friend can provide emotional support, be a second set of ears, take notes, or help you remember questions to ask your health care professional
Bring a third person (e.g., sibling or friend)	A third person can be the note-taker during appointments. This allows you and your caregiver to concentrate on what is being said while notes are taken for you to refer to later.

TOP TIP: For caregivers

If you cannot attend the medical appointment, ask the patient or health care professional to record the discussion so you can review it later

TOP TIP: How couples can work together during medical appointments

✓ **Plan for your appointment**

Discuss together:

- What do we want to achieve out of this appointment?
- Is there anything specific either of us wants to know or ask?
- Who is going to talk about what?
- If there is anything one of us finds difficult to talk about, should the other one take over?
- Do we differ in what or how much we want to know about the cancer and treatment? If so, how will we manage this at the appointment (e.g. one of you leaves the room early to allow the other to talk with the health care professional).

✓ **Set ground rules for the appointment**

It's important you agree on guidelines, such as:

- Allowing the other person to finish what they are saying without interruption.
- A signal (e.g. taking the other's hand) to show you are finding something difficult to discuss and need the other to take over.
- Allowing the other person to ask their own questions and express their own opinions.
- Noting down any issues arising during the appointment that might need further discussion later on.
- Making decisions together.

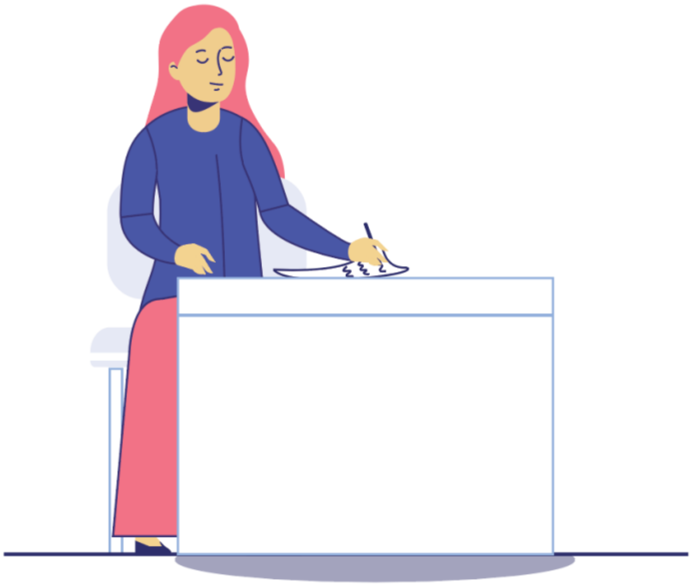
✓ **Debrief (go over things) after the appointment**

- Did we both get what we needed out of the appointment?
- Is there anything further either of us needs to know? If so, how will we go about finding this out?
- Did we both feel comfortable with our teamwork during the appointment?
- Is there anything we can do to make things work better?

Here are some ways that you can take an active role during medical appointments.

Strategy	Example/Explanation
Announce your plan at the start	Hand a copy of your plan, questions or priorities to your health care professional at the beginning of the appointment and read it aloud. For instance, you can say: *“Today, I would like to talk about how to manage my nausea.”*
Let your health care professional know your preferences for information	People’s desire for information varies and changes over time. It’s important you tell your health care professional your exact needs. It can be useful to say: *“I am the sort of person who wants to know everything, even if it is bad news”* or *“I get stressed when I get too much information and at the moment, I only want the basics.”*
Record your appointments and/or take notes	Most health care professionals are happy for you to do this. It gives you a chance to review what was discussed, which can help you better understand what is going on, especially if you feel anxious at the time. You can say: *“Do you mind if I record this? My caregiver will want to hear what you have to say.”*
Ask for explanation in terms familiar to you	Ask your health care professional to show you an illustration that will help you understand what he/she is saying. See the ‘**Understanding what the health care professionals are telling us**’ section in this fact sheet for further suggestions.
Seek clarification when you don’t understand	If you do not understand the health care professionals’ answer, ask the question in a different way, or ask them to explain the answer differently. When you repeat what the health care professional says, it gives him/her feedback on what you understood and allows him/her to clarify if necessary. See the ‘**Understanding what the health care professionals are telling us**’ section of this fact sheet for further suggestions.

Ask how you can learn more	Your health care professional can recommend reading materials to help you understand the diagnosis, procedures or treatments.
Ask for a written summary	Ask your health care professional to send you a letter summarizing the key issues discussed during your consultation.



Suggestion 2: Be assertive to help you feel more satisfied with medical appointments

Being assertive is about expressing yourself effectively and standing up for your point of view, while also respecting the rights of others. Being direct and respectful gives you the best chance of getting your point across.

Communicating assertively with members of your health care team means that you are not being passive or aggressive. The main differences between passive, assertive and aggressive communication are:

Passive communication

Is indirect, and often self-denying
(i.e. you don’t communicate what you want or need).

Allows others to make decisions for you.

Gives the appearance of not caring or just wanting to go with the flow.

Can make you feel anxious, ignored and helpless.

Assertive communication

Is healthy communication where multiple points of view are considered.

Direct, self-respecting and respectful of others
(i.e. creating a win-win situation).

Involves listening, eye contact, appropriate tone and ‘I’ statements
(e.g. “I don’t feel comfortable with my treatment plan.”)

Aggressive communication

Requires one person to win and one to lose.

Makes others feel powerless, shocked, hurt or humiliated.

Can be intimidating, with insults or commands and a loud, angry or sarcastic tone.

May be inappropriately honest or tactless.

Exercise: Identifying communication types

The following scenarios demonstrate the three types of communication.

Scenario 1:

Gabriella has recently been experiencing pain in her shoulder, which makes some of her daily tasks difficult. Gabriella decides to raise this with her radiation oncologist at her next appointment.

DOCTOR:	“I don’t think that physiotherapy will help with your shoulder problems.”
RESPONSE 1: **(Passive)**	“Oh, alright, thank you doctor.”
RESPONSE 2: **(Aggressive)**	“You have no idea what I’m going through, so how can you tell me it won’t work?”
RESPONSE 3: **(Assertive)**	“I have heard of people who have done very well with physio for this sort of problem and I would like a referral.”

Scenario 2:

Nate is experiencing constipation. His oncologist prescribed laxatives but Nate is worried about using them. He has asked his wife to attend his appointment with his oncologist because he is a little uncomfortable discussing some of the issues.

DOCTOR:	“I would recommend that you take the medication for constipation regularly.”
CAREGIVER RESPONSE 1: (Assertive)	“Nate is pretty reluctant to take tablets and I think he would prefer to try some pear juice and see how it goes.”
CAREGIVER RESPONSE 2: (Passive)	“Well, if that is the best option, I suppose Nate should try them.”
CAREGIVER RESPONSE 3: (Aggressive)	“This is now the second appointment Nate has raised this with you and all you have to offer is pills. You won’t even consider other ways to solve this problem.”

If you find it difficult to be assertive, think about other ways of getting your message across to a health care professional. For example:

- ✓ Ask your caregiver to talk to the health care professional on your behalf.
- ✓ Write an email or letter if you feel uncomfortable face-to-face.
- ✓ Talk to someone else in your health care team if you don’t feel confident talking with a particular health care professional.

If you are worried about challenging a health care professional’s authority or questioning their judgement, try a softer approach. For example, try saying:

> “That seems like a good way to go, but it would also be good to look at other options you might know of...”
>
> “I was thinking about [issue]; what do you think?”
>
> “I’d prefer to do it this way, but it’s important for me to have your support.”

Exercise: Identifying communication types

Another way to prepare for appointments is to practise what you are going to say. Pretend your caregiver is the health care professional and you are getting ready to talk to him/her. Think about what you need to say and how you will say it.

Use the skills discussed in this brochure. Be assertive and express how you feel. Use “I…” messages, for example, say “I think…” and “I’d prefer…” when making your point.

It’s okay to be scared or confused and to admit that you are feeling this way. The health care professional needs to know this in order to understand your feelings and respond in the right way.

For further suggestions on being assertive, see the **“Being more assertive with the health care team when making decisions”** section of the **Making Your Treatment Decision** fact sheet.

Suggestion 3: Use other methods to communicate with your health care professionals

Ask your health care professionals if they are happy to communicate by email or phone between appointments. Most health care professionals are willing to take calls and receive emails about your concerns. Busy health care professionals might find that an emailed or mailed list of questions helps them to prepare for your appointment.

Before using other forms of communication with your health care professionals, ask them:

- ✓ Which forms (e.g. email or phone) are acceptable ways for us to communicate with you?
- ✓ How long do you usually take to respond? Health care professionals might not check emails or return phone calls every day and there may be a considerable wait before a reply.
- ✓ What kinds of concerns or issues you are prepared to discuss via email or phone?

Consider this example scenario

Ellen has been prescribed a medication to help with her nausea. However, she feels that it isn’t achieving the results it should and doesn’t think she can wait until her next appointment to do something about it. She decides to send her oncologist the following email.

Dear Dr Tran,
I am writing to let you know I have been taking the medication you prescribed for me but I am still having quite a bit of nausea. I feel it should have taken effect by now and am finding the nausea quite distressing. Do you have any suggestions about what I can do? Should I try something else? I understand you are busy but appreciate any advice you can give me, since my next appointment with you is not for two weeks.
Sincerely,
Ellen Smith

TOP TIP: Using other forms of communication

- ✓ Keep your question or request simple and direct so your health care professional can get to the point quickly
- ✓ Clearly flag the nature of your request in the subject line of an email. Be wary of including, or expecting the health care professional to include, confidential or sensitive information
- ✓ Use straightforward and polite language
- ✓ Wait for a reply. If you haven't had a reply in what you believe is a reasonable time, check with the health care professional's assistant
- ✓ It's important to remember that other forms of communication do NOT replace meeting face-to-face with your health care professionals

Suggestion 4: Do regular physical activity to clear your mind so you will feel more ready for your appointments

Remember to talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

What others say about being prepared and assertive

"At my first visit with the oncologist, I brought along my tape recorder and a piece of paper with all my questions. When my oncologist saw me pull out the sheet, she was surprised and said: 'I see you have a few questions for me!' and we went through each question, one by one. I was so relieved that she could answer my questions. I did listen to the recording a few days after, as it was all too much to take in at once."

Eric, diagnosed with prostate cancer.

Key Points: Getting what you want out of an appointment

1. Try preparing for medical appointments
2. Think about what you want to get out of your time with health care professionals
3. Be assertive and clear

Understanding what the health care professionals are telling us

> *"A couple of times when the doctors spoke to me I would think, 'Well, what are you telling me?' I mean, the doctors and specialists talk in medical terms and so I'd have to say to them, 'Please, no medical terms!'"*
>
> **Robert, diagnosed with prostate cancer.**

Health care professionals often give a lot of information all at once. This can be very confusing, especially that they often use medical jargon. It isn't always easy to take all of this new and unclear information in. Not all health care professionals are good at putting things in clear and simple terms, so you may need to ask them to explain what they are telling you.

Suggestions for clarifying information from health care professionals

1. **Ask** the health care professional **to explain information that you don't understand**
2. **Repeat aloud** what the health care professional has just said
3. **Summarize** what you think the health care professional has just said
4. Manage your thoughts by doing **regular physical activity**

We will now explain how these suggestions can help you and provide step-by-step guidance on how to use these suggestions.

TOP TIP: Use the suggestion right for you:

- ✓ Read the description of each suggestion that follows
- ✓ Choose the strategy or strategies that you prefer
- ✓ Make an action plan to help you fit your preferred suggestion into your daily life
- ✓ Set rewards for the progress you make toward achieving your goal.

Why these suggestions can help?

It’s important that you ask for clarification if you feel you haven’t understood everything your health care professional has said, otherwise they will assume you have understood and you’ll end up getting more and more confused as things progress. Busy health care professionals can get a bit distracted and not notice your non-verbal signals, such as a blank or confused look on your face, so it’s worth speaking up when you’re feeling a little lost. Thinking you can wait until you are back home and able to ‘Google’ it is not a good idea, because you won’t have the same level of knowledge and expertise as your health care professionals and you’ll probably be missing vital details and context. Failing to understand what the health care professional says can leave you and your partner feeling distressed, confused, frustrated or uncertain. At worst, you might make decisions or do things that are not the best for your health and wellbeing.

TOP TIP: Speak up

You may find it hard to talk to health care professionals who use complex medical words and often do not have much time to talk. But it is important for you to have a comfortable relationship with the members of your health care team, so always ask for clarification.

Suggestion 1: Ask the health care professional to repeat or explain information that is unclear

If you don’t understand what the health care professional is telling you, ask him/her to explain medical terms in plain language, spell medical words or draw pictures to help you understand. It’s better to ask for clarification on the spot than to wait until you get home and search for it on the Internet. Information on the Internet can be unreliable and may not apply to your situation.

Here are some tips:

- ✓ Use “I” statements (e.g. “I didn’t quite understand that”).
- ✓ Make your questions specific (e.g. “Did you mean I should do [a particular activity]?” rather than “What should I do?”).
- ✓ Ask the health care professional if there is another time or another way (such as email) that you can discuss it in more detail.
- ✓ Ask your health care professional for additional written information or resources.

Try saying these things to better understand what a health care professional has said:

- ✓ “Can you say that again, using simpler words?”
- ✓ “Could you go over that bit again?”
- ✓ “Could you please repeat that last part?”
- ✓ “Can you clarify what you mean by [particular information]?”
- ✓ “When you said that, did you mean [specific message]?”
- ✓ “I didn’t quite understand that. Can you run it by me again?”
- ✓ “Please spell that word for me.”

TOP TIP: If you understand visual aids better than verbal communication, ask to see the X-rays or slides, or ask your health care professional to draw a diagram.

Suggestion 2: Repeat aloud what the health care professional has just said

Health care professionals give a lot of instructions, such as when to take medication, what to watch out for and how to take care of yourself. To be sure you understand them, repeat the instructions in your own words and ask the professional if your understanding is correct.

Try these phrases: “I think you’re telling me that…”
“Is it correct that you want me to…?”
“So you mean I should...”
“Before my next visit, I will…”
“You want me to call you if…”

Here is an example of how this might work:

DOCTOR: “So we will do 40mg twice a day. It’s just one pill twice a day.”

PATIENT: “So that is one in the morning and another in the afternoon?”

DOCTOR: “Exactly.”

TOP TIP: Use drive-through listening

Think about the interaction that takes place when you order something from a drive-through – you state what you want, and the employee repeats it back to you to confirm they have heard you correctly. You can do the same thing with the members of your health care team.

Suggestion 3: Summarize your understanding of what the health care professional has just said

At the end of an appointment or phone call, summarize what you have heard. If you think you might forget something, write it down (or ask the professional to write it down for you).

Here is an example of how this might work:

PATIENT: "I understand that you think I should continue with the therapy, but I should talk to the oncology nurse about how I might deal with the nausea."

DOCTOR: "Yes, and don't forget to ask the nurse about that medication we talked about."

PATIENT: "Oh, that's right. Do you mind writing the name of that down for me? Is there anything else I need to remember?"

Suggestion 4: Manage your thoughts by doing regular physical activity

Remember to talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

What others say about seeking clarification

"My wife, Shelley and I were waiting in the medical oncologist's examination room to discuss treatment options. The doctor walked in and said 'So, as we discussed the other day, the biopsy confirmed that you have prostate cancer, the Gleason score is six...' I had absolutely no idea what he was talking about so I asked "What does that mean? What does a score of six mean?" He proceeded to explain what he meant in words I could understand. He then said he recommended radiotherapy and we needed to arrange referral to the radiation oncologist who will be able to give me more detailed information and start my planning. I didn't know what he meant by 'planning', so I was really happy when Shelley asked him 'What do you mean by planning?'"

Patrick, diagnosed with prostate cancer.

Key Points: Seeking clarification from your health care professionals

1. Failing to understand what your health care professional has told you can have an impact on your mental and physical wellbeing.
2. When in doubt, ask your health care professional to explain further or in different terms.
3. Repeat what you have been told and summarize what you understand so your health care professional knows you've understood.

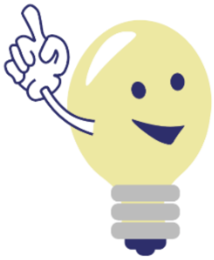
Telling the health care team which decisions we want

> *“I had done some reading and wanted to consider a different treatment option to what my doctor had recommended. But I couldn’t say ‘Hey, what about this?’ I didn’t want him to think I was telling him how to do his job. But, I was really worked up about not knowing whether the right decision had been made”*
>
> **Martin, diagnosed with prostate cancer.**

The relationship between patients and their doctors is very personal. Doctors need to know a lot about you, your family, and your lifestyle to give you the best care possible. It can be intimidating to take a more active role in your health care, however your health care team should support you to make an informed decision about treatment that fits with your needs, values and your preferences. It is your right to choose or reject any form of treatment.

Suggestions for having more of a say in treatment decisions:

1. Assert yourself in the decision-making process.
2. If you still feel your opinion has not been considered, seek a second opinion.
3. Incorporate physical activity into your routine to boost your confidence and clear your mind



Suggestion 1: Assert yourself in the decision-making process

What the experts say

Being assertive is quite different to being aggressive. Being assertive is when you say clearly what you want or think, even when others might think differently, to help you feel more in control in difficult situations. For example, letting your health care professionals know you want to be involved in decisions about care and treatment.

Assertiveness comes more easily to some than others, however most people would agree that our health is incredibly important. It may help to consider this: Would you buy a car without asking questions? A home? You shouldn’t therefore be afraid or feel like you are bothering your doctor. If you feel that your questions or concerns were not sufficiently addressed, it is okay to be assertive.

The assertiveness plan below suggests how to become more assertive in decisions about your care and treatment.

Assertiveness Plan

Step One: Tell your health care professional how you like to interact. For example, “I tend to say very little, but I would like to have a say in all my treatment decisions.”

Step Two: Discuss with your health care professional how you can best get involved. Ask to be provided with all options and relevant information. For example, “do you have a decision aid that can help me decide which treatment option is best suited to my values” (See the resources at the end of this fact sheet for examples of decision aids).

Step Three: Discuss concerns with your health care professional. Tell your health care professional how you feel about your involvement in the decision-making process. Be specific about the problem and what you need. The exercise on the next page ‘making assertive statements’, takes you through a technique you can use to help make your position clear to your health care team.

Step Four: Talk to others. If you’re still not happy with your level of involvement, try talking to your family doctor, social worker or nurse about your options. You are entitled to ask for another doctor or a second opinion. For more information on second opinions, see ‘Suggestion 2: seek a second opinion’.

Exercise: Making assertive statements

Think about the next time you'll be talking to your doctor about treatment options, or remember an appointment at which you weren't satisfied with your involvement in the decision-making process. (Adapted from Davis, Paleg and Fanning, (2004).[5])

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1. Decide what you hope/hoped to achieve during that discussion with your doctor.

Assertiveness is about saying what you want in a clear and effective way and it's difficult to be clear with others when you are unsure of what you want. A specific 'want' might be: "To find out if there are any treatment options beyond what my doctor seems to prefer."

I want:

____

____

2. Work out how to clearly state where you stand.

Once you're clear about what you want, you need to think about how you can set out a clear picture of your position for your doctor. Misunderstandings occur when others don't get the full story. Make sure you cover three key pieces of information:

- ✓ What you think about the situation – "We think…"
- ✓ How you feel about the situation – "We feel…"
- ✓ What you want to do, or would like to see done – "We want/would like…"

For example: State your position assertively by saying, "We think we need to look at more options before a decision is made about treatment. We feel that we don't know enough about what else is on offer. We'd like you to give us some information on other options that are available to us, even if you don't prefer them."

Your assertive statements:

We think ____
We feel ____
We want / would like ____

Suggestion 2: Seek a second opinion

What the experts say

If you feel excluded from the decision-making process because of the way in which your health care professional works with you, it’s your right to ask for a second opinion. Most doctors and health care professionals understand if you explain why you feel you need to see someone else and are happy to provide a referral. A second health care professional might give you more options or could put your mind at ease by confirming what has already been recommended.

FACT: You are entitled to seek another health professional’s opinion. You also have the right to choose which health professional provides your treatment. Remember to tell both health care professionals who you want to continue with your treatment.

TOP TIP: If you feel uncomfortable about telling your doctor you want a second opinion, ask a friend or family member to be there with you to help you explain, or speak to another member of your health care team, for example, your nurse or family doctor, about how to manage this.

Here are some hints for seeking second opinions:

- ✓ Before you act, think about why you feel you need to get another doctor or health professional's advice. For example, is it worth the extra time and expense?
- ✓ Tell your health professional you intend to seek a second opinion – they usually appreciate the courtesy and might even refer you to someone.
- ✓ Be honest about your reasons for asking another health professional's opinion – they're likely to understand your need to be as fully informed as possible.
- ✓ It can take some time to get your second opinion, so ask if there is help to facilitate the process. If you want a second opinion for a specific concern, they might know someone who has expertise in dealing with that issue.
- ✓ Ultimately, people want a well-informed team looking after the treatment. If you let your health professional know you are seeking a second opinion, they can ensure that you have all the information you need to take to your appointment to get an accurate second opinion.
- ✓ Be sure the second opinion comes from a credible source – check with your doctor, your health care team or the Canadian Cancer Society.
- ✓ Be wary of using websites to find a second opinion.
- ✓ If you're considering a second opinion from outside your location, include travelling to treatment and possible impact on follow-up care as factors to consider in your decision-making process.
- ✓ Let your doctor know what you've gleaned from a second opinion so they have a chance to discuss the information and offer their views.
- ✓ Make sure you let both doctors or health professionals know who you've decided to go with for treatment. Keeping everyone informed makes sure you don't slip through the cracks or get overlooked on busy treatment schedules.

Suggestion 3: Incorporate physical activity into your routine to clear your mind

What the experts say

When you feel high levels of uncertainty about a treatment decision, you can feel physical tension, and emotional distress. There are ways to manage physical tension or emotional distress, one effective way is regular physical activity.

Physical activity produces endorphins, which are chemicals in the brain that act as natural painkillers and are sometimes referred to as the "feel-good neurotransmitter". Getting up and being physically active can help you get your mind off the day's hassles and help you to relax. It can also improve your sleep, which might be disrupted by anxiety and stress.

How do I use this suggestion? Step-by-step guide.

Remember: Talk to your health care team before you begin any new physical activity plan. Ask about when you can start, and what type and intensity of physical activity is best for you.

Step One
Choose a physical activity or exercise that you would like to do regularly

Step Two
Make an action plan to fit your exercise or physical activity into your daily routine

Step Three
Set rewards for the progress you make toward achieving your goal.

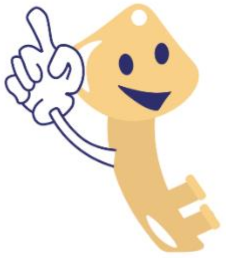
What others say about asserting these suggestions

"At first I was a little uncomfortable telling my doctor I wanted to choose my treatment. I simply told him that choosing what was best for me was important because I would know my needs had been fully considered."

Kenneth, diagnosed with prostate cancer.

FACT: Studies have shown that patients who play the role they desire in decision-making are more satisfied with their treatment and feel less uncertainty about their decisions (decisional conflict).

Key Points: Having more of a say in treatment decisions



1. Every person has the right to make the final decision about what treatments to use.
2. You are entitled to the information and supports you need to make an informed decision about treatments that fit with your needs, values and preferences.
3. Being assertive is about respectfully speaking up for yourself and letting your doctor know what you need.

Resources for assertiveness in decision making

Information about making treatment decisions

American Cancer Society. Making health decisions as a cancer caregiver. https://www.cancer.org/treatment/caregivers/what-a-caregiver-does/making-decisions.html. Last accessed October 19, 2017.

Canadian Cancer Society. Questions to ask about treatment. http://www.cancer.ca/en/cancer-information/cancer-journey/your-healthcare-team/questions-to-ask/treatment-questions/?region=on. Last accessed October 19, 2017.

Canadian Cancer Society. Treatment. http://www.cancer.ca/en/cancer-information/diagnosis-and-treatment/treatment/?region=on. Last accessed October 19, 2017.

Canadian Cancer Society. Treatments for prostate cancer. http://www.cancer.ca/en/cancer-information/cancer-type/prostate/treatment/?region=on. Last accessed October 19, 2017.

HealthLinkBC. Making Wise Health Decisions – Skills for Making Wise Health Decisions. (2016). https://www.healthlinkbc.ca/health-topics/aa112018#aa112229. Last accessed October 19, 2017.

Assertive Communication

CCI Assert yourself! Module 1: What is assertiveness? (2008) http://www.cci.health.wa.gov.au/docs/Assertmodule%201.pdf. Last accessed September 20, 2017.

McGill Cancer and Work. Assertiveness: More honest and balanced relationships. https://www.cancerandwork.ca/survivors/assertiveness/. Last accessed September 13, 2017.

Decision Aids

National Cancer Institute. Treatment Choices for Men with Early-Stage Prostate Cancer. https://www.cancer.gov/publications/patient-education/understanding-prostate-cancer-treatment. Last accessed October 18, 2017.

Queen's University and TrueNTH. Prostate Cancer Decision aid for Early-stage Patients. http://decisionhelp.qcancercare.com/. Last accessed October 18, 2017

The Ottawa Hospital Research Institute. Ottawa Personal Decision Guide. https://decisionaid.ohri.ca/docs/das/OPDG.pdf. Last accessed October 19, 2017.

The Ottawa Hospital Research Institute. Patient Decision Aids. Alphabetical List of Decision Aids by Health Topic. https://decisionaid.ohri.ca/AZlist.html. Last accessed October 18, 2017.

Physical activity:

Canadian Cancer Society. Physical activity. http://www.cancer.ca/en/prevention-and-screening/live-well/nutrition-and-fitness/physical-activity/?region=on. Last accessed September 14, 2017.

Canadian Psychological Association. Psychology Works Fact Sheet: Physical Activity (2014). http://www.cpa.ca/docs/File/Publications/FactSheets/PsychologyWorksFactSheet_PhysicalActivity.pdf. Last accessed September 13, 2017.

Government of Canada. Physical activity (2011). http://www.phac-aspc.gc.ca/hp-ps/hl-mvs/pa-ap/index-eng.php. Last accessed September 14, 2017.