Talking with Your Doctor

Communication Basics for Cancer Patients

Workshop Kit

Canadian Breast Cancer Initiative

Adult Health Division

Health Canada Santé Canada

CBCN RCCS
Canadian Breast Cancer Network
Réseau canadien du cancer du sein

CANADIAN
BREAST CANCER
FOUNDATION

CANADIAN CANCER SOCIETY
SOCIÉTÉ CANADIENNE DU CANCER

Good communication means letting someone know clearly what you are thinking and feeling, and finding out what the other person is thinking and feeling too ... It's like a friendly game of catch. One person throws the ball, so the other person can catch it without too much trouble. Then the second person throws it back. The purpose is to keep the ball — the communication — going.

“Communicating” in the *Cancer Survival Toolbook*,
National Coalition for Cancer Survivors
(Silver Spring, Maryland, U.S.A., 1998)

Table of Contents

Acknowledgements

Development of this workshop involved advice from many people across Canada who are involved in many aspects of breast cancer treatment, support and education. Health Canada thanks them for their important contributions. Suzanne Inhaber (Adult Health Division, Health Canada) provided the leadership and vision essential to the project. Research, writing, design and production were the work of Allium Consulting Group Inc. (Ottawa).

About the Communications Basics Workshop Kit

Cancer patients have a lot to deal with when they are given the terrifying news that they have cancer. As a patient, your entire life has been turned upside down, and you still have to make frightening decisions about medical treatments and adjusting your family life. At the same time you are being introduced to doctors, nurses, and other health care workers — most of them strangers to you — whose knowledge and care are really important to your well-being, even to your survival.

Good communication skills can help. There are two people in the patient-physician relationship, and either one can take steps to improve how they talk — and listen — to one another. Good communication techniques can go a long way.

Talking with Your Doctor — Communication Basics for Cancer Patients was produced through the federally funded Canadian Breast Cancer Initiative. This workshop kit was developed for cancer patients, to help them learn about and try some basic techniques.

Purpose and Objectives of the Workshop

The workshop is designed for cancer patients. The overall goal is for participants to learn why better communication is better for their health, and to understand the factors that influence patient-doctor communication.

More specifically, at the end of the workshop, participants should:

- have a better understanding of the role of good communication in their relationship with their doctor
- know more about some of the unique issues that affect doctor-patient communication
- be more aware of communication problems of particular concern to them
- know some practical techniques to deal with the problems they face in talking with their doctor

In addition, participants should feel more confident about trying one or two techniques that they may not have used before.

A Team Approach

The emphasis of the interactive workshop is on *shared problem-solving* and *group learning*. While every patient has a unique relationship and communication style with her/his doctor, there are some common communication problems — and practical solutions — that can help improve the patient-doctor relationship. Discussion in a group setting can promote sharing of ideas and solutions — all with the goal of enabling each participant to take some action towards better communication with her doctor.

A Two-Way Street

It takes work by both patient and doctor to get the most out of communication. By focusing on only patients in this workshop, the idea is to provide an opportunity for cancer patients to understand the *patient role* in the communication process, and to attempt to improve their *own* skills. Other materials and courses are designed for doctors — they share the responsibility for communicating effectively.

Who Should Attend the Workshop?

The workshop was developed primarily for women with breast cancer. However, the overall approach and techniques can apply to anyone living with cancer or another life-threatening illness. The workshop kit is designed to be flexible — providing core information for leaders to use in a variety of settings such as:

- a formal, stand-alone workshop
- a workshop in an existing support group
- a lesson guide for counsellors working one-on-one with patients
- a "self-learning" guide for cancer patients

Ideally, workshops will include no more than 10 participants. This will allow for full discussion — a central feature of the kit.

Who Should Lead the Workshop?

The workshop is designed to be both flexible and interactive. This means that the workshop leader — a cancer survivor, a nurse, a social worker, a support group leader — needs to be able to pick and choose from the kit material, to design a discussion-based workshop that meets participant needs. Specifically, anyone leading this workshop should:

- be comfortable with frank discussions about living with cancer and coping with the medical environment of cancer care
- have some basic facilitation skills — the workshop is based on group discussion
- be able to deal with emotions — the communication issues to be discussed are not just skills, they're about coping with and fighting cancer. Some strong emotions may emerge and must be handled sensitively

Co-leading with a Health Care Professional

Think about including a physician or other health care professional as a co-leader. The presence of a physician is, in itself, a powerful message about how committed doctors are to improving their communication with patients. Here are some issues to consider when co-leading with a doctor or other health care professional:

- make sure participants know who the other leader is *in advance*, and what her/his role will be
- have the physician-leader explain briefly to the group why she/he is interested in the communication issue
- make the most of the physician co-leader’s insights into why doctors approach communication the way they do
- keep to the issue of the *patient* role in communication ... there may be a tendency for participants to work on improving the physician/health care provider’s communication skills

What’s in This Kit

The kit includes all the basics for running an interactive workshop that runs from one to two hours, depending on the material the facilitator elects to use. In the kit, you’ll find:

- notes for workshop leaders, including a suggested format or plan
- masters for overheads or flipcharts
- handouts for participants
- exercises for participants

All of the materials provided are suggestions — designed to trigger the thinking of the workshop leader and participants. You are encouraged to pick and choose from the ideas, to suit your own needs.

For more information about this kit, and other tools aimed at improving patient-physician communication, please contact:

Suzanne Inhaber
Adult Health Division
Health Canada
Room B1042, Jeanne Mance Building
Ottawa, Canada   K1A 1B4

Suzanne_Inhaber@hc-sc.gc.ca
Tel.: (613) 954-8672
Fax.: (613) 941-2633

This kit is also available through Health Canada’s Web site.

Some Suggestions for Running the Interactive Workshop

You can use the exercises, handouts, overheads and notes in this kit in any way that suits you and the participants of your workshop. For example, if you want to give brief lectures to a group, you can use some of the material provided as lecture notes. If you prefer to get the group talking, you can use the material to ask questions and prompt discussion. The focus of the workshop is on problem-solving for each participant through an interactive group approach. So, however you use the tools provided in the kit, try to help the participants through a process of:

1. identifying their personal communication difficulties
2. generating some ideas for resolving them
3. selecting one or two techniques to try

The following five-step approach is only *one way* of using the material, but you may find it helpful. The time spent on each step is up to you. Bear in mind that discussion takes time — try not to fit too much material into your session. If you decide to use all of the material, you will probably need *at least* two hours.

Step 1 — Getting Started

Help people focus by explaining the goals of the workshop and what's to be covered. Help participants relax by asking them to introduce themselves and tell each other why a workshop like this was of interest to them.

Overall goal of workshop — to give each participant one or two communication techniques to try when talking with her or his doctor.

Step 2 — What About This Patient-Physician Relationship?

Help participants discuss why the relationship is often so difficult, what makes it different. This will help validate feelings of fear or frustration people may be experiencing in relating to their physician. It may be worth making the point that the medical profession, too, are working to improve their skills. This session includes an exercise for participants to explore their own relationship with their physician.

Tools to use:

- Handout: "Points to Ponder — The Patient-Physician Relationship in Cancer Care"
- Exercise: "Some Difficulties I'm Experiencing"

Step 3 — Lots of Things to Try

Guide participants in a discussion of methods for improving communication, drawing on their own experiences in trying out different techniques. You can start the discussions by inviting comments on what to do before, during and after the consultation, then focus on suggestions for resolving difficulties *during* the consultation. If time is short, or if you are running a workshop of less than two hours, concentrate on either *one* of these (i.e., before, during and after, or during (in more detail)).

Tools to use:

- Leader's Notes/Handout: "'Before, During and After' — A Process for Better Communication"
- Leader's Notes/Handout: "How to Deal with Some Common Communication Problems During the Consultation"

Step 4 — Tips for Two of the Most Common Problems

Ask people to concentrate specifically on the problems patients most often point to — being overwhelmed with information and feeling rushed. If these were not identified by the participants as key difficulties, focus this in-depth discussion on one that was. Many of the techniques mentioned will still help. If you are running a workshop of less than two hours, you will probably only have time to discuss one problem.

Tools to use:

- Overhead/Flipchart: "How to Deal with Too Much/Too Little Information"
- Leader's Notes/Handout: "How to Deal with Too Much/Too Little Information"
- Handout: "'What I Heard' — A Powerful Communication Tool"
- Overhead/Flipchart: "How to Manage that Feeling of Being Rushed"
- Leader's Notes/Handout: "How to Manage that Feeling of Being Rushed"
- Handout: "A Glossary of Cancer Terms"

Step 5 — What I'll Try

Wrap up the workshop by asking participants to reflect on what they have heard and jot down what they learned, and one or two things they'll try with their doctor. Encourage people to be realistic in what they take on — one or two changes are enough and are more likely to be acted upon than a long list.

Tools to use:

- Exercise: "What I'll Try"

Points to Ponder — The Patient-Physician Relationship in Cancer Care

On the one hand, it's a relationship like any other.

- it means talking *and* listening, on both sides
- both of the communicators are people (and *only* people)
- unspoken attitudes and feelings can complicate things
- neither one can read minds

On the other hand, it's a relationship that's unique.

- anxiety, fear and uncertainty can take away a lot of your normal confidence
- certainly, at first, you're at a disadvantage — the one being examined, the one lacking medical knowledge, the one who is scared
- the doctor seems to hold your life in his or her hands — it's not unusual to feel that you had better stay in his or her good books
- physicians are trained to concentrate on the medical condition — while your entire life is being affected

Some Difficulties I'm Experiencing

Try to write down some of the problems you are having in your relationship with your doctor. Think about how you feel before, during and after a meeting and what may be the cause.

I feel ...	Because my doctor ...	And I ...
• rushed	• doesn't seem to have time	• feel guilty
• confused	• uses medical words	• nod as if I understand
• hesitant	• seems very kind	• don't want to start crying

“Before, During and After” — A Process for Better Communication

Preparing — Before Meeting with Your Doctor

- **Set some goals for the discussion.** Know what you need. Do you most need to get information? give information? make a decision? get help and support?
- **Think about the *person* you will be talking with.** Put yourself in your doctor’s shoes. What may be her/his concerns or constraints? What communication techniques or strategies are most likely to work, given what you know about this person?
- **Set an agenda for yourself.** Try to identify specifically what you need to discuss and how. Formulate specific questions.
- **Focus your agenda.** Concentrate on what’s most important to you at this time and set priorities. Be prepared to consult with health care workers other than your cancer doctor — oncology nurses, social workers, family doctors, pharmacists, community care workers, to name only a few — may be better able to help with some of your concerns than your doctor.

Tips and Tricks

- prepare by brainstorming with a friend
- group your questions into topics
- help your doctor prepare by sending in your “agenda” and questions ahead of time
- if you’re nervous, build confidence by role-playing the discussion with a friend
- request a special appointment for longer discussions

Talking — During Your Meeting with Your Doctor

- **Review your agenda and priorities with the doctor early on.** Spend a few moments to reach agreement on what to discuss — your doctor will have items on her or his “agenda” too.
- **Be assertive.** Say what you need to say in a way that makes it clear to others that it is important to you. Use “I” messages (“I feel that ...”, “I am concerned that ...”, “I need more time to think ...”). Identify the things that are important to you and your life, and share them with your doctor when planning your care.

- **Use active listening.** Listen carefully and show you are listening by making eye contact, leaning forward. Make sure you understand by repeating to your doctor, in your own words, what you heard (“If I understand you right, you’re telling me ...” or “I’ll tell you what I heard so we can make sure I’ve got it ...”)

- **Express your feelings.** Be honest about what you are feeling (confused, overwhelmed, calm, embarrassed, frightened). This will help both you and your doctor make sure that your needs are being met during the conversation. Try to describe your emotions, rather than *display* them. Displaying anger, frustration, fear, or embarrassment without talking about these feelings usually destroys open communication.

Tips and Tricks

- take a friend with you to take notes or tape-record the discussion
- if you feel that you’re not getting enough information, say so and explain why it is important to you
- ask how you can reach your doctor (or others) if you have follow-up questions

- **Talk about communication barriers, if they exist.** If you feel that there is something inhibiting the communication flow, raise it diplomatically and work towards a common solution. Time constraints may be solved by another appointment. You may need a short “time-out” to handle some emotions. Explaining why it is important that you understand may help your doctor talk in a way that is more meaningful to you.

Reviewing — After Meeting with Your Doctor

- **Take the time to absorb what was said.** Spend some time reviewing your notes and thinking about what your doctor said, as well as your own views and feelings. You may find this “analysis” will help you understand what it all means to you, your life, and any decisions you need to make.

- **Follow up with questions and clarifications.** It is very common that people have other questions and concerns after they have had the chance to think about what they learned during their talk with their doctor. These “follow-up” conversations are important, because they will help you better understand your condition, give you greater confidence in your care plan, and alleviate any worries you may have.

Tips and Tricks

- invite a friend to help you “analyze” what was said
- keep a journal to keep track of what you learn from your doctor and other sources
- jot down in your journal what you will try at your next consultation in terms of communication techniques

- **Try to improve your communication skills.** Think about how the conversation went. Were you able to express what you are thinking and feeling, and did you learn what your doctor was thinking and feeling, too? Did the ball stay in the air? What might you do differently next time?

How to Deal with Some Common Communication Problems During the Consultation

Sometimes I ...	Possibly because ...	What I can try
don’t give my doctor all the information I know	some of it seems silly or useless to me, and she/he hasn’t asked for it	______ ______ ______
don’t ask questions, even when I’m not clear about something	______ ______ ______	write down the questions before my appointment — think about getting help from a friend
feel overwhelmed by my emotions	my mind races, thinking about how my family will cope	expressing my feelings in words, rather than displaying them. I might say ...
feel like I’m being “interrogated,” and interrupted when I try to explain something	my doctor asks so many questions, one after the other, without giving me the time to understand and think	______ ______ ______
ask the questions most important to me at the end of our appointment	I’m very nervous about what the answer might be	______ ______ ______
______ ______ ______	______ ______ ______	______ ______ ______
______ ______ ______	______ ______ ______	______ ______ ______

Sometimes my doctor ...	Possibly because she/he ...	I can try ...
➤ seems to be withholding information	➤ thinks I already know it, or that I don’t need to know it	➤ ________
➤ doesn’t appear to listen to my questions	➤ ________	➤ repeating the question, and saying how important it is to me to understand the issue
➤ seems uncomfortable with my questions	➤ may not know what kind of a role I want in the doctor-patient relationship	➤ ________
➤ ________	➤ ________	➤ ________
➤ ________	➤ ________	➤ ________

How to Deal with Too Much/Too Little Information

Consider these problems and suggestions:

- **“There’s so much information ...”**

  — Take a friend or family member with you.
  — Prepare for the meeting.
  — Give yourself time.

- **“... and so little that I understand!”**

  — Ask if you don’t understand.
  — Keep a journal.
  — Learn a few basic medical terms.
  — Ask for pictures.

- **Other problems I have faced, and suggestions for dealing with them:**

  —
  —
  —
  —

How to Deal with Too Much/Too Little Information

Here are some suggestions that have worked for some people. Think about which ones might work for you.

“There’s so much information …”

- **Take a friend or family member with you** — Someone to give you some emotional support, listen carefully, take notes, and ask questions you may not have thought of.
- **Prepare for the meeting** — Think about what is most important to you at that time. Tell your doctor what these important points are at the beginning of your meeting.
- **Give yourself time** — Not *everything* has to be decided right away. You might want to schedule special appointments for more full discussions.
- **Other techniques** —
  -
  -
  -

“… and so little that I understand!”

- **Ask if you don’t understand** — Try not to feel shy about asking your doctor and other health professionals to repeat something, using simpler terms. The more you understand, the easier it will be for them to help you.
- **Keep a journal** — You can keep track of what you learn from your physician, other caregivers, other patients, or your own reading.
- **Learn a few basic medical terms** — Over time, you may find it helpful to know a few terms, especially those that help you keep track of your progress and manage your care.
- **Ask for pictures** — For some people, an illustration in a textbook or a rapidly-drawn sketch helps them understand (and remember) where the cancer is, how treatments work, or how tests will be performed.
- **Other techniques** —
  -
  -
  -

“What I Heard” — A Powerful Communication Tool

In any communication, messages can get crossed or points missed. For important advice or information, it is often a very good idea to tell your doctor what you think you heard her/him say. Repeat to your doctor *in your own words* what you heard and get confirmation. This will allow both of you to clear up any misunderstandings. It can also help you remember the information or instructions you were given.

You might consider using these (or similar) words to introduce your play-back:

- *“I’ll tell you what I heard so we can make sure I’ve got it ...”*
- *“If I understand you right, you’re telling me ...”*
- *“To make sure I do what I need, let me tell you in my own words what you said ...”*

How to Manage that Feeling of Being Rushed

Some approaches to consider:

- Talk about your “time” concerns.
- Plan ahead — think about what’s important to cover.
- Don’t let time get in your way.

Some other approaches to help avoid feeling rushed:

-
-
-

How to Manage that Feeling of Being Rushed

Your concerns are important and you need time to absorb information, discuss important issues, and make difficult decisions. While your physician is committed to helping you, she or he has other patients to see and has a certain expectation of how long the consultation should take. **You can work together to manage the pressures of time.** Here are some approaches that have worked for many people. Think about which ones might work for you.

- **Talk about your "time" concerns** — If you feel rushed in discussing an issue or making a decision — say so. Try to say what time you need, e.g., *I'm feeling that I need a few days to think this over and learn more before I make a decision. Can we take that time and talk again?* You can then work out together a realistic timeframe for decision making.
- **Plan ahead** — think about what's important to cover — Plan to bring up the most important items right away. If there are issues or questions *you* want to cover, let your doctor know beforehand by sending in a list by fax, or telling the nurse. Plan a special appointment for longer discussions.
- **Don't let time get in your way** — Your issues and concerns are important to your health care — and to your doctor. Don't be silenced by a sense that you shouldn't take up your doctor's time.

What I'll Try

What did I learn today that will help me?

Which techniques will I try?

Some General Tips for Workshop Leaders

- **Make each workshop your own.** Review the material, putting it in the sequence that works best for you and the participants. Draw on your own experience to make the course your own and give it to others.

- **Create a safe, comfortable environment.** Wherever you host the workshop, make sure that those attending will feel physically comfortable and relaxed. Participants must have the confidence to share their experiences and talk about what they may perceive as their own communications shortcomings. Remind everyone that what they will hear from others is to be held in confidence. Keep the tone light and constructive, the personal goals realistic. If participants don't know each other, make name tents to help get the discussion going.

- **Encourage discussion.** Addressing individual concerns and sharing successful techniques others have tried is important in this workshop. Not everyone will talk, but keep an eye on the flow of discussion to make sure everyone feels included. Use open questions (requiring more than a yes or no answer) to prompt participation.

- **Let people express emotion.** Depending on personal circumstances, people will have different experiences, fears, or frustrations. If strong emotions do emerge, it is important to give people the opportunity to express them, but guide the discussion towards the positive — offering ways of resolving the difficulty.

- **Remain flexible.** Depending on the nature and degree of the discussion, you may not cover all the material provided for each workshop. The kit is designed to offer this flexibility. Even if you only cover one topic offered in the workshop, try to respect its overall flow — identifying communication difficulties, generating solutions, selecting one or two techniques to try.

- **Use a presentation method you are comfortable with.** If you prefer to offer brief lectures, use overheads and the detailed material as your lecture notes. You may prefer a more informal, participatory approach, using handouts and referring to the detailed material to guide the discussion.

- **Have fun.** The issue is serious, but that doesn't mean you can't laugh. Leave room in your workshop for a sense of humour — your own and others!

A Glossary of Cancer Terms

Adjuvant Chemotherapy — one or more anti-cancer drugs used in combination with surgery or radiation therapy as a part of the treatment of cancer. Adjuvant usually means "in addition to" initial treatment.

Antiemetic — a medication to prevent or reduce nausea and vomiting, a fairly common side effect of chemotherapy and radiation therapy.

Benign — a swelling or growth that is not cancerous, does not spread from one part of the body to another, and usually is not life-threatening.

Biopsy — a procedure where a piece of tissue or fluid (a group of cells) is taken from a person's body and examined with a microscope to see if the cells are normal or not. A biopsy is a common way of determining if a person has cancer and, if so, what type it is.

Blood Cells — cells that make up the blood. They are produced in bone marrow and consist of (1) red blood cells (which bring oxygen to tissues and take carbon dioxide from them), (2) white blood cells (which fight invading germs, infections, and allergy-causing agents), and (3) platelets (which are responsible for clotting).

Blood Counts — the number values assigned to the major types of blood cells. Blood counts indicate the amount of blood cells circulating in your bloodstream.

Bone Marrow — the soft, spongy centre of the bone. Bone marrow can be thought of as a "factory" that produces blood.

Bone Scan — an image taken after the injection of a tracer radioactive substance into the blood which carries it to the bones. Cancerous areas in the bone where cells are dividing rapidly will pick up more of the radioactive substance, resulting in "hot spots" on the developed film image.

Cancer — a general term for more than 100 diseases characterized by abnormal and uncontrolled growth of cells. The resulting mass, or tumour, can invade and destroy surrounding normal tissues.

Chemotherapy — treatment with anti-cancer drugs.

CT/CAT Scan — a diagnostic procedure combining an x-ray with a computer to produce highly detailed cross-sectional pictures of the body.

Edema — the swelling or accumulation of fluid in a part of the body.

Immunotherapy — use of the immune system or the products of the immune system to control, damage or destroy malignant cells.

In Situ/Noninvasive Cancer — earliest stage of cancer, confined to the original site.

Invasive Cancer — a stage of cancer in which cancer cells have spread to healthy tissue adjacent to the tumour.

Lump — a thickness under the skin that can be felt by the fingers, either by the person who has it or by a doctor. A lump can be a sign of cancer, but most lumps are not cancerous.

Lumpectomy — surgical removal of the cancerous portion of the breast and a small amount of surrounding tissue. Four to six weeks of radiation often follow.

Lymph Node — one of many small, bean-shaped organs of the immune system linked by lymphatic vessels throughout the body. They make and store many different immune cells that fight infections.

Lymphatic System — the network of parts of the body that make and store cells that fight infection, and of vessels that carry lymphatic fluid through the body to bathe its tissues.

Lymphedema — an accumulation of fluid that may collect in the arms or legs when lymph vessels of lymph nodes are blocked or removed, which can result from treatment for cancer.

Lymphocytes — a type of white blood cell which are the most important cells in the immune system.

Malignant Tumour — a tumour that is cancerous.

Mammogram — an x-ray procedure used in the screening and diagnosis of breast cancer which can reveal a tumour in the breast long before it can be felt.

Mastectomy — surgical removal of the breast.

Metastasis — the spread of cancer cells from the original tumour through the bloodstream and lymphatic system to another part of the body. Metastasis also is the word used for a new tumour caused by this movement of cancer cells.

MRI — a technique used in the diagnosis and evaluation of disease and to monitor for the recurrence of cancer. MRI produces internal pictures of the body using powerful electromagnets, radio frequency waves, and a computer.

Neoplasm — an abnormal growth or tumour.

Oncologist — a doctor specializing in diagnosis and treatment of cancer. She or he may prescribe and administer chemotherapy, radiation therapy, or refer a patient to a surgeon.

Oncology — the study and treatment of cancer.

Palliative Treatment — the use of medical remedies to relieve pain, symptoms, and/or prevent further complications rather than to cure.

Platelets — blood cells that help the blood to clot.

Primary Cancer — the original site where cancer occurs.

Prognosis — a prediction of what might happen in a specific case of disease.

Protocol — the outline or plan for a treatment program.

Radiation Therapy — x-ray treatment that damages or kills cells.

Recurrence — the return of cancer cells and signs of cancer after remission.

Red Blood Cells — the blood cells that carry oxygen from the lungs throughout the body.

Regression — growing smaller or disappearing. Used to describe shrinkage or disappearance of a cancer.

Relapse — same as recurrence.

Remission — the disappearance of cancer symptoms; absence of evidence of cancer's existence. When this happens to a person, she or he is said to be "in remission."

Tissue — a group of cells.

Tumour — cells that group together and keep growing and crowding out normal cells. A tumour can be benign (i.e., not cancer) or malignant (cancer).

Tumour Marker — a chemical substance found in increased amounts in the body fluids of some cancer patients. The presence of a tumour marker in the blood for a specific cancer can be an indication that cancer is present in the body. Tumour markers can be used as part of the diagnostic process but generally cannot provide a definitive diagnosis. Tumour markers are also used to monitor the progress of treatment as well as possible recurrence of cancer after treatment.

White Blood Cells — a general term for a variety of cells in the blood that play a major role in the body's immune system. A low level of white blood cells can make a person susceptible to infections.