



Family Caregivers of British Columbia

Tips on Being a Health Care Consumer

(Adapted from "Working with Health Care Professionals")

The concept of the patient or family caregiver as a "health care consumer" is quite a modern one. Many people do not think in terms of choice in selecting a physician (health care treatment) or of questioning the treatment. Most people are not aware that community health services and supports are available to them also. This concept, with the added complication of having to make decisions for a person who may be cognitively impaired, or frail or elderly makes the decision making process even more important for the family caregiver.

When a person is caring for an individual with cognitive impairment, she/he must rely upon the health care professionals to diagnose, and then explain the diagnosis as well as other acute and chronic problems of the care receiver, and what the options are for home services and support. Health care professionals, hopefully, in turn will rely upon the family caregiver to observe and report on the care receiver's condition. Below are some tips for family caregivers to consider when dealing with "the system".

Assume your right to quality care:

- Find a physician who agrees with your philosophy and will work with you.
- Find a physician who understands and respects your role as a family caregiver.

Before a visit to the physician the caregiver must:

- Prepare a list of questions (you can never ask too many).
- Ask for a separate appointment to describe the situation or that the appointment include extra time to allow the physician to ask and answer questions.

If your loved one is receiving home health services or is living in a care facility:

- Assume their right to access services
- Assume their right to quality service and care
- Find out if there is a process in place to provide feedback on the service and to resolve disputes.
- Understand what it means to be an effective advocate (if applicable) on behalf of the care receiver.

At the time of a physician's visit:

- Take a notebook and include your list of questions and a list of the patient's medication.
- Communicate clearly. Consult your notes as you answer the physician's questions. Ask the physician questions.
- Clarify any of the physician's instructions. I.e. list the care directions then repeat back to the physician what you think she/he means, discuss the pros/cons of any treatment and/or drugs.

For the next visit:

- What are the follow-up plans?
- What further information will the physician need?

Understand the overall course of the disease, and if applicable, the aging process:

- Have realistic expectations about the course of the disease, and/or of aging and how it may impact the illness
- What help will you need to continue effectively as family caregivers?

When a case manager from the Long Term Care programs makes and initial home visit with the care receiver:

- It is best that the family caregiver be present.
- Make sure you are clear about all the services available for the care receiver.
- Ask what kind of support is available to you as the family caregiver.
- Develop a rapport with the case manager and inquire about follow-up.

If you are not satisfied with the physician:

- Look for ways to resolve problems.
- Don't use a cannon where a peashooter will do.
- List your concerns and assume your right for information.
- Get a second opinion or choose another physician.

For further information, contact the Family Caregivers of BC office at 250-384-0408.

Communicating With Your Doctor

Non-Assertive Communication is behaviour, which allows and even encourages other people to treat you, your thoughts and feelings in whatever way they want, without your challenging it. It involves behaviour, which is shy and over-apologetic, as though denying any personal rights or preferences.

CHARACTERISTICS: It avoids confrontation, avoids problems (by simply not addressing them), establishes a pattern of others taking advantage of you, builds anger and resentment, build's high hopes (which usually remain as fantasies and are rarely realized).

RESULTS: It wastes time, both that of the patient and physician by "beating around the bush". It causes frustration because needs are not being met and messages are not being conveyed. It may be "hazardous to your health". Inappropriate treatment may result from misunderstanding or incomplete information.

Assertive Communication is behaviour in which a person stands up for personal rights and expresses thoughts, feelings and beliefs in direct, honest and appropriate ways which respect the rights of other people.

CHARACTERISTICS: Attacks problems not people. It establishes a pattern of respect for future dealings; it deals with anger and addresses requests.

RESULTS: You take responsibility for your own statements. Statements become cues and let the doctor know where your understanding is, allowing for objective feedback. Improved care results, as wants and needs are better met.

Skills for Assertive Communication

- Prepare:** Think about what it is you want to say or ask.
Prepare an “ask the doctor” list
Organize important things first
Say it simply. Rehearse.
- Deliver:** Say it simply
Your tone of voice, eye contact and posture should all indicate that you are sincere, honest and determined about your questions and/or comments.
- Persist:** If you are not sure that you are being understood, say it again until you get a satisfactory response and say it with reflecting phrases.

Reflecting phrases **allow you to put the message in your own words**. They let the doctor know exactly how you understand the message and they ensure that you understand what is being said. **Examples of Reflecting Phrases:** “You mean that...” “Are you saying that”...“In other words”...“Does that mean...”

Overcoming Difficulties in Communication

- Partnership:** The doctor is often viewed as the trusted, unquestioned authority, but it is important to realize also that you are always the expert observer concerning your own body and your own family.
- Words:** Technical words may be used accidentally or may be used deliberately. If you don't know the meaning of a word, or aren't sure, ask.
- Time:** Be aware of the time given for your appointment and use it wisely. A hurried visit by your doctor may leave you feeling at loose ends.

Address the issues directly: “I need 15 minutes to discuss some questions I have”.
- Hot Topics:** Those which are very uncomfortable to discuss, such as feelings, cost or a second opinion.
It may be helpful to remember that a discussion may be a sharing of concerns rather than only a question and answer session.
- Set an agenda:** You will save time.
You won't forget the key points.
You won't be distracted.
You'll feel better about the accomplishment of your task the first time.
Your mind will be open to what comes next, not being nagged by trying to remember.