

What is an Advocate?

WHAT IS ADVOCACY?

Advocacy simply means **speaking up**—for yourself or for somebody else.

People with dementia often are unable to make their needs and wishes known, or others may not listen to them. So somebody else has to speak to doctors, caregivers, health-care providers and other professionals. Usually, the advocate is a spouse or other family member. Sometimes it's a friend or a volunteer from the community.

The advocate's main job is to **communicate**, and there can be a lot of communicating to do. One of the first things many families find out is that different government agencies, programs, and services do not communicate well with each other. It is often assumed that the family doctor will coordinate a patient's medical and health-care services, but if someone doesn't have a family doctor, or the doctor doesn't do this (and it can be a big job), patients can fall between the cracks.

Example Story:

Norah, 85, who was in the early stages of dementia, fell in her apartment and broke her hip. It was a couple of days before her nephew, Mark, found out that she was in hospital and went to visit. She was very confused and upset when he arrived, but calmed right down when she saw him. He had to shout loudly because she had lost her hearing aid. A nurse came in and remarked that she was surprised at how differently Norah behaved with her nephew, and how much better she seemed. The staff hadn't realized that she was very deaf. They thought that she was uncooperative due to her dementia. Mark helped them to see that she simply couldn't hear what anyone was saying.

Norah wanted to go home and Mark thought she could move back home if she had home care support, but the hospital social worker was planning to transfer her to a care facility.

Mark was eventually able to help Norah move back home, but it took determined effort. Norah's extremely busy doctor, Dr. Smith, had consulted with the surgeon who operated on her hip, but otherwise was not involved with planning for Norah's care.

To find out all the details of the situation, get appropriate care for Norah in hospital and plan for her discharge, Mark had to talk to her doctor, her surgeon, the hospital's nursing staff (both day staff and night/weekend staff), the hospital social worker, Home and Community Care (for home care support) and Meals on Wheels.

TIPS TO REMEMBER

Here are some of the most important things to remember if you are acting as an advocate for someone:

- You are representing another person—their beliefs, values and wishes are critical. There can be a very big difference between doing what you think is best for somebody else, and doing what

This is one of 10 **Advocacy Fact Sheets** prepared by the Alzheimer Society of B.C. These fact sheets offer tips on advocating for a family member with dementia. We suggest you read through the series, and then use the resources provided to find more specific information.

they want. You have to put your own beliefs aside when you act on behalf of somebody else.

In the example, Mark knew that Norah was passionate about staying in her home and she had supportive neighbours and friends from church who would be willing to assist her. However, Mark also realized that he could make it easier for the health-care system, and even himself, if he just agreed with what the hospital social worker recommended. But Mark knew Norah's wishes and he felt responsible to ensure her wishes were known and respected as much as possible.

- Let the other person speak for themselves as much as possible and make whatever decisions they can.
- Respect the other person's privacy.
- Get all the information you can before making decisions.
- Keep careful records. (See Advocacy Fact Sheet 2: *Getting Organized*.)

PERSONAL PLANNING

If a person with dementia has done advance planning and named an official representative (via a legal document such as an enduring power of attorney or an advance directive), advocating for them is less complicated. Often, however, there are no legal documents in place.

In the story about Mark and Norah, there were no legal documents, but Mark was Norah's closest relative. If a person cannot make their own health care decisions, the law recognizes their nearest relative as their representative for health-care consent. (This does not apply to financial or legal matters such as banking.)

RESOURCES FOR ADVOCATES

Alzheimer Society of B.C. (ASBC)

www.alzheimerbc.org

1-800-936-6033 or 604-681-8651

The Alzheimer Society provides information, education, workshops, and support groups for caregivers and people with early stage dementia. One good starting point is "Ready, Set, Plan," which is available from the ASBC website.

Your Health Authority - Look in the blue pages of your phone book for your Health Authority (See Fact Sheets 4 and 5, *Accessing Services*) or visit the Alzheimer Society of B.C. website, and click on "In My Community".

Organizations in Your Community such as seniors centres, community centres, and Meals on Wheels.

Friends, Family, Neighbours - If friends and neighbours can do a few tasks, like reminding your family member about garbage pick-up, or fetching something from the store, it's a big help.

Tyze Family Networks has started a program to support adults with chronic conditions (including dementia) living in the community. www.tyze.com

BC Seniors Guide - This guide lists programs and services in B.C. It is available in English, French, Chinese and Punjabi from www.seniorsbc.ca or 1-800-663-7867.

Legal Tools for Personal Planning - Visit www.trustee.bc.ca and look for the publication: "It's Your Choice: Personal Planning Tools".

Nidus Personal Planning Resource Centre has a fact sheet on Health Care Consent.

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