

Factsheet 1: What is an Advocate?

What is Advocacy?

Advocacy is speaking up in support of an idea or an action. The person who speaks out is known as an advocate. Usually the person who speaks out is trying to protect a person or insure that the person's rights are maintained.

There are many types of advocacy. Systemic advocacy brings many people together to realize change that will assist a broad group of people. Individual advocacy takes place when one person advocates for another. Self-advocacy is when a person works to achieve a change for themselves.

People with dementia often become unable to express their needs or make their wishes known. Earlier in the progression of their dementia they may find it helpful for a family member or friend to assist them in presenting their situation to health-care providers, legal or financial counsellors or other family members. When the person is experiencing more advanced dementia, they will benefit from having a trusted person who knows them well and who will represent their wishes and values. The one who speaks up for the person with dementia will take on the role of being an individual advocate.

Caregivers of people with dementia may find they need to speak out on their own behalf. Self-advocacy skills are important if the caregiver needs help from other family members, assistance from community care providers or in representing their needs to their personal health care support team. Sometimes caregivers find

that it is valuable for another person to assist them in presenting their case.

Being an advocate is a skill that involves problem solving, lots of communication and often persistence. Using these abilities will bring results.

Harold is the husband and caregiver of his wife of 50 years. Susan was diagnosed with Alzheimer's disease 4 years ago. Harold has been struggling to care for her at home. They have two adult children who live in the city and although they do what they can to help, they are busy with their own lives. At Harold's last doctor's appointment, he was told to get more help or risk his own health. He was given the number for home care and told to call. He finally called and a meeting was set. After meeting with Harold and Susan, home care said that Harold is only eligible for 3 hours of respite a week. Harold is overwhelmed – 3 hours isn't even close to what he needs. He wonders what to do. How will he get home care to understand how tired he is and provide him with more help? As Harold thinks about his problem he wonders if one of his children might be able to help him approach home care to present his case again. Should he ask his son who is his Power of Attorney for assistance or is this something that his daughter in law who has offered to attend appointments could help with?

Common Advocacy Roles

Some advocacy roles require that legal documents be prepared. These include:

Power of Attorney

A power of attorney is a legal document in which one person (the donor) gives another person (called the attorney) the authority to manage their legal and financial affairs. A power of attorney does not include responsibility for personal decisions such as where a person will live. The Power of Attorney Guidebook is available at http://www.gov.mb.ca/publictrustee/pdf/power_of_attorney_guidebook.pdf

Committee

A committee is a person appointed by The Court of Queen's Bench or under the Mental Health Act to make decisions for a person found to be mentally incapable of managing their financial affairs. A committee may be given authority over only the financial affairs of a person or over both financial and personal affairs as necessary. Committeeship - A Guidebook for People Appointed as Committees is available at www.gov.mb.ca/publictrustee/pdf/committeeship_guidebook.pdf

Some advocacy roles do not require that documents be prepared by a lawyer. These include:

Health Care Proxy

A person may choose to appoint a Health Care Proxy when they complete their health care directive.

A Health Care Proxy makes health care decisions for a person who is unable to do so. Decisions are based on the instructions in the person's health care directive and the wishes the person has discussed with their proxy. Wishes expressed in a directive are binding on the person's friends, relatives and health care professionals. See <http://www.gov.mb.ca/health/livingwill.html> for more information.

Patient Advocate

A patient advocate is someone you choose to support you and act on your behalf. He or she will talk with members of your health care team such as your family, doctor or nurse but is not empowered to make health care decisions on your behalf. See <http://www.mbips.ca/pf-advocating-for-yourself---others.html> for more information.

Tips to Remember

There are some important things to remember as you act as an advocate for someone else:

- Make every effort to include the person in the process. Talk to them about what they would like to have happen.
- If the person is not able to tell you about their preferences, think about the things the person valued and their long held beliefs. Did they like to take risks? Were they someone who enjoyed being with people? Were there causes they were passionate about? From these and other questions you will learn how the person might approach the current situation. The answers will help you make decisions that are reflect what the person would want. Remember you have to put your own beliefs aside when advocating for someone else.
- Become knowledgeable about the issue. Consider the results that you think would best suit the person you are representing.
- Respect the person's privacy. You are not free to share the decisions you are making with others.
- Plan the advocacy actions you want to take and keep records of the progress you are making.

Harold called his son, Ben, and daughter in law, Moira, in tears; he felt like the system had let him down. As they talked Moira sensed that Harold had not told home care the complete story of the impact caregiving was having on his health. She offered to call home care on Harold and Susan's behalf to provide more information and to request a second meeting. Moira said she would attend the next meeting with Harold to take notes if he wished. She told him she was willing to be there to support him as a Patient Advocate, though all decisions would be his.

Resources for Advocates

Alzheimer Society of Manitoba

The Alzheimer Society provides information, support and education to people with dementia, their families and their advocates. The checklist, **Future Planning: Are You Ready?** is a helpful tool for advocates. www.alzheimer.mb.ca
Call 204-943-6622 or 1-800-378-6699 or the regional office nearest you.

The Seniors and Healthy Aging Secretariat

The Secretariat works with all departments to create an environment within Manitoba that promotes health, independence and well-being of all older Manitobans. Seniors Information Line:
In Winnipeg: 204-945-6565
Toll-free: 1-800-665-6565

Manitoba Seniors Guide

The guide lists services available in communities across Manitoba. It is available in English and French and is online at www.gov.mb.ca/shas

The Public Guardian and Trustee of Manitoba

This Special Operating Agency manages and protects the affairs of Manitobans who are unable to do so themselves and have no one else willing or able to act. 204-945-2700

Manitoba Institute for Patient Safety (MIPS)

MIPS promotes patient safety for patients, families, the public and healthcare providers. Visit www.mbips.ca

Manitoba Tax Assistance Office

The office administers Manitoba's tax programs including the Primary Caregiver Tax Credit.
In Winnipeg: 204-948-2115
Toll-free: 1-800-782-0771
Email: TAO@gov.mb.ca

Manitoba Pharmacare Program

Pharmacare is a drug benefit program for eligible Manitobans, regardless of disease or age, whose income is seriously affected by high prescription drug costs. In Winnipeg: 204-786-7141
Toll-free: 1-800-297-8099 or visit <https://www.gov.mb.ca/health/pharmacare/>

Medication Information Line for Everyone (MILE)

Do you have questions about your medications?
In Winnipeg: 204-474-6493
Toll-free: 1-800-432-1960 ext. 6493
Email: mile_resource@umanitoba.ca

Service Canada

For information about Service Canada programs such as Canada Pension Plan, Old Age Security Pension and Guaranteed Income Supplement visit <http://www.servicecanada.gc.ca/eng/audiences/seniors/index.shtml>

Veterans Affairs Canada

For information about services for Canada's veterans, call Toll-free: 1-866-522-2122 or visit information@vac-acc.gc.ca

Your Regional Health Authority

Check your local phone book for the services in your community.

Other Community Organizations

Seniors Resource Councils, Seniors Centres, Meals on Wheels, churches and other local services can assist.

For support in preparing for an advocacy action, contact the Alzheimer Society of Manitoba at 204-943-6622 or 1-800-378-6699 or the regional office nearest you. For other factsheets in this series visit www.alzheimer.mb.ca

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