



Advocacy Skills for Caregivers

The Alzheimer Society of Manitoba thanks
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Advocacy Skills for Family Caregivers Project

Alzheimer Society
MANITOBA
Dementia Care & Brain Health



Advocacy Skills for Caregivers

What is Advocacy?

- Advocacy is speaking up in support of an idea or an action. The person who speaks up is known as an advocate.

ADVOCACY

"Never be afraid to raise your voice for honesty and truth and compassion..."
-William Faulkner

Kinds of Advocacy

- Systemic Advocacy
 - The effort of many people leads to change for many people
- Individual Advocacy
 - The effort of one person leads to change for another person(s)
- Self Advocacy
 - A person works to achieve change for themselves

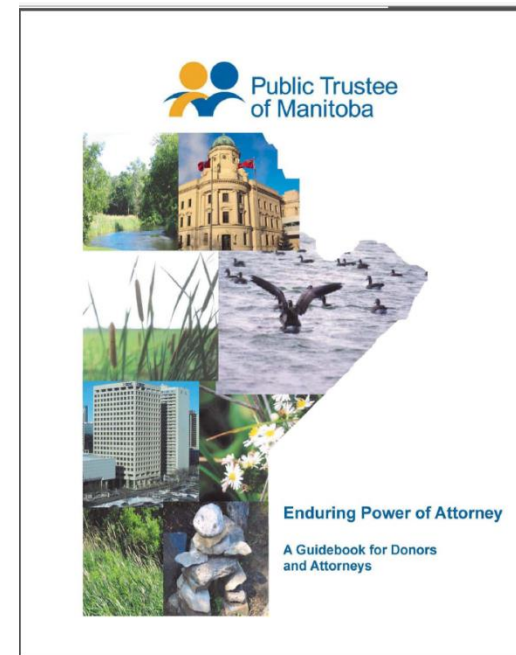
“I learned a long time ago that wisest thing I can do is to be on my own side, be an advocate for myself and others like me.”

Maya Angelou




Common Advocacy Roles

- Legally drawn or appointed advocacy roles:
 - Power of Attorney
 - has authority over legal and financial affairs
 - Committee
 - may have authority over financial matters only or financial and personal affairs



Common Advocacy Roles

- Advocacy roles that do not require a lawyer to prepare legal documents:
 - Health Care Proxy
 - makes health care decisions for a person who is unable to do so
 - Patient Advocate
 - supports a person in making health care decisions

Health Care Directive Manitoba 
Please type or print legibly

This is the Health Care Directive of:
Name _____
Address _____ City _____
Province _____ Postal Code _____ Telephone () _____

Part 1 - Designation of a Health Care Proxy
You may name one or more persons who will have the power to make decisions about your medical treatments when you lack the ability to make those decisions yourself. If you do not wish to name a proxy, you may skip this part.
I hereby designate the following person(s) as my Health Care Proxy:
Proxy 1
Name _____
Address _____
City _____
Province _____ Postal Code _____
Telephone () _____
Proxy 2
Name _____
Address _____
City _____
Province _____ Postal Code _____
Telephone () _____
(Check one choice only.) For an explanation of "consecutively" and "jointly" please see the reverse side of this form.
If I have named more than one proxy, I wish them to act: consecutively OR jointly
My Health Care Proxy may make medical decisions on my behalf when I lack the capacity to do so for myself (check one choice only.)
 With no restrictions
 With restrictions as follows:

Part 2 - Treatment Instructions
In this part, you may set out your instructions concerning medical treatments that you do or do not wish to receive and the circumstances in which you do or do not wish to receive that treatment. **REMEMBER** - your instructions can only be carried out if they are set out clearly and precisely. If you do not wish to provide any treatment instructions, you may skip this part.

Part 3 - Signature and Date
You must sign and date this Health Care Directive. No witness is required.
Signature _____
Date _____
If you are unable to sign yourself, a substitute may sign on your behalf. The substitute must sign in your presence and in the presence of a witness. The proxy or the proxy's spouse cannot be the substitute or witness.
Name of substitute: _____
Address _____
Signature _____
Date _____
Name of witness: _____
Address _____
Signature _____
Date _____

MS 1008 (2/04) 1002

First Steps for Advocates

- When ever possible, include the person in decision making
 - Break decision making into manageable pieces
 - Plan discussions for when the person is at their best
 - Ask: “What would you like to have happen?”



First Steps for Advocates



- If the person cannot be part of decision making ask yourself and others questions such as:
 - Was the person a risk taker?
 - Did the person like being with people?
 - What was the person passionate about?
 - What activities did the person enjoy?

First Steps for Advocates

- Gain understanding of the person's situation:
 - Health and medical needs
 - Social and spiritual wishes
 - Legal and financial matters
 - Housing needs



First Steps for Advocates

- Gather important information
 - Legal documents
 - Banking and investment information
 - Insurance policies
 - Social insurance number
 - Veteran's Affairs number
 - Health care numbers
 - Physician's name
 - Medication list



First Steps for Advocates

- Learn about the services the person is using and will need in the future
 - What services does the agency offer?
 - How is the service accessed?
 - Is the service publically funded?
Are there user fees?
 - Who is your contact?



Tips for Successful Advocacy

- Make an appointment
- Do your homework
- Prepare for the meeting
- Be polite



Tips for Successful Advocacy

- Take your concerns to the right person

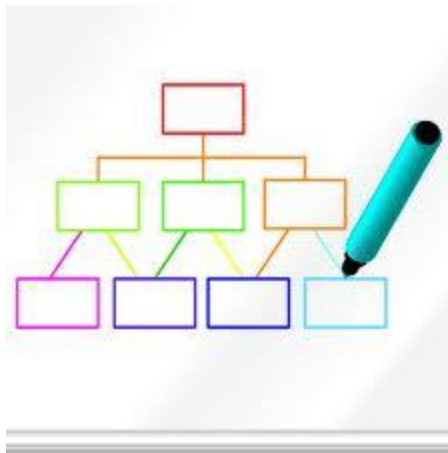
- Choose the right decision maker

Examples:

- For increased home care respite service?
- For concerns about apartment rent payment?
- For medication review?
- For choosing a wheel chair?
- For changes in personal care home rates?
- For a personal care home resident's care plan?

Tips for Successful Advocacy

- Take your concerns to the right person
 - ❑ Choose the right decision maker
 - ❑ Follow the chain of command



Tips for Successful Advocacy

- Be clear in your request for action
- Listen carefully
- Avoid confrontation
- Follow-up
- Say thank you



Advocacy Tools

- Use the advocacy tool that fits you and the situation best
 - Face to Face meetings
 - Phone calls
 - Email
 - Letter

Subject Line: Alma Delorme's Meals on Wheels Service

Attention: Joan Nelson, Meals on Wheels Coordinator

My mother, Alma Delorme, has recently been diagnosed with high blood pressure. The dietitian has recommended that my mother be placed on a low sodium diet. Please update your records about my mother's dietary needs and begin providing her with meals that meet this request.

If you need further information about my mother's recommended diet, please contact her dietitian, Sandra Green at (204) 456-1234.

Please confirm that you have received my message and let me know the date on which delivery of low sodium meals will begin.

My mother greatly appreciates her Meals on Wheels and enjoys meeting the volunteers who deliver to her door each day.

Sincerely,
Catherine MacKay
Alma Delorme's daughter
(204) 345-6789

A question often asked:

“How do I proceed when my first efforts are not achieving the results I was hoping for?”



Negotiating to Win



- Ask the reason they have said “no” to a request
- Ask how they suggest you meet your care goal – request alternative solutions
- If the alternative is acceptable – work together to create an action plan

Negotiating to Win

- If the alternative is not acceptable – suggest your ideas and ask for feedback
- Be prepared to discuss the pros and cons openly
- Do not accept something that you believe is a “worst case scenario”



Negotiating to Win



- If either party is becoming angry, suggest you take time to consider other solutions
- Request another meeting
- Seek an outside person that can mediate your discussion or who can present on your behalf
- Keep records of discussions and communications

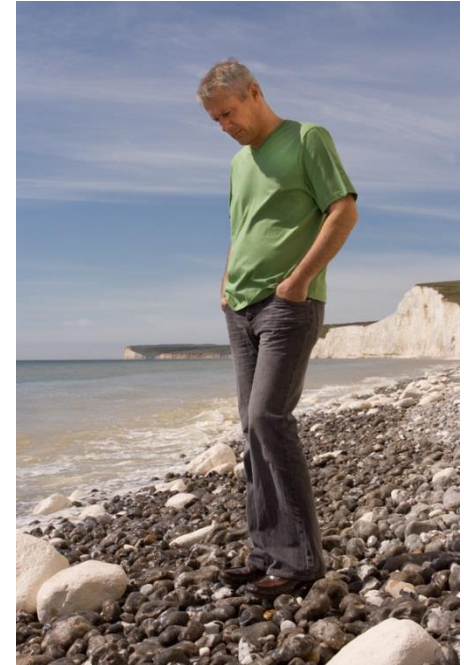
*“When someone beats
a rug, the blows are not
against the rug, but
against the dust in it.”*

Rumi



Self Care for Advocates

- Place value on self care
- Create time for self care
- Choose self care activities that you value
- Engage in self care activities
 - Quality sleep, exercise, healthy eating, personal interests, times of reflection



Self Care for Advocates

- Identify sources of support
 - Family and friends
 - Alzheimer Society
 - Employee assistance programs
 - Counselors
 - Spiritual advisors
 - Support groups
- Let others help you



advocacy

to change “what is”
into “what should be”

The Alzheimer Society of Manitoba



alzheimer.mb.ca
204-943-6622 or
1-800-378-6699