

Factsheet 2: Getting Organized

Advocating for yourself or someone else may be a new experience for you. Taking time to organize yourself and the information you will need when speaking to health and community service providers can make your advocacy tasks easier.

Plan Early

When a person receives a diagnosis of dementia they and those close to them are wise to begin discussing their plans for the future. The diagnosis does not mean that the person with dementia will immediately be unable to care for their personal business, but it is a good time to review the person's legal and financial affairs and their preferences for the future. Being sure that substitute decision makers are named is essential. Getting assistance from family members and trusted professionals will help make planning for the future easier.

Collect Important Information

Have copies of Power of Attorney and Health Care Directives available. Remember that financial institutions and other service providers will want to see original documents and make their own copies as needed. You may even choose to provide businesses that you deal with a copy of the Power of Attorney document in advance of the first time you need to do work on your family member or friend's behalf. Prepare a list of important information such as health care numbers, the person's Social Insurance Number and Veteran's Affairs number if applicable. Listing the person's doctor's contact information and medications is also important.

Prepare Your Story

Because you will need to explain why you are advocating for someone to a number of people, consider preparing a short story that will tell others about the person you are supporting. Include information about the person's age, family members, past occupations, current living situation and health in the story. You may choose to write out the story as well as being prepared to tell it. The story will help medical staff and community service agencies better understand the needs of the person you are representing.

Your uncle, John Funk, age 74, came to Canada in the mid-1970's at age 35 having lived in Mexico from childhood. He speaks both English and low German. He farmed in Southern Manitoba growing sugar beets and later potatoes. His wife Mary predeceased him. They had no children. John has developed dementia and is unsafe to live alone. You are a nephew of Mary's who John chose to care for his legal, financial and health matters when he developed mobility issues related to his arthritis 5 years ago.

Educate Yourself

Become informed about the medical and social needs of the person you are assisting. Learn about the care and treatment options available. Becoming familiar with medical terms that may be used will help you understand the things health care providers discuss. If you find them using words that you do not understand, do not hesitate to ask them for an explanation. Also find out about the policies that may govern the services your family member or friend uses or that you wish to engage for them. Being informed will help you to ask better questions.

PROVINCIAL - WINNIPEG 10-120 DONALD ST R3C 4G2 204-943-6622 alzmb@alzheimer.mb.ca

INTERLAKE / EASTERN - BEAUSEJOUR
UNIT B, 31 1ST STREET ROE OCO
TEL 204-268-4752 FAX 204-268-4799
EMAIL: alzne@alzheimer.mb.ca

NORTH CENTRAL - PORTAGE LA PRAIRIE
108 B SASKATCHEWAN AVE E. R1N 0L1
TEL 204-239-4898 FAX 204-239-0902
EMAIL: alznc@alzheimer.mb.ca

PARKLAND - DAUPHIN
214 MAIN STREET NORTH R7N 1C4
TEL 204-638-4483 FAX 204-638-4493
EMAIL: alzprk@alzheimer.mb.ca

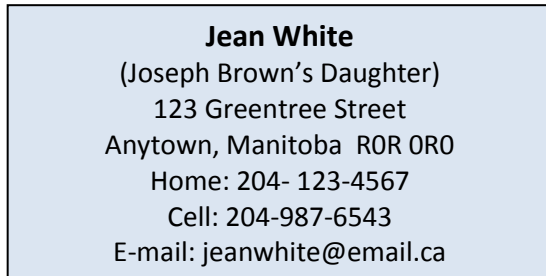
SOUTH CENTRAL - WINKLER
BOX 119, 204 MAIN STREET R6W 4A4
TEL 204-325-5634 FAX 204-325-6496
EMAIL: alzsc@alzheimer.mb.ca

WESTMAN - BRANDON
UNIT 4B-457 9TH STREET R7A 1K2
TEL 204-729-8320 FAX 204-726-1082
EMAIL: alzwm@alzheimer.mb.ca

Make a Business Card

As you will be asked many times for your contact information, a business card will make it easier. These can be printed at home or handwritten and photocopied.

Example:



Learn about the Decision Makers

Each place you will advocate on behalf of your family member or friend will have a different group of decision makers. Whenever possible, learn who to approach for each decision. If you are seeking additional home care services, the person's home care Case Coordinator will be the person to contact. If you are concerned about a housing matter, the building manager will be an important person to call. When seeking assistance in caring for someone living in a long term care home, you may need to talk to different people about each issue. The following chart may help you to direct your questions:

When seeking help about	Person to contact
Medication reviews	Physician or Pharmacist
The person's care plan	Nurse
Helping the person to choose their daily clothing	Health Care Aide
Activities the person would enjoy	Recreation staff
Personal Care Home rates	Social Worker
Television services or use of electrical equipment	Maintenance Department
Choosing a wheel chair	Occupational Therapist
Special dietary needs	Dietician
An opportunity for someone to take part in a religious observance	Spiritual Care

If the personal care home does not have all the staff members suggested at their site, ask the unit nurse who can direct you to the right person for the needed information.

Keep Records

Every time you make a phone call or have a meeting with someone record the details in a paper or electronic file. Important information to note includes:

- Who you talked to (name, job title and phone number)
- When you spoke (date and time)
- What you discussed
- Actions each of you are going to take
- When you will talk again to check progress on the planned actions

Also keep copies of letters or emails that you write in follow-up to discussions.

Take Care of Yourself

Being an advocate takes time and energy. Looking after yourself is very important. Remember your health and wellbeing is important too. If you know you are going to meet with someone for an important meeting, plan to get a good night's rest. If the upcoming meeting is causing you to be stressed, consider seeking out a friend to review your plan of action or invite them to attend the meeting with you to take notes.

To learn more about getting organized 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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