

## Factsheet 4: Building Agreement for Action

Imagine this situation: You and your siblings all care very much about your Dad (Mr. Lozinsky). He is widowed and living alone in the house where you grew up and shared wonderful family times. He is lonely and greatly misses your mother, who died last year. You had all known he was having some problems with memory but since your mother's death you have become aware of how much your Mom helped him with daily things from banking to personal hygiene. Your brother thinks that your Dad needs to move to assisted living and you and your sister believe that your father could stay in the house longer if you each "just did more" for him. Your family is going to meet to try to decide what to do.

Building agreement can be challenging when each of the people involved believe that they know what is best for the person they care about. It is important to build agreement between family caregivers so that the messages you give to health care professionals and community service providers can be united.

### The Place to Start

People with dementia can continue to contribute to decisions about their lives with support from family and friends. When given options and asked what they would like to do, the person can often state their preference. If their answer is not clear, think about the non-verbal messages they are communicating as the matter is being discussed. If the person shows tension when the suggestions are presented, the options may not be well accepted. If the person is accepting of the idea, they will often appear relaxed and interested.

Remember that the role of an advocate or substitute decision maker is to focus on the needs and wishes of the person they care for and not their personal desires. When those with differing views step back and see the decision through the eyes of the person they care about, often the conflicts become less significant. Typically, everyone wants what is best – it is the idea of "best" that is the sticking point.

When working with others to decide a plan of action avoid taking a stand from which you feel you cannot deviate. Saying you will *never* let something happen can back you into a corner that you feel you must defend even if you later believe it is not the best plan of action. Be open to making decisions as the needs change and as new options become available.

Mr. Lozinsky and the family have decided that he will move to a smaller assisted living complex in a town nearby. The daughters will drop in a couple times each week as they both work in that community. The son who has taken over the family business and who is the Power of Attorney will look after setting up all the required banking and bill payments for the new living arrangement. As they are all concerned whether Dad is properly using the eye drops prescribed for his macular degeneration, they decide to meet with home care to see what services can be arranged.

### Working with Service Providers

Learn about the services that each provider has to offer. Housing providers may offer handbooks about the services that are available in their buildings. The Manitoba Home Care Program is described at <http://www.gov.mb.ca/health/homecare/> and the

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Personal Care Home Program at <http://www.manitoba.ca/health/pcs/index.html> To learn about an individual personal care home's unique features, visit the home and ask for their information brochures or website. Knowing what is offered makes it much easier to ask for services knowledgeably.

One of the best ways to build a positive working relationship with service providers is by showing appreciation for the work they are doing on behalf of the person for whom you care. A word of thanks will foster future cooperation.

The family arranged for daily medication checks by a home care attendant for their Dad. This is working well and he enjoys their brief, twice daily visits. The daughters are noting however that Dad's suite seems to be untidy and they wonder why the building housekeeper is not doing a better job of cleaning. One of the daughters happened to meet the housekeeper in the hall and asked about the cleaning service. The housekeeper maintained that it is hard to clean a room that is so "full of stuff." The daughter tried to explain that her father needed things "out" because he cannot see to find things in cupboards or drawers. The housekeeper seemed resistant to working with the situation and turned away. The daughter chose not to argue and thanked the woman for how she was prompting Dad to get to the evening meal in the dining room.

### **Following the Chain of Command**

Each site or service has a chain of command. Where possible, address concerns with the person directly involved before taking your concern to someone higher in the organization. If your efforts to find a solution do not work out, then approach the person's supervisor.

Mr. Lowzinky's son approached the assisted living supervisor with the family concern about the cleanliness of their father's suite. The son was firm in saying they wanted better attention from the housekeeper. After discussion with the supervisor, it was decided that the family will tidy things a bit the day before the housekeeper is to clean so her task will be easier. The supervisor decides he will ask the Alzheimer Society and the local Seniors Resource Coordinator to do education sessions for the housekeeping and food service staff so that they will better understand the needs of residents.

### **Negotiating to Win**

If you find that the solution you felt would be best is not possible, a compromise may be needed. Both the advocate and the service provider will need to look for new possibilities that will meet the need and yet maintain a high standard of care. Staying polite and respectful as you negotiate is important. Some steps that will help you to negotiate successfully include:

- Ask the person why they have said "no" to a request.
- Ask the person what advice they have that would help you to achieve your care goal.
- Ask the person what alternative solution they would recommend.
- If the alternative is acceptable, ask when the new plan can begin.
- If the alternative is not acceptable, present your ideas and ask the service provider to respond.
- Discuss the pros and cons of all ideas openly. What is the best alternative?
- Consider best and worst case scenarios. Do not accept a solution that is your worst case scenario.
- If you find yourself becoming angry while negotiating, suggest that each party take time to think about the problem and possible solutions. Ask for a second meeting.
- Research other potential solutions. Consider asking others about solutions they have used in similar situations.
- Keep a record of all telephone conversations, meetings and written communications related to the situation.

### **Seek Help**

If you find that you are not able to come to an agreement, consider seeking an outside person to assist you in the decision making process. The person may mediate the discussion, help you present your case or you might choose to have them speak on your behalf.

For support in building agreement when advocating, 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](http://www.alzheimer.mb.ca)

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