Alzheimer *Society*

Dementia Care & Brain Health

Factsheet 3: Successful Advocacy Meetings

You have just been to see your Mom at the personal care home and you notice that for the third week she is not as tidy as she had been previously. Today she seemed more tired and uninterested in your visit. You remember that last time you spoke to the Resident Care Manager she said something about having changed your Mom's medications. At the time you felt satisfied with the change but now you are wondering if there is more information that was not shared with you. That evening you call your brother who encourages you to have another conversation with the Resident Care Manager. You are wondering how to prepare for the discussion.

10 Tips for Successful Advocacy Meetings

- 1. Make an appointment in advance Time is at a premium for everyone, both for you and the person you wish to speak to. By making an appointment, you will know that the person you need to speak to is available. An appointment also gives you a time by which to be prepared. When making the appointment it is a good idea to give a brief description of the concern you will be discussing.
- 2. Do your homework Prepare for the meeting by learning all you can about the matter that is concerning you. You may choose to read about the medications the person you are concerned about is taking, the policies of the place providing care or learn about options that others have found successful when faced with similar situations. Also consider the outcomes you would like from the meeting.

- 3. Prepare for the meeting Make notes about the things you want to tell the doctor or health care staff. Having notes will ensure that you do not miss an important point in the conversation. List specific examples of your concerns and avoid using generalities such as "it always happens" or "they never do" as rarely are these kinds of sweeping statements true. Also make a list of the questions you want to ask. Consider asking another family member or a friend to attend the meeting with you to take notes. This will allow you to focus on the discussion and have a record of the details of the conversation.
- 4. Identify yourself Open the meeting by identifying yourself, the person on whose behalf you are advocating and your relationship to the person. If you are the Power of Attorney, Health Care Proxy, Committee or Patient Advocate, provide that information. This will help the person with whom you are meeting to understand your responsibility and authority to speak on behalf of the person you are representing.
- 5. Be polite expecting a good result Always approach discussion believing that the person you are speaking to wants things to go well too. Use a calm and respectful tone of voice. Open the meeting by mentioning positive things that you have noted then present your concerns. Do not threaten or begin telling the person how to do their job as this seldom works. Remember your conversation is a bridge to better care for the person you care about.

- 6. **Be clear in your discussion** Plainly state your concerns and stay "on message." Because you know the person for whom you are advocating best, you may be able to present a possible solution that those who are providing care may not have considered. Tell stories that will help them understand your family member or friend better and help them recognize why your request for improved care is so important. Do not assume a general conversation will create the action you desire, make a definite request for a specific change.
- 7. **Listen carefully** As the person you are meeting with begins to explain why they have followed a course of action and starts to give potential solutions, allow them to present without interruption asking questions of clarification as needed. You may find that a suitable solution comes forward quickly or you may need to be prepared to negotiate a result that will meet your approval.
- 8. Avoid confrontation Even when the discussion is not progressing as you had hoped it would, stay calm. Becoming confrontational can lead to a loss of respect on the part of both parties. As an advocate you are representing someone else for whom you want the best. Remember to speak and act as the person you are representing would want you to. When you need to take a strong stand, practice assertiveness not aggression or manipulation.
- 9. Follow-up At the end of the meeting summarize the things that you have talked about and the decisions that have been reached as you understand them. Your comments could also include the time by which changes discussed will be made. Confirm with the person that you met with that they have the same understanding. Consider asking when you might meet again to review progress on the agreed plan of action. After the meeting, review the notes you or the person who accompanied you took. You may choose to write a letter outlining the points on which you have agreed.

10. Say thank you – At the conclusion of your meeting, thank the person for meeting with you and hearing your viewpoint. A follow-up email or letter of thanks is appreciated by those with whom you have met.

You call the personal care home Resident Care Manager to arrange a meeting. After your meeting with the personal care home staff you call your brother again. You are able to report that you now understand that your mother has had an infection for which her physician had prescribed some medication that along with the effects of the infection had made your mom more tired and listless. The good news is that the nursing staff explains that the medication has done its job and that your Mom is now off the medication. Though happy about the report about your Mom, you reminded the personal care home Resident Care Manager that you had requested that you be notified of any of your mother's medication changes. You also tell your brother that you have discussed your Mom's hygiene with the care home staff and they have agreed that your Mom needs more help. Your Mom has been doing her own morning washing up and dressing on her own but the care home staff will now assist her by providing verbal cues and encouraging her to choose clean clothes each day. You also tell your brother that today's visit with mother went well. Your Mom was more alert and cheery.

For support in planning an advocacy meeting, 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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