

Working With Family And Friends

This pamphlet is part of a series on dementia-related diseases. This series was prepared by Kenneth Hepburn, Ph.D., Geriatric Research, Education and Clinical Center (GRECC) of the Department of Veterans Affairs Medical Center, Minneapolis, Minnesota.

"A chronic illness places a heavy burden on families. It may mean a lot of work or financial sacrifices. It may mean accepting the fact that someone you love will never be the same again. It may mean that responsibilities and relationships within the family will change." Mace and Rabins, *The 36-Hour Day*, Chapter 11

Family and friends play a major part in providing care to an impaired person. Too often one family member (or one part of the family) winds up providing most of the care. The primary caregiver for a person with Alzheimer's disease or a related disorder may need a lot of help. This help is not always easy to come by. If you are caring for a person with a dementing illness, try to involve your family and friends as early as you can. Try, also, to keep them involved throughout the illness. You have many good reasons to ask for their help. First of all, your health depends on getting regular respite from your hard and sometimes exhausting caregiving job. Secondly, spending time with other caregivers is good for the impaired person. It is good for the person to see other faces and to have a fresh, well rested caregiver. From time to time, you will need a substitute. If the person is only used to you, the substitution will be harder to make smoothly. Finally, getting family members involved helps them overcome their own ignorance or fear about the impaired person's illness. It can also help them cope better with any grief they feel over the loss of the person who used to be. There can be many reasons why other family members or friends aren't helping you. Some may not feel as responsible for the impaired person because they aren't as close to the person as you are. Some truly might not know that you need help that they could provide. They may not know how the disease works and what it does to a person. Some might not know how to offer their help. People are sometimes afraid that they might insult you if they implied that you needed help or that the impaired person was unable to function well anymore. Some may fear that helping would take too much time and would disturb their own lives too much. And still others might be frightened by the disease or by what they think the impaired person might do. You may have been trying to protect your family members from full knowledge of the impaired person's state. Perhaps you simply have not thought of

some of your family members as potential helpers. Children, for instance, can play a special role in caring for an impaired person and in helping you. There are likely quite a few things that the person you care for enjoys that your children would enjoy too. For instance, they can go on walks (unless the impaired person might wander away), or play simple board games or cards. Just talking and listening and keeping the person company are helpful too. It helps if you can tell people just what you need them to do. For instance, you may need someone to sit and watch TV with the person for a few hours. An open ended plea for help, on the other hand, might make the potential helper uneasy. The time involved might seem greater than it would need to be, and the helper might be afraid of an over-commitment. People will often be glad to help, when asked, even though they might not get around to offering on their own. As a primary caregiver who needs help, one of your first jobs will be to tell your family and friends that the patient has a disease that will steadily worsen. Make them aware that the impaired person will need a lot of care for a good deal of time to come. Extra communication, cooperation and planning will all be needed. A good way to make all this clear, to ask for help and to begin organizing the help you need is to call a family meeting. This meeting may include close friends.

Planning a family meeting

You will likely find that the need for a family meeting will come up several times in the course of the illness. Start this practice early. A family meeting offers you a major resource for sharing information and feelings. It is a way to make plans and to improve communication and cooperation between family members. Use the questions below to help you plan a good meeting. What should the meeting achieve? Think about what you want to have happen as a result of the meeting. Be as detailed as you can. Do specific decisions need to be made? Do you need any certain kind of help? Do you just want to share information? Who should attend? Think about which family members and which close friends you want to be at the meeting. While older children should, of course, be part of the family meeting, younger children need to be thought about in special ways. The illness of a parent or older family member and the process of caregiving can cause stress in children. They may, on the other hand, benefit from being a part of the planning. There may also be a special role for children in caring for the impaired person and in helping you. Think this over carefully, and perhaps discuss the subject with your doctor, clergy member or other counselor. Each case should be decided on its own merits. NOTE: If the idea seems practical in your case, you may want to include the impaired person in your meeting. Seeing and feeling the concern of the family can be helpful and reassuring to the person. When and where should the meeting be held and who will see to the details? The meeting doesn't have to be at your house. You don't have to do all the preparing for it either. Ask others to host the meeting, if you prefer, and to let other family members know of the date, time and place. Who should conduct the meeting? You need to be very clear about the purpose of the meeting, but there is no need for you to run the meeting. If you want to, fine. If you feel uneasy in this role, you may want to ask a family

member or friend to preside. People outside the family can also help. An outside professional like your clergy member, lawyer or social worker can help keep the meeting orderly and to the point. These people may also have useful information or good advice to share. NOTE: You should also assign one person (not the person who will run the meeting) to take notes. You may want to ask someone ahead of time, or you may just ask for a volunteer at the meeting. The note-taker should clearly list all major points discussed as well as any conclusions or agreements reached. (This record can be copied and sent to all who were at the meeting and to any absent family members.)

Planning what you want to discuss

To get the most out of your family meeting, you need to be very clear in your own mind about the purposes of the meeting and about what topics need to be discussed. You need to plan ahead what you want to say (or have others discuss) during the meeting. Once again, seek help in your planning. You may want to discuss the "agenda" with other family members or close friends to be sure you haven't overlooked anything. If you will not be conducting the meeting yourself, be sure to discuss the agenda with the person who will preside. Others can also help you gather any needed information ahead of time. Use the questions below to help you structure what you want to say or have others bring up during the meeting. What is the nature of the illness of the impaired person? What is the diagnosis, and what lies ahead? What care tasks may be involved and for how long? What is happening now? What is the impaired person's current state? What care is needed now? Who is providing that care now? What help is needed now and what will be needed in the future? What care tasks could helpers readily do? (For instance, is help needed with cleaning, yard work or repairs around the house? Would help with legal or money matters be of use?) How could the work be most fairly divided, both now and in the future? What are the costs of caring for the impaired person now, and what will they be in the future? What are the current expenses? How are these expenses being met now? How will these expenses change in the future? How can these future expenses be met? Who will share in meeting these costs?

After the meeting

Be sure the note-taker sends copies of the meeting notes to each who attended and to anyone else who might be involved but had to miss the meeting. The meeting notes can serve as a contract between you and your family and friends. Whoever sends out this "contract" should remind everyone that all need to uphold the terms of the contract. Anyone who can't do what's agreed to, should let the others know, so new plans can be made. Problems always arise, both in the impaired person's illness and in the larger family situation, making cooperation and flexibility among family members and friends very important. Keep the lines of communication open, and actively look for ways to help each other. Call family meetings regularly, if need be. A special word of caution concerns children. The impaired person's illness and the process of caregiving can cause special

stress in children. You need to be careful not to rely on them too much for help or for your own emotional support. Watch children closely for signs that they are having a hard time. If they begin to seem unusually troubled, you might want to find a counselor who could work with them, perhaps together with you. Be prepared to go outside your circle of family and friends for help. The caregiving task may grow to be more than you can handle, even working together. Resources do exist for providing respite care. (See the pamphlet in this series titled, "Respite Care: When You Need a Break") Be sure to explore these options. You should also find out what others have learned. Many others have faced the task of providing care for a dementia victim. You can meet them in support groups that may be found through local hospitals, churches and community organizations or through the Alzheimer's Disease and Related Disorders Association. For information on the location of local ADRDA chapters, you can call, toll free, 1-800-621-0379. Plan ahead to seek outside help when you need it.