

Working with Bureaucracies

What to do?

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

Government agencies and community services exist to help people. They exist to help you. Using the services they offer can be complex. You can become frustrated trying to use them to help you care for an impaired person. Here are some guidelines for using these resources:

1. Decide what you need.
2. Learn what resources are available to you.
3. Communicate your needs clearly.
4. Follow through fully.

In following these guidelines, keep in mind that you will be dealing with many different ideas, many people and a lot of details. Don't rely on memory alone to keep these all straight. You will find it very helpful to keep accurate records.

Buy a small notebook.

Use it to record your thoughts and questions. Jot down what help you could use, and where you might look for such help. Later you can also use the notebook to write down names, dates, and brief notes about your contacts with community agencies.

Start a file of relevant correspondence.

In the file, keep all letters and informational materials you receive. You should also save a copy of any letter or forms you are asked to send to agencies. This will help you avoid problems and confusion later.

Deciding what you need

Before you call an agency, decide just what you are looking for in the way of help. You need to keep in mind both the impaired person's needs and your own. Start by thinking about the current situation, but also look ahead to what the future may bring. Do you need help with the actual physical care of the impaired person? Do you need this help on a daily basis? On a weekly basis? Do you need financial help? Are you looking for an adult

day care center where the impaired person could be with other people and enjoy activities in a supervised setting? Do you need counseling for family or personal problems? Do you need legal advice?

Think over your entire situation carefully, and answer the following questions. Be as detailed as you can. You may find that talking with a friend, a family member or a counselor can help you to get your thoughts in order about these questions.

List: What problems am I having right now with care arrangements?
Costs? Personal health and emotional needs?
What kind of help could I use now?
What problems do I foresee in the future?
What kind of help will I need in the future?

Learning what resources exist

Once you have answered these questions you should have a clearer idea of exactly what help you need. Your next task is to find out who provides this kind of help in your community.

It is sometimes hard to know where to start to find the help you need. The key is to find someone who knows how the system works. Local **Senior Citizen Centers** can be a good starting place, so can **Area Agencies on Aging** (these are State agencies). Many communities sponsor **"Information and Referral"** services that can help you. Your doctor or nurse, family members and friends might know about community resources that might help in your case. If you belong to a support group, other members may have ideas.

In other communities, the **United Way** may have the information you need. **Churches** also can often refer you to sources of help. Another good source of information is the **Alzheimer's Disease and Related Disorders Association**. Once you have a list of possibilities, call each one. Start with the most promising-sounding agencies. Be sure to ask each place you call if another service exists which might better suit your situation. Expressing yourself clearly Here are three rules to follow when calling agencies: Be well-organized, brief and to the point. Be prepared to repeat your request a number of times, courteously. Don't be put off easily. If you feel nervous, you might want to consider rehearsing the call with a friend. REMEMBER: The first person you speak to will usually be the secretary or receptionist. Briefly state the question or problem you have, and ask to be transferred to the right person or section. Before your call is transferred, ask the receptionist for the name of the person or section, and write this down for your file. Then, be prepared to be "put on hold" while your call is transferred to the right section or worker. (Sometimes, when calling a very

large agency, you may have your call transferred several times before you finally reach the right person.) Use the following suggestions when you finally reach the person who has the information you need. Remember to make notes and summarize the results of your call in your notebook. Greet the worker by name and give your own name at the outset. Explain why you're calling. Referring again to your notebook, if necessary, state the problems you are having and what you think you need. Ask if the agency can meet this type of need. If yes, ask if you (or the impaired person) would be eligible for such assistance. Ask if there is a charge for services. If there is a charge, ask if there is any way to offset all or part of the fee, and if you (or the impaired person) would be eligible for such assistance. Ask for the worker's office telephone extension number. Record the phone number so you can call back easily, if need be. Finally, ask what you should do next. Following through fully Working with community resources and government agencies often means red tape. You may have to read through detailed instructions, fill out long forms, or wait in lines and offices. Unfortunately, these forms and waits are a part of getting help from agencies. The waits are generally longest at first, and workers usually don't have the authority to let you skip filling out a form. If you find any of this hard or annoying, ask a friend, family member or counselor to help you. Don't let the problem keep you from seeking the help you need. Your first contact with an agency can have one of three outcomes. You may find out right away that the agency will be able to provide the help you have asked for, or at least part of it. Even in this case, you may have to follow through by filling out forms or keeping track of information. The worker may not be able to tell you for certain whether or not the agency can help you. Perhaps you will have to gather more information (about finances, for example) before the worker can judge your eligibility. In this event, gather the needed information promptly, and call the worker back. Quite often the agency worker will have to check with a supervisor and call you back to confirm your eligibility or other arrangements. Your role here is not to wait forever. Call back if you don't hear from the worker at the scheduled time. You may be told that the agency can't help you. Either you don't qualify, or this agency really doesn't offer what you need. Especially in these cases, how you follow through matters. You will do best for yourself and your family if you don't simply take an agency's first refusal to help as final. Ask questions, and look for other options. Ask the worker to check with a supervisor. Better yet, talk to the supervisor yourself. Be sure to ask if the worker can refer you to another potential source of help. Be sure to ask for the name of a contact person at the new organization. Then call that person promptly, and explain that you have been referred by the worker at the first agency. When you're not satisfied Even after following every lead, you may still be unable to find the help you need. Perhaps the type of help you need doesn't exist yet in your community. Or perhaps you feel you have been unfairly treated that the rules are unfair to you and the person in your care.

Perhaps you just feel put off by the way an agency worker has treated you. Whatever the reason, if you feel you have been unfairly treated, speak to the worker's supervisor. Restate your case. Perhaps a misunderstanding can be cleared up this way, or the supervisor will have the authority to help you when the first worker couldn't. If the problem proves to be too difficult to resolve this way, the trouble may lie with the rules or regulations which narrowly define who may be served and who may not. People in your situation may "fall between the cracks" or into gaps in the agency's guidelines. The possibility also exists that such rules or laws may illegally discriminate against certain people. This discrimination may be deliberate or not. Although changing such rules or laws may be difficult, it can be done. You may need to join with others to make your needs known and to make changes. Seek assistance from such sources of help as your city council member, your state or federal congress member or your lawyer. You may also be able to obtain assistance from the Alzheimer's Disease and Related Disorders Association by calling toll free at 1-800-621-0379. Don't give up easily!