

Working with Health Care Professionals

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.

You care for a person with Alzheimer's disease or a related disorder. You play an important role in that person's dealings with doctors, nurses and other health professionals. You rely on them to diagnose, treat and explain the illness and to guide the care you're giving. They rely on you to carry out treatments and to manage the care program. They also rely on you to be a careful observer and reporter of what is happening with the patient.

The effects of dementing illnesses can rarely be reversed. There may be limits to what your health care providers can do. They may be able to help with certain problems that arise during the illness, but no one can halt the steady progress of the disease. There are four things you must do to get the most out of visits with your health care team.

- Be well prepared.
- Communicate clearly.
- Follow through on the doctor's instructions.
- Have realistic expectations.

To best meet the impaired person's needs and your own, you will need a network of resources. Over the course of the illness, your health care team will be a major resource. This pamphlet discusses ways to improve how you work with health care providers. It offers some suggestions for finding other resources.

Organizing your thoughts and questions

To be well prepared for a meeting with health care providers, organize your thoughts ahead of time. You will likely have questions on many topics: the illness itself, care problems and your own needs. Being organized will help you remember what you want to say. It will also help you learn as much as you can from each visit. Here are some suggestions.

Buy a small notebook Questions about caregiving come up all the time. They may arise as you provide care, watch TV, read the paper or try to get to sleep. These may be questions about how to provide care, about the illness itself, about where and how to get help or how to take care of yourself. Record these questions in your notebook. You can also use the notebook to keep track of the person's schedule and habits as well as problems that come up between doctor's visits. Later you can bring the notebook with you to the doctor's office to refresh your memory and to jot down notes or instructions.

Before you visit the doctor go over your notes and make a list of the things you wish to discuss. Be specific. Describe your concerns about the impaired person's condition and about care problems. How often and when do problems occur? Don't neglect questions about yourself. Questions about your feelings, your needs and your own health also deserve consideration.

Make a list of all medications being taken by the impaired person. Include both prescription and nonprescription drugs. Also include on this list how much the person smokes and how much alcohol, coffee, tea, cola and chocolate the person uses. These all may affect the other drugs the doctor prescribes.

Reverview what you want to discuss and set up your appointment with this in mind. If you have a lot of questions, make this clear when you set up your appointment. The receptionist can then find a way to make sure you have enough time with the doctor or nurse. You might want to ask for a separate conference, without the impaired person, to discuss at length the issues that concern you.

Organizing the help you need

Organize, in advance, the help you will need on the day of the visit to the doctor's office. You play a major part in the visit to the doctor, but you don't have to do everything. The visit has a lot of parts: getting the patient ready; driving both of you to the doctor's office; filling out routine paperwork; and following up on the doctor's instructions (picking up any prescriptions, for example).

Think about all that goes into a visit, and then think about whom in the family or among your friends might help you. Ask for their help. You need to reserve your strength for the impaired person and for communicating clearly during the visit.

Communicating clearly Communicating clearly with health care providers can sometimes be hard because you and they may seem to "speak different languages." You may not be familiar with all the terms the doctor uses. Or you may recognize the words but not realize what the doctor really means.

Two other problems can make communications harder. First, the doctor is trained to look for "factual evidence" in making a diagnosis or setting up a treatment plan. The doctor may want to do tests or observe the patient more. This may seem unnecessary to you. You may feel that the doctor doesn't trust what you say or doubts your judgment. Second, you may feel embarrassed to ask too many questions. You may worry that the questions will make you sound silly, or you may not want to bother the doctor with minor problems or take up too much time.

Other sources of help

Your health care team should be a major resource to you in your caregiving, but they are not the only resource you will need. You will need other sources of practical coping ideas and tips. You will need relief help in providing actual day-to-day care. You will also need advice on money and legal matters to help you plan for the future. You need to find sources of emotional support for yourself. Family, friends, community services and professional counselors can all be good resources for you.

Support groups offer you a source of many kinds of help. It can help to meet and talk with others who may have similar experiences. The Alzheimer's Disease and Related Disorders Association may be able to help you locate a support group near you, or you can ask for a referral from your local hospital, church or community organization.

What if you are not satisfied

You may feel unhappy with your health care team because they cannot cure the person in your care. They may not even be able to tell you for certain what is wrong with the impaired person.

You may come away from a doctor's visit feeling frustrated or angry. You may feel you are not getting the help you need to manage or care for the patient. You may feel that your concerns have not been heard. Not every doctor will be able to deal well with the needs of Alzheimer's disease patients and their caregivers. Some may not fully understand the nature of the disease or have much experience working over the long term with a caregiver. Some may just be too busy to give you the kind of time and attention you need.

Don't stay in an unsatisfactory situation. You and the impaired person both deserve to have your problems taken seriously. You need help working out a plan to address each problem. You both need an ongoing relationship with a health care team that will offer treatment and guidance over the course of a long disease.

Pinpoint what seemed wrong about your meeting with your doctor, nurse or other health care provider. Write down your main concerns, and discuss them with your primary physician. If the primary physician is the source of your concerns, you may want to ask a family member, a friend or another professional to help you make yourself clear and to give you support in a hard situation. You may even decide to seek another doctor. If you do decide to seek a new doctor, ask for advice and referrals from other families who may have experience in this problem. The Alzheimer's Disease and Related Disorders Association can help you find such families in your area. The Association may also be able to refer you to other doctors.

Following up your visit

Not every treatment or care plan will work. You and your health care team may need to work together over an extended period of time to find the treatment or care techniques that work best. To ensure that you work together well you will need to communicate promptly and thoroughly about any problems that arise or any changes in the impaired person's symptoms or behavior. You should also discuss any new care ideas you may wish to try. Be very cautious about giving over-the-counter drugs. Check first with your doctor about possible side effects.

Not properly following the doctor's instructions for treatment and care can be another major source of problems. If, for any reason, you are having trouble carrying out the doctor's instructions, call back promptly. Don't be shy in admitting that a task is hard for you. The real issue is how to make sure the impaired person and you both receive the help you need.

Ask about the pros and cons of any suggested treatment or drug. Ask also about any other alternatives. Make sure you understand the pros and cons of each of these. If a drug is prescribed, ask about the side effects it might have. Also ask if the drug should not be mixed with other medications or foods. Liquor, for instance, is dangerous when taken with some drugs.

Finally, tell the health care team what kind of help you need. Do you need more facts and ideas on a certain problem? Do you need help with day-to-day care? Do you have health problems of your own? Even if the doctor or nurse can't help you directly, they may be able to refer you to other sources of help. Then, too, your health care team members can learn from people like you. Many do not understand the full scope of problems that go along with treating and managing a person with Alzheimer's disease. You can help teach the health care team working with you.

Here are some ideas to help keep things simple

- Bring your notebook, your list of questions and the patient's drugs (all of the bottles and boxes) with you to the visit.
- Don't be shy about asking too many questions. One of the main tasks of the doctor or nurse is to tell you about the impaired person's illness and care.
- Take notes during the visit. Jot down answers to questions you ask and any new facts or ideas the doctor or nurses give you. This will help you to recall later what you learned and what you are supposed to do.
- Get in the habit of repeating back to the doctor, in your own words, what you think he or she meant. This will give the doctor a chance to clear up any confusion promptly. It will also prevent needless worry for you or errors in treatment or care.
- Your health care team members need information, both in treating the impaired person and in planning and watching over a care program for you. Ask them what kind of information they need about the impaired person. What kind of information on your caregiving routine would be useful?
- Ask, also, about what follow-up plans they would prefer. How often or when should you consult them? Make clear that you expect to manage the care of the impaired person, but that you want to do so under the direct and ongoing guidance of your health care team. (If more than one professional is involved, ask if they can appoint one person you can call with questions.).