

The Role of the Caregiver

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 person takes on the role of caregiver to provide for the needs of a close relative or friend during a period of illness or disability. People do not often expect or want to take on this new role. They are seldom well trained for it.

Caregiving can be an occupation with no clear goals. Too often it is an occupation that has no description and no limits. As a caregiver, you will need to think through your goals as frankly as you can and then develop your own "job description" for working toward these goals.

Caring for patients with an illness such as Alzheimer's disease poses special problems. You can only predict parts of what will happen in the course of a dementing illness. There is a steady decline of the patient's abilities to think, remember and act in appropriate ways. But there is no way to predict what pattern the disease will follow, which symptoms will occur or when these symptoms will occur.

If you are or will be caring for a person with Alzheimer's disease or any other dementing illness, you cannot expect the person to improve. The patient will become less and less able to function. You may be able to learn what ranges of potential care problems exist, but you will not know which ones will arise for you.

You will need to be prepared to adjust your daily routines and your ways of giving care when new symptoms appear. At the same time you will need to avoid thinking about care problems that might be possible but may never occur. The rest of this pamphlet discusses what caring for a person with Alzheimer's can mean to you and what skills you will need to develop to cope successfully with your new role. The following ideas will be addressed:

- 1 - Setting goals**
- 2 - Changing care needs at each stage of the illness**
- 3 - Your tasks as Learner-Observer-Manager**
- 4 - Your need for self-care.**

Other pamphlets in this series address specific issues in managing patient care and safety, finding help when you need it, and planning for the future. Use them as guides, and discuss any questions or reactions you may have with your doctor or nurse. Let them know what is helpful for you and what isn't. Tell them what ideas you have come up with on your own. This sharing of ideas can help all of you and will be necessary many times over the long course of the illness.

Setting Goals

Your most basic care goal throughout the illness will be to ensure, to the extent you can, the patient's **physical comfort and safety**. You will also want to help the patient preserve a sense of **emotional calm and self-esteem**.

To do these things, you will have to play many roles. You may have to learn many new skills. You will provide comfort just by being with the person. You will need to watch the person and, perhaps, explain his or her actions to others (for instance, to a friend or doctor). You will have to take control of the places the person goes and the things the person does. You will have to be the person's nurse and his or her advocate. You will decide the person's future-and your own.

Throughout the impaired person's illness, the work of caregiving is largely concerned with watching and problem-solving. To become an accurate observer and effective problem-solver in daily care, you will need to learn as much as you can about the disease itself and about the needs, feelings and reactions of the impaired person. You will also need to learn about yourself. Your own needs, feelings and reactions to the impaired person play a big part in how you care for the patient. Your skill at self-care is an important part of ensuring the patient's good care through each stage of the illness.

Care at different stages of the illness

Your basic care goals may not change throughout the patient's illness. Still, your role is a constantly changing one. As each new symptom appears or as an old one fades, the impaired person's needs change. A new set of problems and losses must be taken into account.

Each stage of the illness brings its own special care problems. In the early stages, the patient's main problems might be forgetfulness and impairment of learning ability. Your role might be to help find ways to maintain the person's ability to act on his own, as much as possible. This is the time to put a good health care team in place and to plan for the future. Talk with a lawyer and start a financial plan for yourself and the patient.

Safety is a big concern in the middle stage of the illness. The person's memory is failing and judgment is poor. The person may wander or get into things around the home that pose a danger. You may have to watch very carefully to see that the person doesn't get hurt. During this stage, the job of caregiving may well expand beyond the abilities of any one person. You will need to set up a network of care arrangements to support your efforts.

In the final stages, the patient becomes less and less able to attend to basic activities of daily living, such as bathing and dressing; and more nursing care may be needed. This is the time you will need to consider placing the impaired person in a nursing home. This is a hard choice. Talk about it with people you can trust and who know what you are going through (for instance: family, friends, a social worker, a clergyperson, your doctor). Whether you choose to place the person now or to wait, talking with these people can provide good information and support.

The Caregiver as Learner

You will be better able to cope with the problems Alzheimer's disease causes if you know what an impaired person can and cannot be expected to do. Try to keep in mind that many behaviors of the Alzheimer patient are the result of damage to the brain and are, therefore, beyond the person's direct control.

As a result, the patient may react in ways that seem wrong to you and in ways that trouble you or cause you pain. He may even become so confused by events and be so frustrated by not being able to put things together that he will strike out at you or others (with angry words or actions). You will need to learn how to respond calmly to the person's confusion, how to reassure him and how to settle his outbursts.

Learning to accept the impaired person's confused actions and respond

with kindness may well be easier than learning how to control these actions. A very hard part of this disease is that the impaired person doesn't learn well. You can't teach the person how to act when they are confused or upset.

You will have to learn "tricks of the trade" as you try to find ways to prolong the patient's ability to act on his own. For instance, doing things in a set routine may help the person retain the ability to do them. Praise, rewards or small treats may also help keep the person in the patterns you want. At different stages of the disease, you may have to do different things. Signs and picture cues may work for some time. Simple spoken commands may also work. Breaking actions into small, step-by-step units may be useful. You may have to help the person start an action.

The Caregiver as Observer

One of the most important things you can do as a caregiver is to observe the impaired person carefully. In effect you become an expert on the person. You become skilled at predicting what the person might do in certain situations, at knowing what will calm the person, catch the person's waning attention, make the person happy, or keep the person busy.

Your observations of the impaired person play a major part in **good health care** for the patient. Your health care team will rely on you for clear information about the person and his or her state. As observer, you need to be objective, detailed and nonjudgemental. You are called upon to see and to report promptly any changes in symptoms or actions.

Observing the impaired person can also protect the **safety** of the patient and of others. You need to watch the impaired person's declining abilities carefully, to remove hazards from the environment and to restrict or supervise activities as needed.

In addition to observing the impaired person, you need to become a good observer of yourself. You need to try to see yourself as the impaired person might see you to be sure your actions don't affect how the impaired person acts. You don't want to trigger troubling or hard-to-handle reactions. This may entail altering or, at least, controlling your natural reactions to the impaired person's actions. You must also watch your reactions to fatigue and to emotional stress so that you can protect your own health and happiness, both for your own sake and for the sake of the person who depends so heavily on you.

The Caregiver as Manager

As the caregiver for a person with Alzheimer's disease, you become manager of that person. Management skills include **relating well**, **coordinating and supervising** the activities of others, **delegating tasks** when appropriate, and **planning for the future**. A good manager draws on all of these skills.

A care manager must relate well with the patient and a wide variety of other people, including family, friends, professional advisers and health care providers. The care manager also needs to work as a team with these others and to coordinate their efforts in providing care and in long-term planning. Finally, the good care manager needs to structure and to supervise the patient's environment and day-to-day activities in a way that meets the changing needs of both patient and caregiver.

The care manager is the major link between the impaired person and family and friends. As such, you will need to let family and friends know what the person's condition is and what help might be needed. As an expert on the impaired person, you may also be able to help the impaired person relate with others, by explaining actions, for example.

The caregiver manages the medical care that the patient receives. As care manager, you find the right help and work with the health care professionals to carry out treatment or care plans.

You may also need to manage legal affairs and finances for the impaired person, with the help of skilled advisers. Current affairs need to be managed, and long-term financial plans must be made to meet the impaired person's future care needs.

The care manager also organizes and directs a network of helpers and an assortment of care arrangements. Perhaps you will simply coordinate family help at first, but later you may need to find and oversee other kinds of help, either at home or in separate care facilities.

Clearly, a good care manager is a very key person in the life of an impaired person. As a care manager, then, you need to pay special attention to your own self-care, too.

The Need for Self-Care.

Experts agree that caregiving puts a great strain on body, mind and spirit. You will need to look after yourself as well as the impaired person.

Physical health

Caregiving is physically tiring, so you need to pay special attention to your physical well-being. The health care team you consult on the impaired person's behalf should be a resource for you as well. Keep these health care providers informed about how you are, and ask them for suggestions as you need them. Even for people who are not under the strain of caregiving, eating well and getting enough sleep and exercise may be difficult.

As a caregiver, you may well have so many extra demands on your time that you may decide to skimp in these areas. Skimping can take a heavy toll on your ability to function. Try to keep in mind your responsibility to yourself. Your ability to provide care to the person depends on your health. Your ability to pick up the strands of your life when your caregiving tasks are done also depends on your good health.

Emotional health

Caregiving often brings a large emotional burden. The patient, probably someone close to you, is a victim of an incurable, terminal illness. You may well endure a prolonged period of loss and grief. Other strong feelings may occur: anger, a sense of despair, sorrow, guilt, frustration, a feeling of being alone or overwhelmed. This period can also be a time of considerable anxiety and uncertainty about the future. Many people become very depressed.

One of the harder emotional issues of caregiving is the distance that grows between you and the person in your care. There comes a time when the impaired person is no longer the person you once knew. He or she is no longer reliable and cannot be trusted to remember to do what you ask or to provide you with accurate information. The disease reduces both memory and judgment. Your relationship with the person will surely become different from what it was before the onset of the disease. You will need to give orders and be in charge. You may have to learn how to do things you relied on the person to do. For instance, many men who

provide care report they have to learn how to cook or do laundry; many women have to learn how to deal with finances and home repair.

The following ideas may be helpful in caring for your emotional health:

 **Don't deny your feelings.**

Find ways to let your feelings come out. Don't try to keep them bottled up inside you. People have different ways of expressing their feelings. Some talk with counselors, psychologists, social workers or members of the clergy. Others are comfortable talking with a doctor or nurse. Still others would prefer to confide in family members and friends. Everyone can benefit from taking time alone to think and sort out feelings.

 **Consider joining a support group.**

Many caregivers have found emotional support and good suggestions for managing difficult care problems from members of support groups. Such groups bring together people in similar situations, so group members have valuable experience which can be the source of good tips and ideas for you. The group can also offer a safe place to let out your feelings. (Your health care providers or local hospital can refer you to a support group in your area, or you can get information from the Alzheimer's Disease and Related Disorders Association by calling, toll free, 1-800-621-0379).

 **Make life as easy as possible**

During the time you are providing care to the impaired person, you may find many instances which call for compromise. You will need to look closely at standards and values for yourself and for the person in your care. The progress of the disease and the work of caregiving put pressure on these standards. You may find yourself trading off your own ease and comfort against your sense of the way things ought to be. For instance, if you are used to sitting down to dinner in the dining room for a formal meal, there may come a time when the difficulties of doing this offset the pleasure. Serving meals at the kitchen table may well be easier even though less appealing to you personally. There is no easy rule for making these decisions, but, when the time comes, you may find them easier to make than you might have expected.

 **Be sure to give yourself credit for the work you are doing.**

All the while you care for the impaired person, you are learning and becoming more skilled. You need to see that you have learned new things, have solved problems and have come up with new ways of managing. While these accomplishments may not prepare you for each new care problem that arises, the knowledge of what you have done so far

should give you confidence that you will be able to handle the next problem too.



Anticipate problems by planning ahead

and developing options for alternative care arrangements. At any point in the illness, you may begin to feel that taking care of the person is too much for you. You will do best for yourself and the impaired person if you have thought through some options for alternative care arrangements. Your health care team can help you get started. Your family and friends can also be a source of help. Community agencies may offer you a wide range of resources and types of help. Nursing homes offer the option of temporary or permanent placement. Explore your options early, and be prepared for your need when it comes.



Finally, remember that the impaired person doesn't always come first.

Your needs for regular rest, relaxation and pleasurable activities should be considered important too. An exhausted, depressed caregiver can't provide better care than a person who regularly takes breaks, keeps in touch with friends and occasionally takes a vacation. Sometimes putting yourself first will actually make you a better caregiver.