

Respite Care: When You Need a Break

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

“Taking time out, away from the care of an impaired person, is one of the single most important things that you can do to make it possible for you to continue to care for someone with a dement “

--Mace and Rabins, **The 36 Hour Day**

Giving care to a person with Alzheimer's disease or some other dementing illness can be very hard work. All too often in the course of providing care, caregivers forget about their own needs and well being. Seeking 'respite;' a break, is an important part of providing care to an impaired person. The needs of the impaired person do not always have to come first. You need time to yourself, either with friends or by yourself. This need should be thought of along with the needs of the impaired person when you make plans.

Getting away for a break is not always easy. The chief problem is to find the right care for the impaired person. This will take time, planning and preparation. You may have to pay for this care. You may also have to learn to accept a tradeoff between the benefits and problems of any care arrangement you set up. For instance, some forms of respite care require moving the impaired person temporarily into a care facility, and such a change may upset the person. Your need for some time off, however, may justify such a step.

Two keys to solving problems

There are two keys for solving these problems:

- Ask for help.
- Be well prepared

This pamphlet deals with five practical steps you can take to get time off for yourself and to ensure the safety and comfort of the impaired person.

- Decide what help you need and when.

- Identify everyone who might possibly help.
- Select the helpers that best suit your needs.
- Prepare the helper, the impaired person and you as well as you can.
- Watch the care arrangement carefully, and promptly handle any problems that come up.

What do you need?

This is the most important question. You need to keep in mind that you are concerned about your own needs and those of the impaired person.

First, think about what you need. Do you need time alone to rest and relax? Do you, for instance, need an afternoon or evening out each week? Do you need to get away for a weekend every month or two? Do you need a week or two off for a complete break?

You may need help with home care. Perhaps someone to come in three or four times a week while you were home to perform specific chores. Or someone to bathe the impaired person, do housework or take the person for a walk while you nap.

You may need company, someone to visit with you. The day-to-day routine of providing care can leave you feeling very isolated, no longer part of the world. Even short visits by friends or family can relieve this feeling.

Second, what does the impaired person need? Keep in mind the three basic care issues of ensuring the person's physical safety, maintaining the daily routine and providing companionship.

Note: If possible slowly increase the amount of time you spend away from the person. For instance, you may want a weekend to yourself, but you might have to build up to that over the course of a month or two by being away at first for just an hour or two, then for half a day, then overnight.

Who can help you?

Leaving a **mildly** impaired person alone for short periods can be practical and safe, especially in the earlier stages of the illness. You must make the home as safe as possible, and you may want to alert your neighbors to the times you are leaving and expect to return. Tell the impaired person, too, of course. **Decisions to leave an impaired person alone must be made on an individual basis.**

In all other cases, you will need to identify **all** the people who could help you care for the impaired person. There are many people who can be called on to

help you. Some will volunteer their time. Others you will need to pay. You can even get help locating these other helpers. Ask your family members, friends, clergy, physician or social worker for suggestions.

Relatives, Neighbors, Friends—Ask for help

Many people have a hard time asking for help. This might be true of you. Try to keep in mind that people will often be glad to help, but they might never get around to offering on their own. They may also not know what to do or how to offer.

The more specific you can be about what you are asking for, the more likely you are to find help. For instance, you might ask someone to spend a few hours watching television with the impaired person. Or you could ask someone to shop for groceries for you, or to take the impaired person for a walk or a drive. An open-ended plea for help, on the other hand, might make the potential helper uneasy. The time involved might seem greater than it actually would need to be.

Hired Help

A number of friends, often connected with hospitals, can supply a wide range of helpers trained to deal with care tasks. Nurses can come into your home to provide specific skilled care. Home health aids can provide more routine nursing care. Some helpers do home chores, and others will stay with the impaired person but do not do any work around the house.

You will have to pay for this help. Most health insurance does not pay for this kind of help. Prices will vary from place to place. In most cities, a skilled nursing visit will cost anywhere from \$35.00 to \$50.00 (a visit can be as little as 15 minutes or as much as two hours). Homemaker help is much less costly, but there is often a minimum amount of time you must contract for. For example, it may cost \$8.00 per hour for a homemaker, but the agency will expect you to hire the person for at least four hours.

Adult Day Care

Some hospitals and some senior centers offer adult day care service. These centers provide activities and (usually a meal for ill and impaired persons). Some centers offer health and rehabilitation care as well. Some programs last all day; others run just a few hours. Churches, the VA, and fraternal organizations also might offer adult day care programs. Almost all adult day care programs charge for the service. Most health insurance will not pay for this form of care.

Community Organizations

You can obtain referrals and even the helpers themselves from a local United Way Agency or the Alzheimer's Disease and Related Disorders Association. Information and referral services at the city, county or state level offer another source of ideas. Keep in mind, too, that the local high schools, colleges, churches and senior centers can be sources of referrals or actual helpers.

Hospitals and Nursing Homes

The VA Medical Center and other local hospitals--and even some nursing homes--may offer respite care for short periods (usually up to seven days). In these cases, the impaired person actually moves into the care facility. This kind of stay requires a doctor's order. Again, there will be a charge for this respite. If the person is admitted for reasons of an acute illness or event, it is possible that health insurance or Medicare will cover all or part of the cost of this stay.

Selecting the helpers

When you know what help you need and who might be able to help, get in touch with the most promising of those people and "interview" them. You should be able to come up with a range of choices. Try to find at least three so you will be able to compare.

Before you talk with anyone, write out a list of questions. When you interview people who might help, be sure to describe in detail just what you want them to do. Try to be sure the helper understands what the tasks involve and feels willing to do the m. Being clear with each other now can prevent problems later.

You will want to be sure the helper is physically able to do the work you want done. You need to find someone who is able to work when you need help most. Most of all, you need a helper who can deal with an impaired person in a sensible, gentle and tactful way.

It will help to prepare questions ahead of time. For instance, you might ask if the helper has experience with Alzheimer patients. Does he or she know how to help an impaired person to the bathroom or in and out of a chair? Can the helper meet special requirements the impaired person has?

Last, but not least, you must consider what you can afford and how much each type of help will cost.

List: What information do I need to give? What questions do I need to ask?

After each interview, use the following questions to help you rate each person. Keep a record of your answers, and compare the pros and cons of each helper or care arrangement.

- Which of the tasks that you have in mind can this person perform?
- Which tasks will not be possible for this helper?
- Can this helper work when you need help most?
- Do you feel at ease with this helper? Does the impaired person seem to like the helper? How would you feel leaving the impaired person alone with this helper?
- What costs, if any, would be involved? (If you have contacted facilities offering daytime or overnight respite care, be sure to compare what you will receive for the fee charged.)

Now you are in a position to make choices. While cost is a big factor in choosing, the most important factor is **how well the care arrangement meets the needs**, for both the impaired person and you. For instance, having someone come in three times a week may cost less than placing the person in an overnight respite. But you may really need a night by yourself, so the extra cost might be worth paying. This doesn't mean that the best arrangements will always be the ones you pay for, of course. If family and friends can fill many of your needs for free, so much the better. Needs, costs and the availability of help will vary in every case. The best you can do is to make an informed decision, using the best process you can in selecting your helpers.

Training a helper

You have to train a helper. The helper needs to know, in detail, what you want him or her to do. The helper needs to know how the patient might act or react and how to calm the person. Ideally, you should arrange to have the helper spend some time with the person while you are home too. This way the helper can watch how you care for the impaired person, ask questions, and learn where to find needed supplies. Here are some other ideas for preparing the helper to work with the person in your care. Use the space provided to make notes.

To-do list

Leave a list of the things you expect the helper to do during each visit. Be sure you have given the helper all the necessary information to do what you ask. For example if the helper will also be doing housework, be sure he or she can find needed equipment and supplies.

Emergency numbers

Be sure the helper knows how to reach you, your doctor, or other family members in an emergency. Keep a list of these phone numbers right beside the telephone. Include other important numbers such as police and fire department numbers.

Making decisions about care

Explain clearly that any decisions about care are to be made between you and the helper. The impaired person has a limited understanding of the situation, at best, and cannot cancel your orders. So prepare the helper for the situation where the impaired person might tell him or her to leave. What would you like the helper to say and do in this event?

Describe how the person normally acts

The helper needs to know what is normal for the person. How does the person eat? Does the person need help going to the bathroom? If so, what is the best way to give this help? Does the person nap in a chair or in bed? Can the person walk in the yard alone? Describe any problems. Be sure to include information about early signs of health emergencies. For instance, if the impaired person has occasional seizures, the helper should know the early signs. Be sure also to describe what is normal for the person. If some normal events look like emergencies but really aren't, the helper will need to be watchful without panicking. For instance, perhaps the impaired person seems to gag often but has never had a true choking incident.

Daily routine

Outline the daily routine of the impaired person. Describe when the person eats meals or snacks, takes medicines, and needs to be bathed or taken to the toilet. Mention any special events such as watching TV or listening to music. Mention any special preparations that might be needed. Describe problem behaviors that might arise, and be sure to offer ways to deal with these problems.

Communication techniques

Describe how you communicate with the impaired person. Do you and the person use any special words or terms? Does the helper need to touch the person to get his or her attention, or would the person prefer not to be touched? Are there any special communication problems the helper should know about?

Preparing for the impaired person

Here are some general ideas. You will undoubtedly think of other good ideas that apply in your case. When you have a good idea, make a note of it, so you don't forget.

Pick the best time of day to leave

You may have noticed that the impaired person seems more alert and better able to function in the morning, but the evening may be a bad time. If you can be away during the impaired person's best time of day, he or she will be better able to adapt to the other caregiver. You may have to balance this with your own need for relief from the hardest part of your day. Explain to the impaired person in terms he or she can understand, that you are leaving, where you will be and when you will return. Let the helper know what you have said. Then your helper can better answer questions and reassure the impaired person if necessary.

Getting to know the helper

Stay around while the impaired person becomes acquainted with the helper. Allow extra time in your schedule so that you don't have to rush the impaired person in getting to know (or adjusting to the presence of) a helper.

Plan some special event or treat for the impaired person and the helper while you are gone. Arrange for them to share the impaired person's favorite snack or a record the person likes, for instance.

Preparing yourself to leave

Decide in advance what you will do with this free time. You should do this not only so you will feel you have used the time well, but also so that you will have something to look forward to. Make sure that at least some of what you do is a real treat for yourself. In spite of your best efforts, you may find that the impaired person becomes upset when you leave. This may, in turn, upset you. Try the following suggestions for dealing with your own feelings.

Be prepared for emotional reaction

Be prepared for the emotional reaction of the impaired person. Try to keep in mind that the person cannot understand the situation and may be fearful. This does not mean that your leaving is bad for the person. Accept crying and clinging behavior simply as signs of the affection the person feels for you.

Respond calmly and in a matter-of-fact way

If you seem worried or anxious, your feelings will only upset the impaired person more, making your leaving even harder. Seeming confident may be hard at first, but experience with the helper should help.

Rest assured that the impaired person will almost always be content and busy with other things minutes after you leave. If the person does get upset when you leave, ask the helper how long the upset lasted and what worked to calm

the person. After a while, you and the helper should be able to work out ways to make your leaving easier and to calm the person sooner.

You need a break

Do not feel guilty about taking your break. Even if leaving seems hard, a break will be better for both you and the impaired person who depends so much on you and your good health.

Your new role

When you set up respite care, you will take on a new role as the Supervisor of your helper. Even though your helper seems able, you still need to guide and watch his or her work. Becoming a good manager may take some practice.

Explain clearly to the helper

Start by explaining clearly each time what you want the helper to do. If you find you need to make any changes in your original agreement with the helper, be careful to discuss these thoroughly. Make sure your helper fully understands and agrees to the changes.

Make sure tasks have been done

Make sure that all the agreed-upon tasks have been done and that the impaired person is receiving the kind of care and attention you expect. Be sure to thank the helper and offer a compliment for a job well done.

If a problem arises

If a problem arises, bring it up with your helper promptly. Try to do this in a constructive rather than critical way. If, for instance, you noticed a task was not done, ask if there might be any special reason why. Don't wait until the problem has gone on for a while and then angrily demand to know why the helper hasn't done the job right. If, after several attempts to clear up a problem, you still feel dissatisfied, you may have to cancel your arrangements with this particular helper. Don't be discouraged! Put what you have learned to good use in planning another arrangement for help. Your efforts will be well-rewarded if they result in giving you the time you need to refresh yourself.

A manager has to listen

When you return from your time away, allow some time to talk with the helper. The helper may have had a problem that neither of you had anticipated. He or she may have come up with a new way of working with the patient, and you may want to use it. Or the helper may just need to vent feelings about what it's like to work with an impaired person.