

# Alzheimers Disease Supplements

## DEALING WITH A PATIENTS DECLINING ABILITIES

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As an illness like Alzheimer's disease progresses, the impaired person becomes less able to do many things safely. The world seems confusing, even frightening. The person becomes less and less able to recall what things are and how they work, what is dangerous and what is safe. He or she loses both adult judgment and the physical skills to perform adult tasks. These abilities are not lost all at once. Different ones decline below safe levels at different times. As a result, judging when an impaired person's activities pose a danger to self or others becomes a hard task for the caregiver. Some things that may become dangerous come to mind at once. These are complex tasks using equipment which could be dangerous. Tasks like driving, cooking on a stove, working with power tools and using guns or sharp tools are among these. Some activities such as smoking seem simple enough but require great caution. The person may dispose of matches safely, for instance, but forget a burning cigarette. The danger of other tasks may be less easy to see. Watering the lawn can be a problem if the person might wander off, for instance. Taking a shower, using a hair dryer, even climbing stairs can be dangerous if a person's skills and judgment have declined past a certain point.

These changes can frustrate and make the impaired person feel useless and unhappy. An activity may mean a great deal. A lot of the person's self-esteem may be wrapped up in being able to perform that task. Perhaps it had to do with something important about the person's role in the family. Fixing meals for the family or being the driver, for instance, may seem like his or her special job.

These losses can lead the impaired person to angry outbursts and difficult behavior. Even safe tasks then become problems. For instance, setting the table could be a problem if the person is no longer able to remember all the needed steps and becomes angry and upset.

As caregiver, you will often be called on to deal with problems caused by the impaired person's waning skills and judgment. As the disease goes on, you need actively to manage the daily life of the impaired person. This will involve taking over more and more. You will first take over the harder tasks themselves. Then you will take over deciding what the impaired person should and should not do. This is a big job in itself. You will also need to look carefully at your home. Does the home make life easier or harder for the impaired person (and for you)? You may well have to change your home as time goes by to work better for the impaired person and for you. The next section "Creating a Safe and Workable Environment", deals further with controlling the impaired person's surroundings and watching over activities.

The first step in dealing with the impaired person's growing needs involves overcoming any fear you may feel about the problem. Admitting that the impaired person is losing skills may heighten the sense of loss you feel already. You may feel swamped with new burdens. You may prefer to look the other way a little longer. Try not to wait so long that a crisis occurs. Begin as soon as you can to regularly assess the impaired person's skills and the home setting.

In bringing up these issues, the subject of finding help when you need it comes up, too. You can't be alert and on-the-job all day every day. You will need a network of care to cope with the increasing need for supervising the impaired person.

Your goal becomes seeing to the safety and reasonable happiness of the impaired person while also making sure that your caregiving tasks don't overwhelm you. What do you need to do? The answer to this question involves three steps: observation, judgment and response.

## **Observation**

You can't spend your day following the person in your care to see if he or she can still function well. This would be a grim chore for you and would likely upset the person. Instead you will need to become sensitive to early clues and then follow them up with care. Often some small event will occur that will alert you to the need to observe an activity more closely. Perhaps the person has left the electric coffee pot plugged in after taking the last cup of coffee. Or perhaps he or she failed to observe a traffic light change and had to slam on the brakes to avoid running a red light. You may find that the oven has been left on, the phone is off the hook, or cigarettes have been left to burn down in the ash tray.

When you pick up a clue or have a hunch, then observe more carefully. You may want to seek help from an expert. Occupational therapists or visiting nurses

are trained in what to look for and can suggest what activities might pose problems. Here are some questions to help you:

1. Is the person able to concentrate long enough to do an activity safely? When cooking, for instance, does he or she become too distracted by the radio to tend to the food properly or to turn off the stove?
2. Does the person have enough judgment and good sense to perform the task safely? Does he or she know when food is fit to eat or not? Are matches properly disposed of?
3. Can the person perform all the coordinated actions needed to do a certain task? Can these still be done in a time you think is safe? For instance, is the person able to stop the car quickly when needed?
4. Is the person apt to become frustrated or angry too easily? Does the person become flustered and lose control often?

## **Judgment**

If you are the primary caregiver for an impaired person, keep in mind that you have the authority to judge when an activity is no longer safe. Once you have observed carefully, your job is to decide whether or not any activity might be dangerous enough to harm the impaired person or anyone else. If yes, you will need to respond promptly. If no, leave well enough alone for the time being. You want to avoid giving yourself extra work sooner than need be. You also want to guard against becoming too protective. Do watch carefully, though.

## **Driving**

One activity deserves mention as a special case. Impaired persons should not drive. Driving is one of the most complex activities most people do. Accidents cause an enormous number of deaths and injuries every year. Most experts who write about caring for persons with dementia stress the importance of stopping the patient from driving very early in the disease.

You may want to seek help in deciding that a certain activity has to be stopped or curtailed. Once again your health care team members can be of great help. They can assess the person's skills. Your family can also help observe the impaired person and help you decide about setting limits. Support groups are another source of help and of ideas. Members can offer each other useful tips about many types of problems. Contact the Alzheimer's Disease and Related Disorders Association toll free at 1-800-621-0379 to learn more about a support group near you.

## **Response**

Once you have decided an activity is no longer safe, you need to restrict that activity. There are a number of ways you might go about doing this tactfully.

Don't bring up the subject. Learn to choose your words with care, and don't invite trouble. Don't suggest, for instance, that you fix dinner together if the impaired person becomes upset during the bustle of preparing meals. Try to get in the habit of not even mentioning what needs to be done, if the impaired person will not be involved.

Be prepared to offer a diversion when the need arises. Keep a written list of simple, repetitive activities the person enjoys doing. Then you will be ready with a good substitute activity on short notice.

Learn any advance signals the impaired person may give, and try to divert the person's attention when you notice these warnings. When the person seems about to begin a problem activity, you should suggest without delay one of the activities from your list. Preventing problem activities.

Develop other techniques for preventing certain problem activities. If diversion does not work, you will need to develop other techniques to prevent the impaired person from attempting the problem activity. You may find it helpful to equip your home with devices that prevent the impaired person from beginning activities you feel are unsafe. These need not be fancy or costly. At the simplest level, what you want is something that will slightly distract the person until the impulse to try a certain activity has passed and been forgotten. Latches in odd positions (up high or down low) can stop an impaired person at a door or window. You may hide the car keys, or your garage mechanic can show you several simple things to do to keep a car from starting. Your gas or electric company can help you find ways to make the stove and furnace safe. Many inexpensive products designed to "childproof" the home will also work with an impaired person.

A special problem arises if you decide that a certain activity is unsafe, but the person is still alert enough to outsmart your preventive measures. For instance, a person who may still be able to figure out how to get the car started may not have the skills to drive safely. In a case like this, the person still must be kept from the activity.

How you do this will vary from person to person and will depend on how much the impaired person is still able to understand. You may be able to explain, very simply, that the activity is no longer safe and that the person must not do it. You may have to deny access (take away keys, lock a room). Or you may have to enlist outside help. The authority of other family members, a doctor or nurse, a police officer or a member of the clergy can be helpful in convincing a person that he or she is no longer allowed to perform certain activities. For instance, showing

a written statement from the doctor may help persuade the impaired person that an activity such as driving or hunting is no longer allowed.

### Dealing with Your Own Feelings

Caring for a person with declining powers presents you with many hard problems. You may need to change your home to fit the person's needs. You will surely have to increase the amount of time you spend watching over the person. You will also have to deal with your own feelings. You may grieve to see the impaired person's declining powers. You may feel that you are losing the person to the illness.

Another major source of trouble comes up when the impaired person can no longer do tasks that you have always relied on him or her to do. These may include driving, cooking, cleaning, yard work, home finances, home repairs or clothes mending. Then the loss will mean that you may have to take over these jobs yourself. At the very least you will have to find someone else to do them or decide you can live without them. If you decide to do the jobs yourself, you may have to learn how to do them first. You may begin to feel swamped.

All in all, you may find that you do not want to look too closely at how well the impaired person is doing. Deep down, you may not be fully ready to accept the illness and what it means.

Such feelings are normal. Don't keep these feelings inside. Talk to your doctor, a counselor, family member or friend about how you feel. Sharing your feelings with members of a support group can be very helpful too.

Give yourself time to adjust, and make sure you get away from your caregiving role once in a while. Even a few hours to yourself can refresh you.