

Special Care Problems: Restlessness, Wandering and Sleep Disturbances

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.

Many persons with Alzheimer's disease or a related disorder seem to have excess energy. This can show up as restlessness, wandering and/or disturbed sleep. Each of these can pose special problems for caregivers.

Restlessness and Wandering

Restlessness means fidgeting, not being able to sit still or not being able to stay with one thing for very long. Restlessness is a problem mostly because it may be annoying to others. Wandering, on the other hand, can be a major cause of worry. Wandering poses a real danger. The impaired person might walk out of the house and be hurt or become lost. Restlessness and wandering may have many causes. As the disease progresses, the person's energy level may not decline as fast as his or her abilities do. Restlessness and wandering may result from this excess of energy with nowhere to go. Since the disease damages memory, the person may feel lost and confused most of the time. Wandering and restlessness may be a symptom of the person's anxious search for peace of mind. They may be a sign that the person is frustrated at not being able to express himself or herself. They could also be side effects of drugs the person is taking.

Disturbed Sleep

Most older people no longer need eight hours of sleep each day. Age brings with it a reduced need for sleep. Older persons tend to wake up often and to have lighter sleep. Disturbed sleep may have other direct physical causes. A full bladder, pain or leg cramps will awaken a person.

When the normal decline in deep sleep mixes with the confusion of dementia, problems may occur. Waking in a dark house, the confused person may wander around and even out of the house. This wandering puts the person at risk of injury. For instance, he or she might fall in the dark. This wandering might also put others in danger. For instance, the person might turn the stove on and then forget to turn it off.

Disturbed sleep has a longer range effect. If an impaired person's sleep is disturbed, the caregiver's sleep is normally disturbed. Both face a serious health threat. Lack of sleep can worsen the symptoms of the illness in the impaired person. It can threaten the caregiver's health and undermine the caregivers ability to cope and to perform the caregiving tasks.

Some causes of restlessness, wandering and disturbed sleep will respond to medical treatment. Thus, all problems of this sort should be promptly examined by a doctor. It may be that these behaviors are caused by the progress of the disease and that they will not respond to treatment. Even so, your health care team should have ideas about how to manage and cope with the problem. As a caregiver, you play a key role in helping your health care team look at and solve these problems. You will need to provide detailed reports about the person in your care. You will have to carry out any treatment or care plan and cope with the extra work and worry. You will need to find ways to ensure the impaired person's comfort and safety as well as your own. All these add up to a very hard task. You may need help. Don't be afraid or too shy to ask for it. The rest of this section offers ideas for finding the help you need and for dealing with the problems caused by restlessness, wandering and disturbed sleep.

Observation and diagnosis

If the person in your care begins to be restless or to wander or have disturbed sleep, the doctor will want to look at him or her promptly. This visit will be to make an early diagnosis of the problem. You may then be asked to watch the problem for a while. (Be sure to ask the doctor how you can keep the person safe during this time.) The doctor will tell you what to watch for. You may need to look for signs of a pattern or of a worsening trend. You may be watching for side effects from prescribed drugs. These facts will help the doctor make a final diagnosis. The doctor can then plan the treatment routine with you. As you care for the impaired person, try to observe the patient carefully and answer the following questions. Your doctor may have other questions or comments pertaining to your case.

Questions:

- Can you see any pattern in the wandering? (For instance, does the person often go to a certain place or in a certain direction?) *Does wandering or restlessness occur at certain times of the day? (Or, does the person normally wake at a certain time of the night?)
- When you first noticed the problem, were there any other changes in the way the person was acting? (For instance, were there changes in mood?)
- Were there any big changes in the home around that time? (Did anyone move in or out? Did anyone in the family die or become ill? *Did you acquire new pets or furniture? Were any of the rooms painted?)
- Does anything seem to trigger the restlessness, wandering or sleep disturbances? (For instance, do they occur when the person needs to go

to the bathroom? Do they occur after the person has taken a prescribed drug? What about after having caffeine in drinks like tea, coffee or cola? Cigarettes or chocolate may also bring on restlessness in some people. Do the problems occur when there are visitors? What about when there is a certain show on TV? Do they seem to have anything to do with the size or timing of meals?)

- Have there been any changes in the kind or amount of food or drink the person consumes? (Keep track of what the person eats and drinks in an average day.)
- Has the person started any new drugs? Has he or she changed the dosage of a drug?
- Has the person fallen recently?

NOTE: Be sure your doctor knows all the drugs the person takes, even those bought over-the-counter.

Treatment and management

Once you have a diagnosis, your doctor can treat any symptoms that can be helped. If a good treatment exists, you may be asked to carry it out at home. Treatment may be simple: cut out all caffeine, for instance. Or you may be asked to give the person drugs and to watch for effects.

The prescribed treatment may not work, or it may solve part of the problem. It may be that there is no real cure for the problem. Times of restlessness or disturbed sleep may just be part of the progressing disease. Still, you and your health care team should work to set up techniques to manage the care problems that remain.

The goal of your caregiving task is to ensure the safety of all and your own peace of mind. A number of techniques which may help you meet this goal are discussed next. These do not involve restraining the impaired person, either with drugs or with physical restraints.

In some cases, your goals may only be achieved by controlling the impaired person's symptoms with the careful use of drugs. Drugs may reduce restlessness or wandering and might help with sleep, but there might be unwanted side effects. Some drugs which slow people down also cause (or worsen) confusion. Discuss this subject with your doctor carefully. NOTE: Never give the person over-the-counter medicines or drugs prescribed for you or someone else without talking first with your doctor. The sleeping pill or anti-anxiety pill that works well for you might be all wrong for the impaired person.

Coping tips

Here are some general ideas for managing problems of restlessness, wandering and disturbed sleep. Talk these over with your doctor or nurse and make a plan. Then see what works best. If a plan doesn't seem to be working, discuss the

problems as well as any new ideas you may want to try. Support group members can also be a valuable source of ideas for managing the problems you are having.

Keep a regular pattern in your life and in the patient's life. Make sure the person gets exercise and eats well. Try to keep the impaired person awake and active during the day. This might help to ensure a restful night. Be sure to include work and recreational activities in the daily routine. For instance, assign sweeping up to the person who is still able to do easy chores around the house. Plan outside events, like taking walks together. Limit the number and length of naps in the daytime. If the person needs rest periods, make them short. In general, try to make the hours before the evening meal the active time and the hours before bedtime the calm time.

Try serving the major meal at midday and avoid large meals at night. Avoid overly fatty or salty foods. To reduce night waking due to a full bladder, limit the amount the person drinks after dinner. Make sure the person uses the toilet before going to bed. Review the person's problem habits. Use any patterns or cues to predict problems and plan ahead. Do you see any patterns? Does restlessness, for instance, occur at any certain time or in response to any event? Try to cut out any triggering events. Try, also, to figure out ways to distract the person when restlessness or wandering begins.

Set up safeguards in case the person wanders away. Get the person a "medic-alert" bracelet. This should include the person's name, address and phone number. It should also say that the person is "memory impaired".

Let your neighbors and local business owners know that the person may wander. Give them your phone number and ask them to call you if they should see the person out alone. You might want to leave this information (along with a photo of the person) at your local police precinct.

Consider ways to prevent the person from wandering away. There are a number of ways to make it hard to get out of the house or yard. Bells on the doors will let you know when they have been opened. A hard-to-open door knob (used to child-proof doors) may prevent the person from using it. You might want to install on your doors the kind of deadbolt locks that can only be opened with a key. Even an oddly-placed latch (up high or down low) may make it hard for the person to use the door. You might put up a sturdy fence around your yard. This would allow the person to wander but keep him or her from wandering off. You might want to try the least costly of these first.

Make sure the person feels safe and at ease. Check the room. Is it too hot or too cold? Is there good light? Is the room calm or noisy? Is too much going on around the person? Think carefully about any changes you make around the house. If the pattern of things changes, the person may become confused and upset.

Seek help. You need to be well and rested. Be sure you take some time away so that you can keep up with your rest. At the very least, take naps when the person in your care naps. Ask friends or family members to take over for you once in a while. Perhaps they can just sit with the person while you sleep. Think about

hiring help. Perhaps you can find someone to come into your home, or you might want to arrange for the impaired person to be in a respite care facility for a while.

Living with the problem

Restlessness, wandering and disturbed sleep add to your caregiving task. Work with your doctor or nurse to plan coping techniques. If you can, figure out ways to predict and prevent the problem. Also protect your own health and peace of mind. As caregiver, you have a lot on your shoulders. This does not mean you have to do it all yourself. Ask for help.

Don't ignore your own needs and feelings. Dealing with these problems can exhaust you. You may also feel any number of emotions ranging from anger to depression and guilt. Try to keep in mind that these problems are not happening because you are a poor caregiver. These problems are part of the disease itself. Other people have had these problems, so don't feel alone in this. And don't keep these problems and your reactions to yourself. Speak to a friend or family member, a counselor or member of the clergy. Or go to a support group. (The Alzheimer's Disease and Related Disorders Association may be able to help you find a support group near you. Ask your health care team or a local hospital for a referral.) At times like this, sharing what you feel can be very helpful.