Treatment of Dementia and Agitation: A Guide for Families and Caregivers

If someone you care about has been diagnosed with dementia, you may feel that you are the only person facing the difficulties of this illness. But you are not alone. As people in our society live longer, many of us have to face the decline in memory and thinking of someone we love. Living with someone who has dementia can be painful, confusing, and stressful. Although dementia is a disorder of memory, many people affected by it also develop agitation and other behavioral symptoms, making it much harder to care for them. Even in the best situations, families are often surprised by how angry or guilty they feel when they lose patience with their loved one.

But there is good reason to be optimistic. Research concerning Alzheimer's disease has increased at a tremendous rate, with over 29,000 scientific papers published in the past 15 years according to the Alzheimer's Association. Support groups and national organizations offer practical advice and support that can help you solve problems and better care for your loved one. You can learn about ways to structure daily routines and activities to help a person with dementia feel calmer and more secure and reduce his or her agitation. There are also medicines that can help. In this guide, we discuss treatments that may slow the progress of memory loss and cognitive impairment and strategies for reducing agitation. The treatments discussed here are based on recent recommendations of a panel of physician experts on the treatment of dementia.

WHAT IS DEMENTIA?

The term *dementia* refers to a severe loss of thinking abilities, especially memory. In addition to memory loss, a person with dementia may have trouble carrying out everyday tasks. The person may get lost in familiar surroundings or show poor judgment. A person with dementia may also show changes in personality and lose interest in activities he or she used to enjoy. Dementia happens most often in later years and is especially common in people over age 85. Some memory loss is normal as we age, but dementia is not. Many of us may worry that we are becoming "senile" if we become slightly forgetful or absent-minded as we age. But these memory changes often remain mild and do not interfere with our functioning and are thus not part of dementia. Unlike memory changes that are

*This guide is adapted from Kahn D, Gwyther LP, Frances A, et al. A Guide for Families and Caregivers. In *The Expert Consensus Guideline Series: Treatment of Agitation in Older Persons with Dementia*, Postgrad Med Special Report April 1998, pp 81–88. Treatment recommendations in this guide are based on a recent survey study of experts published in Alexopoulos GS, Jeste DV, Chung H, et al. *The Expert Consensus Guideline Series: Treatment of Dementia and its Behavioral Disturbances.* Postgrad Med Special Report January 2005. The authors thank the following organizations for their valuable help in reviewing this guide: Alzheimer's Association, American Federation for Aging Research, and National Citizens' Coalition for Nursing Home Reform. Abbott Laboratories, Eli Lilly and Company, Forest Pharmaceuticals, Inc., and Pfizer Inc. provided independent educational grants in support of this project. An Adobe Acrobat file of this guide can be downloaded at www.psychguides.com.

part of the aging process, memory loss in dementia becomes increasingly severe over several years. If you have questions, a doctor can help you tell the difference.

Dementia is caused by a disease that damages tissues in the brain, causing disturbed brain functioning. The most common kinds of dementia are *Alzheimer's disease* and *vascular dementia*. Some people have a combined type of dementia involving both Alzheimer's disease and vascular dementia. Two other kinds of dementia are dementia with Lewy bodies and frontotemporal dementia. Other less common causes of dementia include Parkinson's disease, alcoholism, and head injury.

Alzheimer's disease causes the gradual death of brain tissue due to biochemical problems inside individual brain cells. Scientists have found 2 types of abnormal proteins, amyloid plaques and tangles, in the brains of people with Alzheimer's disease. These proteins appear to be associated with the disease in some way. Researchers are also working to develop better tests to tell if someone has Alzheimer's disease, since it can be difficult to make a clear diagnosis in the early stages of the illness.

Vascular dementia is caused by changes in the brain's blood vessels. As a result, oxygen does not reach a part of the brain supplied by the blood vessel, and a section of the brain is damaged or dies. This causes the person to suddenly lose the functions performed by that part of the brain. This is what happens when a person has a stroke. Depending on the part of the brain that is affected, a stroke can cause a person to lose thinking abilities, muscle control, or sensation, or a combination of these. Vascular dementia can be caused by a single large stroke or the combined effect of many small strokes and other changes in blood vessels.

When an older person's memory declines, it is important to obtain a complete medical examination. The doctor can often find out if the problem has a temporary cause that can be easily reversed (such as an infection, a side effect of medicine, or a hormone problem), or if Alzheimer's disease or vascular dementia is the cause. To diagnose dementia, doctors do a complete physical examination, including special brain and memory tests. They sometimes also order specialized pictures of the brain taken by computed tomography (CT) or magnetic resonance imaging (MRI).

ARE THERE WAYS TO PREVENT DEMENTIA OR SLOW ITS PROGRESSION?

Since we do not yet know the exact causes of Alzheimer's disease, researchers have not been able to develop effective treatments to prevent it. We know more about preventing vascular dementia. The following strategies may lower the risk of dementia or slow down memory loss:

- Control of high blood pressure and diabetes is important in possibly preventing dementia.
- Aspirin helps prevent some types of strokes and is recommended for people at risk for vascular dementia, such as those who have high blood pressure or atrial fibrillation.

- Lipid-lowering medications (statins) are recommended for people with high cholesterol. They may reduce the risk of vascular dementia. Recent research suggests that statins may be associated with some short-term changes in cognition or memory but there is no evidence that these agents contribute to the development of dementia.
- Cholinesterase inhibitors may slow progression to dementia in a person who has early signs of memory loss and is at risk for Alzheimer's disease because of advanced age or a family history of Alzheimer's.
- Antioxidants (vitamins C and E) may be helpful in preventing progression to dementia but more research is needed. Recent findings suggest that treatment with high doses of vitamin E may be associated with increased mortality rates.

Ask your doctor if you have questions or concerns about any treatments that are prescribed.

WHAT TREATMENTS ARE AVAILABLE FOR DEMENTIA?

Although there are no treatments that can definitely stop loss of brain cells, medicines have been developed that can help slow the progress of cell loss and cognitive impairment. Two kinds of medications have been approved by the U.S. Food and Drug Administration (FDA) to treat cognitive symptoms of dementia.

Cholinesterase inhibitors

Cholinesterase inhibitors are drugs that prevent the breakdown of acetylcholine, a brain chemical involved in memory and other functions related to thinking. By increasing the levels of acetylcholine, these drugs may help maintain or improve cognitive abilities in some people with dementia. The doctor may recommend one of the following cholinesterase inhibitors:

- Donepezil (Aricept)
- Galantamine (Reminyl)
- Rivastigmine (Exelon)

Tacrine, the first cholinesterase inhibitor, which was approved in 1993, is rarely used now because it can cause liver damage.

NMDA antagonists

In 2003, the FDA approved memantine (Namenda), the first *N*-methyl-D aspartate (NMDA) receptor antagonist, for use in moderate-to-severe dementia. It is believed that memantine modifies the functioning of the NMDA brain receptor in a way that reduces the negative effect of too much exposure to the brain chemical glutamate. High levels of glutamate can cause the death of nerve cells and worsen memory loss.

When are these treatments used?

Cholinesterase inhibitors are often prescribed during the early phases of Alzheimer's disease and other types of dementia. The doctor may suggest using a combination of a cholinesterase inhibitor and memantine if the person does not

respond to a cholinesterase inhibitor by itself. Memantine is approved by the FDA for more severe cases of dementia, and the doctor may combine memantine and a cholinesterase inhibitor in severe dementia. Cholinesterase inhibitors and memantine can reduce memory loss, but the progress of the dementia itself may make it hard for caregivers to notice this beneficial effect. Generally, physicians consider treatment with these medications successful if memory remains unchanged for 6 months.

WHAT IS AGITATION?

Many people with dementia experience irritability, restlessness and explosive behavior best summed up by the term agitation. A person with dementia is more agitated because the brain has physically changed and no longer functions in a healthy manner. The symptoms of agitation can be disruptive or even dangerous. Agitation tends to persist and grow worse over time, and severe agitation is often the reason that families eventually decide to place loved ones in nursing homes. Here are some behavioral symptoms you may encounter:

- · Irritability, frustration, excessive anger
- "Blow ups" out of proportion to the cause
- Constant demands for attention and reassurance
- Repeated questions or telephone calls
- Stubborn refusal to do things or go places followed by explosive behavior
- · Constant pacing, searching, rummaging
- · Yelling, screaming, cursing, threats
- Hitting, biting, kicking

WHAT CAUSES AGITATION IN DEMENTIA?

In this guide, we focus on 4 of the most common problems that can cause agitation: physical and medical problems, environmental stresses, sleep problems, and psychiatric syndromes.

Physical and medical problems

If a person with dementia has become agitated for the first time or shows a change from usual behavior, the first thing to look for is a medical or physical problem. Sudden illnesses can weaken the brain and cause agitation to worsen. Your doctor might use the term delirium to describe an episode of agitation and confusion that begins suddenly because of a medical illness or too much medication. Delirium improves when the medical problem gets better or the medications are stopped. The most common medical problems that can cause agitation or delirium are bladder infections, bad colds, bronchitis or pneumonia, and dehydration or poor nutrition (especially in people who forget to eat or can't feed themselves). It is also very important to be sure that the person has not recently had a new stroke or been hurt in a fall. Flare-ups of chronic diseases such as diabetes or heart, liver, or kidney disease can also cause agitation or delirium, especially if the person cannot take medications reliably or follow a special diet.

A bad reaction to medication can cause delirium, with the person developing sudden confusion and agitation. Older people are often taking many different medications that can interact with each other. It is important to tell the doctor about any

medication the person is taking to find out if side effects of a new medicine, an interaction between medicines, or taking the wrong dose might have caused a bad reaction.

Physical problems can cause pain, discomfort, worry, or lack of sleep that can make the person upset and tired and lead to agitation. Such problems include arthritis, sitting all day in an uncomfortable position, constipation, and problems seeing or hearing.

Environmental stresses

People with dementia are more sensitive to their environment than people without dementia. The ideal environment for a person with dementia is one that provides clear, calm, and comforting structure. It is helpful to maintain a routine, since changes in schedule or rushing can cause disappointment, frustration, or fear. A physically comfortable environment is important. Being in an area that is noisy, poorly lighted, or too hot or cold can cause agitation. People with dementia can also become agitated if they are left alone for too long or if there are too many people around. A person with dementia may find it very upsetting to have to undergo a medical or dental procedure and especially to be hospitalized. These situations can cause a person who was calm at home to become very agitated and confused.

Sleep problems

People with dementia often have trouble falling asleep or staying asleep. Although the cause is often unclear, it is sometimes possible to pinpoint a reason that can be corrected—such as too much activity just before bedtime, using caffeine or alcohol, or drinking fluids before bedtime and then having to urinate. Depression or physical pain can also cause insomnia. Keep in mind that people with dementia often sleep during the day and no longer need to sleep as much during the night.

"Sundowning" is another kind of sleep problem. Sleep patterns are controlled by an internal clock in our brain that senses day and night, telling us when to rest and when to be active. This clock is often damaged in dementia leading to a problem called "sundowning," in which confusion, disorientation, and agitation appear or grow worse during the evening and night hours.

Psychiatric syndromes

People with dementia may become agitated because of psychiatric syndromes. These include psychosis, aggression or anger, depression, and anxiety.

• Psychosis means being out of touch with reality. There are two kinds of psychotic symptoms: *delusions* (incorrect beliefs) and *hallucinations* (hearing, seeing, or smelling things or feeling sensations on the skin that are not there). People with delusions cannot be convinced that their delusional beliefs are incorrect. People with Alzheimer's disease may have delusions that people have stolen their money or possessions, that a spouse is unfaithful, that unwelcome guests are living in the house, or that a relative is an imposter and not really the person he or she claims to be. The person may have visual hallucinations such as seeing nonexistent visitors or burglars. This can cause the person to fearfully report events that have not actually occurred.

- Anger and aggression. Dementia causes individuals to lose their normal ability to control angry impulses, a problem called disinhibition. A person with dementia who becomes aggressive and disinhibited may threaten another person verbally or physically, or destroy objects. Aggression may happen because the person misunderstands or misinterprets the actions of others, and then lashes out because he or she feels ignored, afraid, or mistreated. The person may also become angry because he or she feels frustrated at being unable to complete tasks that were once easy, such as fixing something that is broken, using the stove, or going to the bathroom. Sometimes there is no obvious cause for the person's frustration. Anger and aggression can lead to verbal accusations and insults, aimless screaming, refusal to cooperate with requests to eat or bathe, and even physical assaults. Aggression can also cause people to hurt themselves, for example by banging their head against the wall or bed or biting themselves. When a person with dementia becomes aggressive, it is important to evaluate the environment and make changes to improve safety. Aggression can usually be helped by providing reassurance and a comfortable soothing environment. It is more helpful to distract rather than confront an agitated person with dementia. Medication may also be needed.
- Depression. Dementia can cause brain changes that lead to depression. Even though the depression is related to the dementia, it can be treated and should not be ignored. When depression is successfully treated, people with dementia are more able to enjoy time with their families and other pleasurable activities. If your loved one looks sad, is tearful, appears unable to enjoy anything, frequently expresses feelings of discouragement, failure, or being a burden, or says he or she wants to die or commit suicide, tell the doctor so that he or she can evaluate the person for depression. Depression often causes physical symptoms such as loss of appetite and weight, trouble sleeping, or complaints of physical pain. If no other medical cause is found for these physical symptoms, depression should be considered, even if the person denies feeling sad but just seems withdrawn or to have lost interest in things. Depression can also make people agitated. This might appear as extreme tearfulness, hand-wringing, an excessive need for reassurance, or other signs of extreme unhappiness. Depression can also cause the person to have delusions, most often guilty feelings about having done terrible things in the past.
- Anxiety means being very worried. The person may become nervous, fidgety, shaky, or frightened because of exaggerated fears that often have little basis in reality. During the early stages of the illness, the diagnosis of dementia itself can cause anxiety because of concerns about the future and fear of the disease. The person may also feel anxious and worried about making mistakes, forgetting things, or having trouble joining a conversation. An anxious person may not always be able to put the feelings into words, but instead may appear tense or have physical symptoms such as a racing heart, nausea, or butterflies in the stomach. People with dementia may become especially anxious when they are separated from caregivers, when their schedules are changed, or when they are rushed or tired.

TREATMENT OF AGITATION

How soon should agitation be treated?

Agitation does not go away by itself. Research shows that it usually continues for 2 or more years, especially if it is associated with aggressive behavior. If treatment is begun early, there is a better chance to find the most effective and safest treatment before agitation causes safety or health risks for the person or the family.

How is agitation treated?

There are a number of ways that you and the clinicians working with you can help an agitated person:

- · Providing the right environment
- Supervising activities
- · Learning to communicate with a person who has dementia
- Getting support and improving coping skills
- Medication

PROVIDING THE RIGHT ENVIRONMENT

It is important to evaluate the person's environment—his or her bedroom, daytime areas, and schedule—to see if any of the following problems may be contributing to agitation:

- Some people with dementia become particularly agitated at certain times of the day. Would it help to change the person's routine to avoid these problems? It is helpful to try to do things in the same place at the same time each day.
- Agitation may result from thirst or hunger. If a person with dementia forgets to eat, offer frequent snacks and beverages.
- Agitation may result from physical discomfort. Has the person remembered to use the bathroom? Is he or she constipated? Could there be aches and pains from sitting in one place?
- Does the person have a regular, predictable routine? Unexpected changes or last minute rushing can cause people with dementia to become scared and disoriented.
- Getting dressed can be frustrating for someone with dementia. Try to simplify this task, for example, by using Velcro fasteners and not insisting on matching outfits.
- Is the person feeling stressed, hungry, tired, scared, cold, or hot? Does he or she need to use the bathroom? Fresh air or air conditioning can reduce agitation. It is also important not to rush individuals with dementia.
- Is there a chance for regular exercise? Walks and simple exercises are good ideas. If a person wants to pace and isn't disrupting anyone, that's OK, too.
- Is the room well lighted? Good lighting can help reduce disorientation and confusion. Provide night-lights.
- Is the environment too noisy or confusing? Are there too many people around? It may be helpful to use picture cues, to personalize the room, and to decorate and highlight important areas with bright contrasting colors.
- Is the environment safe? If not, take necessary steps to
 ensure the safety of the person and his or her caregivers (e.g.,
 lock up knives and guns, take stove knobs off at night, put
 safety latches on doors, camouflage unprotected exits, install
 inconspicuous locks to restrict access to cleaning solutions
 and other hazardous substances or poisons). It is a good idea

to register the person with the Alzheimer's Association SAFE RETURN program (p. 108) in case he or she wanders off and gets lost.

SUPERVISING ACTIVITIES

People with dementia often need help or supervision in dealing with activities of daily living, such as getting dressed and bathing. Giving the person something useful or interesting to do, especially when directions and structure are offered, can help prevent anxiety and agitation. Here are some suggestions:

- Structure and routine. Try to follow regular predictable routines that include pleasant, familiar activities. Remind the person that everything is going according to plan.
- Pleasant activities. Make time for simple pleasant activities
 the person knows and enjoys. Listening to music, watching
 a movie or sporting event, sorting coins, playing simple
 card games, walking the dog, or dancing can all make a big
 difference.
- Keep things simple. Break down complex tasks into many small, simple steps that the person can handle (e.g., stirring a pot while dinner is being prepared; folding towels while doing the laundry). Allow time for frequent rests.
- Redirect. Sometimes the simplest way to deal with agitation
 is to give the person something else to do as a substitute.
 Someone who is restless and fidgety can be asked to sweep,
 dust, rake, fold clothes, or take a walk with the caregiver. A
 person who is rummaging can be given a group of items to
 sort and arrange.
- Distract. Sometimes it is enough to offer a snack or put on a favorite videotape or some familiar music to interrupt behaviors that are becoming difficult.
- Be flexible. Your loved one may want to do something or behave in a way that at first troubles you, or may refuse to do something you planned, like taking a bath. Before trying to interfere with a particular behavior, ask yourself if it is important to do so. Even if the behavior is bizarre, it may not be a problem, especially in the privacy of your own home.
- Soothe. Simple, repetitive activities, such as massage, hair-brushing, or a manicure, may help reduce agitation.
- Compensate. It is important to let people with dementia do things they are able to do, so that they will feel empowered. At the same time, helping the person with tasks that are too demanding for them is comforting and prevents frustration.
- Reassure. Let the person know you are there and will keep him or her safe. Try to understand that fear and insecurity are the reasons the person may "shadow" you around and ask for constant reassurance.
- Getting to doctor appointments. Is the person upset about going to the doctor or dentist? Here are some helpful hints: Stress the importance of having regular check-ups rather than talking about a specific test. Try to figure out if your loved one does better with advance notice in order to prepare or if he or she responds better without being told ahead of time. Present the trip in a matter-of-fact way as part of the day's plans. Allow plenty of time to avoid having to rush. If possible, have the relative or caregiver who works best with the patient come along to the appointment. If the person resists, don't argue; instead, try distractions like "We will go out to lunch afterward."

LEARNING TO COMMUNICATE WITH A PERSON WHO HAS DEMENTIA

People with dementia often find it hard to remember the meaning of words or to think of the words they want to say. During the late phases of the illness, people with dementia may communicate mainly by gestures and expressions. The following suggestions may help you communicate with a person who has dementia:

- It is understandable that you may sometimes feel angry; but showing your anger can make the person's agitation worse. If you are about to lose your temper, try "counting to ten," remembering that the person has a disease and is not deliberately trying to make things difficult for you.
- Try and talk about feelings rather than arguing over facts.
 For example, if the person with dementia is mistakenly convinced you didn't see him yesterday, focus on his feelings of insecurity today: "I won't forget you."
- Identify yourself by name and call the person by name. The person may not always remember who you are; don't ask "Don't you remember me?"
- Approach the person slowly from the front and give him or her time to get used to your presence. Maintain eye contact. A gentle touch may help.
- Try to talk in a quiet place without too much background noise such as a television or other people in conversation.
- Speak slowly and distinctly. Use familiar words and short sentences.
- Keep things positive. Offer positive choices like "Let's go out now," or "Would you like to wear your red or blue cap?"
- If the person seems frustrated and you don't know what he
 or she wants, try to ask simple questions that can be
 answered with yes or no or one-word answers.
- Use gestures, visual cues, and verbal prompts to help. For example, if suggesting a walk, get out the coats, open the door, and say "Time for a walk." Set up supplies in advance for tasks such as bathing and dressing; have a special signal for needing to go to the bathroom. Try to break up complicated tasks into simple segments; physically start doing what you want to happen.
- If a subject of conversation makes a person agitated or frustrated, it is better to drop the issue rather than keep trying to correct a specific misunderstanding. He or she will probably forget the issue and be able to relax in a short while.

GETTING SUPPORT AND IMPROVING COPING SKILLS

Some of your loved one's behaviors may be difficult, exhausting, and even frightening for you. When you feel frustrated, try to remember that these behaviors are part of the disease that is affecting the person's brain. Many caregivers struggle with feelings of guilt and anger and need support and reassurance to remember that the disease is creating the behavior, not the person they once knew.

Social support is important for caregivers, whose own mental health can be affected by the stress and sadness of caring for someone with dementia. Help is available from support organizations, newsletters, books, and sites on the Internet—many of these are listed at the end of this guide. Joining a support group allows caregivers to meet and share ideas with others

who are coping with similar problems. Group members who have "been there" can often share good ideas for dealing with day-to-day problems. You can locate the nearest support group by contacting the Alzheimer's Association or sometimes through a community organization (e.g., senior center) or a local hospital.

Therapists can help caregivers deal with stress, anxiety, or depression and sort out conflicts about priorities in time or living arrangements. Religious organizations can also help through support groups, and some individuals may find solace in counseling from a member of the clergy.

Caregivers sometimes find it hard to arrange time to attend meetings or groups outside the home. In this case, you might want to try calling one of the telephone help lines, most of which are toll-free, where clinicians and counselors as well as trained peer counselors are available to answer questions or just talk about problems you may be having. There are also a number of Web sites, Internet chat groups, e-mail listserves, and bulletin boards that can provide support and information for caregivers. In addition, there are many good educational publications and videotapes. Some have been written or produced by experts for families and caregivers; others have been written by family members or even people with dementia. Refer to the end of this guide for information on available resources.

MEDICATIONS FOR AGITATION

When are medications used to treat agitation?

Sometimes it is impossible to help a person become calm, despite your best efforts at providing warmth and structure. Medication for agitation can help you avoid caregiver "burn out" and make it easier for the person to respond to your efforts. The more severe the agitation, the more important it is to consider medication. Medication does not "cure" dementia or agitation but can lessen the frequency and severity of agitated behavior.

The authors of this article conducted a survey study of experts on the treatment of dementia to find out which medications they consider most helpful in reducing agitation in people with dementia. The information in the following sections is based on their recommendations and recent research findings. It is important to remember that some trial-and-error is often involved in finding the right medication, dose, and schedule-every treatment plan is "custom made." Although the doctor will of course be prescribing the medication, it is a good idea for you to learn as much as you can about the various treatments, their likely benefits, and possible side effects. Ideally, you can become the doctor's partner, since you see the person more than anyone else and may be in the best position to know how a medication affects him or her. Families sometimes worry that medicines for agitation will just sedate a person or make confusion worse, or that they are shirking responsibility by relying on medication. However, careful use of medication can lessen agitation without unwanted sedation and help you better care for and communicate with your loved one.

How do doctors choose specific medications?

The doctor will consider a number of factors in recommending a medication for your loved one:

- Is the goal short-term or long-term? The goal of short-term treatment is to calm the person down quickly during a crisis. Often this means making the person somewhat drowsy for a few hours. Since agitation is often a long-term problem, the goal is often to find a medicine that can be used for weeks or months without causing unwanted sedation or harmful side effects. Since it can take several weeks for these longer-term treatments to start working, it is important to try to be patient as doses are slowly and carefully adjusted.
- What other medical problems does the person have and what other medicines is he or she already taking? Medical illnesses can make a person more sensitive to medication side effects. Older people often take many medicines, so that it is very important to avoid adding a drug that will interact with what the person is already taking. Certain illnesses can also make it harder to use some medications. For example, people with lung disease should avoid medicines that might slow down breathing. People who are unsteady on their feet or have a history of falls should avoid medicines that might affect coordination.
- What types of agitation does the person have? In choosing a medication, the doctor will consider the kinds of agitation symptoms the person has. For example, some

medicines are better for agitation that is due to psychosis, whereas others may be more helpful if the agitation is caused by anxiety or depression.

What medications are used for different types of agitation?

Many kinds of medication can be used to treat agitation, depending on the person's main symptoms. The table on this page shows medicines that were recommended for different problems in a recent survey study of experts on dementia. Each type of medicine is discussed in detail in the sections that follow. In prescribing medications for your loved one, the doctor may have to try several before finding one that will help. Doctors usually try to use as few medications as possible to treat older patients with dementia in order to avoid interactions among medications.

Antipsychotics

Antipsychotic medications (sometimes called neuroleptics) have been the mainstay for treating agitation for many years. Two kinds are available:

- Conventional antipsychotics, such as haloperidol (Haldol), that have been available for the past 40 years
- Atypical antipsychotics, such as aripiprazole (Abilify), olanzapine (Zyprexa), quetiapine (Seroquel), risperidone (Risperdal), and ziprasidone (Geodon)

Medication Strategies	
Main problem	Usual choices to start with
Delirium from a sudden medical problem	Atypical antipsychotic*
Psychosis	Atypical antipsychotic* Also consider a conventional antipsychotic for short-term use
Aggression, anger	Atypical antipsychotic* Also consider a conventional antipsychotic for short- term use and divalproex for long-term use
Insomnia or "sundowning" (confusion in late afternoon or early evening)	Trazodone Also consider quetiapine, zolpidem, or zaleplon for short-term use and quetiapine for long-term use
Anxiety	Benzodiazepine or atypical antipsychotic* for short-term use only Selective serotonin reuptake inhibitor (SSRI) for long-term use
Depression	Antidepressant, especially an SSRI, possibly combined with a cholinesterase inhibitor. An atypical antipsychotic* may be given with the antidepressant for psychotic depression.
Pain from arthritis if over- the-counter pain medicines don't work	Tricyclic antidepressant, SSRI, venlafaxine, duloxetine, trazodone

^{*}e.g., aripiprazole, olanzapine, quetiapine, risperidone, ziprasidone

Antipsychotics help reduce delusions, hallucinations, aggression, and sundowning. They work quickly and can make the person drowsy, so that they are useful in emergencies. Haloperidol, olanzapine, and ziprasidone can be given in a shot (injection) if the need is urgent.

The older conventional antipsychotics (such as haloperidol) can cause some unpleasant side effects. These include a kind of muscle stiffness called dystonia (rare in the elderly), slowed down movements and tremor that resemble Parkinson's disease, a restless feeling called akathesia that makes a person want to pace around, and, sometimes after months or years of use, involuntary movements of the mouth or hands called tardive dyskinesia.

Because of these side effects of the older medicines, the newer atypical antipsychotics are now the first choice for treating agitation in people with dementia. The newer antipsychotics are less likely to cause movement side effects than the older drugs, especially with long-term treatment.

Antidepressants

The selective serotonin reuptake inhibitors (SSRIs) are a group of antidepressants that are most often recommended for older people with dementia. These include citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), and sertraline (Zoloft). Other antidepressants the doctor may prescribe include bupropion (Wellbutrin), duloxetine (Cymbalta), mirtazapine (Remeron), venlafaxine (Effexor), or a tricyclic antidepressant

(e.g., desipramine or nortriptyline). The doctor may need to try more than 1 antidepressant before finding the best one for an individual. It is important to be patient, since it often takes several weeks to see if an antidepressant is helping. During that time, you can sometimes help keep up a person's spirits with activities, a day program, or a support group.

People with depression sometimes have delusions; they may fear that their body organs are not working, that they have been abandoned by everyone, or that they have no money (when in fact they do). Delusional depression can be life-threatening: It may increase the risk for suicide or cause the person to refuse to eat and drink leading to severe weight loss and dehydration. It can also cause agitation and trouble sleeping. If the person has severe depression and delusions, the doctor may either give an antidepressant and an antipsychotic medication together, or prescribe electroconvulsive therapy (ECT, sometimes called shock treatment). Most patients who receive ECT have not responded to medication. Although there are many negative myths about ECT, research has shown that it can be used safely in older patients.

Antidepressants can help treat conditions besides depression. Some antidepressants, especially the SSRIs, can help with anxiety. Tricyclic antidepressants, SSRIs, venlafaxine, duloxetine, and trazodone are also used to give relief in arthritis pain and certain types of nerve pain. Trazodone is sold as an antidepressant but is usually too sedating for this purpose; it is often used as a sleep aid (see below).

Divalproex (Depakote)

Divalproex was developed as a treatment for epilepsy and is also used to stabilize mood in bipolar disorder (manic-depressive illness). Divalproex can help people with dementia who are showing aggression or anger. It is often combined with an antipsychotic medicine. Side effects of divalproex are nausea and sedation, which can be reduced by starting with low doses, making gradual adjustments, and monitoring the level of medication in the bloodstream.

Trazodone (Desyrel)

Trazodone is a relatively safe, non-habit-forming medication that works as an antidepressant at high doses. However, doctors often use low doses of trazodone to treat insomnia. It can also be used as a short-term treatment for anxiety or when a mild sedative is needed. To help with sleep it is usually given about 1 hour before bedtime. The main side effect is drowsi-

ness if the dose is too high. Other side effects include dizziness when standing up and, very rarely, painful erections in men.

Benzodiazepines and other sedatives

Benzodiazepines and other sedatives can relieve anxiety and make people drowsy. These sedatives are mainly used when someone needs to be calmed down quickly. Benzodiazepines can be habit-forming if used steadily for more than a few weeks; even single doses can cause unsteady gait and interfere with memory. Because of these problems, doctors usually avoid using them for long-term treatment of insomnia, anxiety, or agitation unless other choices have failed.

Among the benzodiazepines, lorazepam (Ativan) and oxazepam (Serax) are preferred in older patients because they are cleared from the body almost as quickly in older patients as in younger patients. Zolpidem (Ambien) is a non-benzodiazepine sedative. Its effects last 6 to 8 hours and it is usually given to help with sleep. Other benzodiazepines, such as flurazepam (Dalmane) and clonazepam (Klonopin) stay in the body longer and are usually avoided because they can cause daytime sedation or falls.

A FINAL WORD ABOUT AGITATION IN DEMENTIA

It is painful to see a family member change and decline because of dementia, and especially difficult if agitation is also present. It is helpful to remember the following points in caring for an agitated family member with dementia:

- The agitation is caused by a medical illness; it is not the fault of the person with dementia.
- It is important to provide a calm, structured, safe, and caring environment.
- Carefully chosen medications can relieve distress and help the person function.

Research in treating agitation is only in the very early stages. We have presented the best of current opinion, but much remains to be learned. The organizations listed on the next page can help you find information about research studies of new treatments in which your loved one may be able to participate. Learn as much as you can about dementia and the agitation that can occur with dementia—your knowledge will make a difference in the quality of life for you and your family member.

INFORMATION, ADVOCACY, AND RESEARCH

Alzheimer's Association

World leader in Alzheimer's research and support. Largest and oldest voluntary health organization dedicated to Alzheimer's prevention, treatment, care, and support. Provides reliable information and care consultation, creates supportive services for families, increases funding for dementia research, and influences public policy changes. Provides care and support through more than 300 points of service. Extensive materials are available through the Green-Field Library: 312-335-9602. Maintains the Safe Return Program (see below).

225 N. Michigan Ave., Floor 17 Chicago, IL 60601 800-272-3900 www.alz.org

Alzheimer's Association Safe Return

Nationwide program to provide assistance when a person with dementia wanders and becomes lost. Assistance is available 24 hours a day, 7 days a week. One call activates community support network. Safe Return faxes enrolled person's information and photo to local law enforcement. When the person is found, a citizen or law official calls the 800 number on the identification products and Safe Return notifies listed contacts. One time enrollment fee of \$40 (scholarships are available in some areas). Enroll online, by phone using a credit card (888-572-8566) or by mail (form available in several languages online or by calling 888-572-8566).

Alzheimer's Association Safe Return P.O. Box A3687 Chicago, IL 60690-3687

Alzheimer's Disease Education and Referral Center (ADEAR)

Service of the National Institute on Aging (NIA), the primary U.S. Government agency for research on Alzheimer's disease. ADEAR provides up-to-date and comprehensive information on Alzheimer's disease for health professionals, people with Alzheimer's disease and their families, and the public. Makes available answers to questions, free publications in English and Spanish concerning Alzheimer's disease, and referrals to supportive services and research centers.

ADEAR Center PO Box 8250 Silver Spring, MD 20907-8250 800-438-4380 www.alzheimers.org

American Federation for Aging Research

Leading national organization supporting medical research on aging and age-related diseases. Publishes *Lifelong*, a monthly newsletter for patients and families. Maintains a consumer Web site with useful information on aging at www.infoaging.org.

American Federation for Aging Research (AFAR) 70 West 40th Street, 11th Floor New York, NY 10018 888-582-2327, 212-703-9977 www.afar.org

National Citizens' Coalition for Nursing Home Reform

Offers information on getting the best care in nursing homes, about regulations that protect nursing home residents, and other useful information for caregivers.

1424 16th Street NW, Suite 202 Washington, DC 20036 202-332-2275 www.nursinghomeaction.org

Other Useful Resources

- Children of Aging Parents (www.caps4caregivers.org) 800-227-7294
- National Association for Continence (www.nafc.org) 843-377-0900, 800-BLADDER (800-252-3337)
- American Association of Retired Persons (AARP) (www.aarp.org) 888-687-2277
- National Insurance Consumer Helpline 800-942-4242
- National Hospice and Palliative Care Organization (www.nhpco.org) 703-837-1500, 800-646-6460
- Eldercare Locator (www.eldercare.gov) 800-677-1116
- Medicare Hotline (www.medicare.gov/CallCenter.asp) 800-MEDICAR (800-633-4227)
- Social Security Information (www.ssa.gov) 800-772-1213
- Agency for Health Care Policy and Research Publications Clearing House: Early Alzheimer's Disease: Patient and Family Guide can be downloaded at www.ahcpr.gov/clinic/alzcons.htm
- Alzheimer's Caregiver Support Online (www.alzonline.net) 866-260-2466

FOR MORE INFORMATION

Alzheimer's disease: unraveling the mystery, NIA, 2002. Available on www.alzheimers.org or by calling 800-438-4380.

Bell V, Troxel D. A dignified life: the best friends approach to Alzheimer's care: a guide for family caregivers. Health Communication Press, 2002

Bryan J. Love is ageless: stories about Alzheimer's disease, 2nd ed. SCB Distributors, 2002

Davis R. My journey into Alzheimer's disease. Tyndale, 1989 Gruetzner H. Alzheimer's: a caregiver's guide and sourcebook, 3rd ed. Wiley, 2001

Mace NL, Rabins PV. The thirty-six hour day: a family guide to caring for persons with Alzheimer's disease, related dementing illness, and memory loss in later life, rev. Warner Books, 2001

Mittelman MS, Epstein C. The Alzheimer's health care handbook: how to get the best medical care for your relative with Alzheimer's disease, in and out of the hospital. Marlowe & Company, 2003

Rose L. Show me the way to go home. Elder Books, 1995 Shanks LK. Your name is Hughes Hannibal Shanks: a caregiver's guide to Alzheimer's disease. University of Nebraska Press, 1996

Newsletters

Alzheimer's Association: National and local chapter newsletters Lifelong. Monthly newsletter of the American Federation for Aging Research (www.afar.org)

The Caregiver. Newsletter of the Duke Alzheimer's Family Support Program. Available along with other publications on www.geri.duke.edu/service/dfsp/index.htm or by calling 919-660-7510.