

The Expert Consensus Guideline Series

Agitation in Older Persons with Dementia



A Guide for Families and Caregivers

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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. In the United States, more than 10% of the population over age 65 has dementia (more than 4 million Americans). As people in our society live longer and in better overall health, it is sad that many of us have to face the decline in memory and thinking of someone we love—we slowly seem to lose the person we knew even while life continues.

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, which makes it much harder to care for them. Even under the best circumstances, 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. There are many things you can do to help your loved one and yourself. Support groups and national organizations offer practical advice that can help you solve problems and feel better about the job you are doing. You can learn about ways to go about daily routines and activities that help a person with dementia feel calmer and more secure, reducing his or her agitation. There are also medicines that can help. In this guide, we discuss these strategies for reducing agitation, which are based on the recent recommendations of a panel of expert doctors.

WHAT IS DEMENTIA?

The term *dementia* refers to a severe loss of thinking abilities, especially memory. It occurs most often in later years and is especially frequent in those 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, but these normal memory changes remain mild and do not impair our functioning. In contrast, dementia progresses to more and more serious problems, usually over several years. If you have any question, a doctor can help determine the difference for you.

Dementia is always caused by an underlying disease that damages brain tissue, leading to disturbed brain functioning. The most common such diseases are Alzheimer’s disease and strokes (vascular disease). There are also less common causes, including Parkinson’s disease, alcoholism, head injury, and others.

Alzheimer’s disease causes gradual death of brain tissue due to biochemical problems inside individual brain cells. There is important research under way to determine the exact cause of the abnormality, which is not yet known. There are promising medicines that sometimes slow the pace of memory loss in Alzheimer’s disease—we will not be discussing them in this guide, but you may want to ask your doctor about them. Researchers are working to find even better treatments as well as better tests to tell if someone has Alzheimer’s disease, since it is often hard to make a clear diagnosis in the early stages. To learn more about these and other research advances, you can contact one of the organizations listed at the end of this guide.

I am more than memory—

I am still here.

A musician with Alzheimer’s disease

A stroke occurs when a blood vessel in the brain is blocked or leaking. As a result, oxygen does not reach the area supplied by the blood vessel, and a section of the brain is damaged or dies (called an *infarct*). This causes a sudden loss of the functions performed by that section of the brain. Depending on its location, a stroke can cause loss of thinking abilities, of muscular control, or of sensation, or combinations of these. Dementia can result from a single large stroke, or the accumulated effect of many small strokes (*multi-infarct or vascular dementia*). Agitation after a stroke can be very severe. Stopping smoking and maintaining normal blood pressure and cholesterol levels all help prevent strokes. Medicines such as aspirin are also used to prevent some types of strokes. Your doctor will be familiar with these preventive approaches.

When an older person appears to have major changes in memory or thinking, a complete medical evaluation is essential. The evaluation determines if the problem has a temporary cause that can be easily reversed (such as an infection, a drug side effect, or a hormone deficiency) or if there is truly ongoing dementia from an underlying condition such as Alzheimer's disease or strokes. The doctor will perform a complete physical examination, including special neurological and memory tests, and will probably take blood tests. A specialized picture of the brain (such as a computed tomography [CT] scan or a magnetic resonance imaging [MRI] scan) is also sometimes taken.

WHAT IS AGITATION?

Many people with dementia experience emotional distress or behavioral changes best summed up by the term *agitation*. Very mild agitation may seem like a personality change in which a person acts in ways that are uncharacteristic or inappropriate for him or her, such as being very stubborn, worried, or nervous. More severe agitation forces caregivers to constantly supervise or reassure the person. These distressing symptoms can be disruptive or even dangerous. Agitation tends to persist and to 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 problems you may encounter:

- Irritability, frustration, excessive anger
- “Blow-ups” out of all proportion to the cause
- Constant demands for attention and reassurance
- Repetitive questions, demands, or telephone calls
- Stubborn refusal to do things or go places
- Constant pacing, searching, rummaging
- Yelling, screaming, cursing, threats
- Hitting, biting, kicking

WHAT CAUSES AGITATION IN DEMENTIA?

We will discuss four problems that can cause agitation: physical and medical problems, environmental stresses, sleep problems, and psychiatric syndromes (psychosis, anger and aggression, depression, and anxiety). Remember that, in all these situations, a person with dementia is more easily agitated because the brain has physically changed and no longer functions in a healthy manner.

Physical and medical problems

If a person with dementia has recently become agitated for the first time or has a change from his or her usual behavior, the first thing to look for is a medical or physical problem.

Sudden illnesses may weaken the brain, causing worsened agitation. Your doctor might use the term *delirium* to describe an episode of agitation and confusion that begins suddenly because of a medical illness. Delirium improves when the medical problem gets better. 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 make sure that someone who has become more agitated has not recently had a new stroke or been injured in a fall. Finally, flare-ups of chronic diseases such as diabetes or diseases of the heart, liver, or kidneys can cause agitation or delirium, especially if a person with dementia cannot take medications reliably or follow a special diet.

A toxic reaction to medication is an important cause of sudden confusion and agitation. Older people often take many different medications that can interact with each other. It is crucial to find out if side effects of a new prescription, interactions between medicines, or taking the wrong dose have led to a bad reaction.

Common physical problems that cause pain, discomfort, worry, or lack of sleep can lead to agitation by making the person upset or fatigued. Examples of such problems include arthritis, sitting all day in an uncomfortable position, constipation, and impaired vision or hearing.

Environmental stresses

People with dementia are very sensitive to the environment they live in. They are less able to handle changes, uncertainty, and other situations that they could manage when they were well. The ideal environment for a person with dementia provides clear, calm, comforting structure—often not an easy situation to arrange. Routine is very important, since changes in schedule or rushing can cause extreme disappointment, frustration, or fear. A physically comfortable environment is important. Noisy, poorly lit, or improperly heated areas can cause increased agitation. Extremes in the social environment can also cause problems (for example, if someone is left alone for long periods or is overwhelmed by being around too many people). Medical or dental procedures, and especially hospitalization, are particularly disruptive and can lead to sudden agitation or confusion in a person who was calm at home.

Sleep problems

Sleep problems are common in dementia. One type of problem is insomnia—trouble falling asleep at night or waking up throughout the night. Although the cause is often unclear, it is sometimes possible to pinpoint a reason that can be corrected, such as busy activities just before bedtime, using caffeine or alcohol, or drinking fluid before bedtime and then having to urinate. Conditions such as depression, nervousness, or physical pain can also cause insomnia. It also helps to keep in mind that many people need less sleep as they age, but that the person with dementia has a very hard time finding purposeful things to do during longer waking hours.

“Sundowning” is another type 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. The person may be awake and overactive at night, thinking it should be daytime and trying to get dressed and out of bed. This type of confusion, disorientation, and agitation is called sundowning because it usually begins in the early evening in a person who might otherwise be fairly clearheaded when awake during the daylight hours.

Psychiatric syndromes

Psychosis, aggression or anger, depression, and anxiety are common psychiatric syndromes seen in agitated persons suffering from dementia.

It's like her eye can take my picture,
but her brain can't develop it.

A granddaughter

- **Psychosis** means being out of touch with reality in an irrational way. The person imagines things and is convinced these things are real. There are two types of psychotic symptoms: delusions (believing things that are not true) and hallucinations (hearing, seeing, or smelling things or feeling physical sensations on the skin that are not there). You cannot convince a person with psychosis that his or her beliefs are untrue. The most common delusions are believing that one is in danger from criminals, that others have stolen items or money, 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. These are also sometimes referred to as paranoid delusions and reflect fear and insecurity that result from being confused. Visual hallucinations such as seeing nonexistent visitors or burglars can cause a person to fearfully report events that have not actually occurred.
- **Anger and aggression.** Dementia causes the brain to lose its normal ability to control angry impulses, a problem called *disinhibition*. Anger becomes aggression when the person acts on these feelings by verbally or physically threatening another person or attacking objects. It may occur because the person with dementia often misunderstands or misinterprets the actions of others, and then lashes out because he or she feels ignored, in danger, or mistreated. Another cause of anger is frustration 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 of frustration. Anger and aggression can include verbal accusations and insults, aimless

screaming, refusal to cooperate with requests to eat or bathe, and even physical assaults. Aggression can also include self-injury such as head banging or biting oneself. When a person with dementia becomes angry and aggressive, it is important to evaluate the person's environment to be sure it is safe and to see if some simple adjustments might reduce the likelihood of injury. Although aggression is among the most distressing problems for caregivers, it can usually be helped with extra attention and sometimes medication; it should not be ignored in the hopes it will go away by itself.

- **Depression.** A person with depression feels sad or loses interest in things he or she normally enjoys. Although depression is an understandable reaction to an illness such as dementia, it is a treatable symptom, not a “normal” reaction, and should not be ignored. Successful treatment of depression helps individuals with dementia enjoy time with their families and other pleasurable activities. A diagnosis of depression should be considered if a person is often sad, tearful, or unable to enjoy anything or expresses constant thoughts of discouragement, failure, being a burden, or wanting to die or commit suicide. Depression often includes 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 more withdrawn, apathetic, or disinterested. Agitation in depression can include extreme tearfulness, hand-wringing, an excessive need for reassurance, and other signs of extreme unhappiness. Depression can also cause delusions, most often guilty feelings about having done terrible things in the past.
- **Anxiety** means being very worried, overly fearful, nervous, fidgety, shaky, or frightened, either because of exaggerated fears or sometimes for no apparent reason. An important cause of anxiety may be the diagnosis of dementia itself, especially in the early stages when a person can feel embarrassed by 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 racing heart, nausea, or “butterflies in the stomach.” Anxious people worry about things such as being alone, or they may fear that visitors will be late, that loved ones have been harmed, or that plans will be disrupted. They may become especially nervous when they are separated from caregivers, when schedules are changed, or when they are rushed or tired.

TREATMENT OF AGITATION

How soon should agitation be treated?

Agitation should be treated early, because it means the person with dementia is suffering emotionally or physically. Agitation doesn't go away by itself. Research studies show that it usually persists for 2 or more years, especially if it is associated with aggressive behavior. If treatment is begun early, there is an opportunity to find the most effective and safest treatment before agitation poses 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 how to talk with a person who has dementia
- Getting support for families and caregivers and improving coping skills
- Medications

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:

Whoever thought she'd eat
the pebbles in the fish tank?
A husband

- Some individuals become particularly agitated at specific 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 those 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 matched outfits.
- Is there a chance for regular exercise? Walks and simple exercises are good ideas. If the 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 air temperature comfortable? Try to provide fresh air, heating, or air conditioning as needed.
- 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 the necessary steps to ensure the safety of the patient and caregiver (e.g., lock up knives and guns, take knobs off the stove 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 SAFE RETURN program through the Alzheimer's Association in case he or she wanders off and gets lost.

SUPERVISING ACTIVITIES

People who are getting agitated can sometimes feel better if they have something useful or interesting to do. However, they usually need direction to find appropriate activities and to prevent frustration. Here are some suggestions that can help:

- **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 agitated behavior is to get the person to do something else as a substitute. For example, a person who is restless and fidgety can be asked to sweep, dust, rake, fold clothes, or take a walk with the caregiver. Someone who is rummaging can be given a collection 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 might want to do some activity or behave in a way that at first troubles you, or may refuse to do something you have planned, like taking a bath. Before trying to interfere with a particular behavior, it is important to ask yourself if it is necessary to do so. Even if the behavior is bizarre, it may not be a problem, especially in the privacy of your own home.
- **Soothe.** When the person is agitated, it may help to do simple, repetitive activities such as massage, hair brushing, or giving a manicure.
- **Compensate.** Help the person with tasks that are too demanding. Don't put the person in a position where demands will be made that he or she cannot handle.

I sit for hours. My mind is blank.
I don't have a single thought.
Woman with early Alzheimer's disease

- **Reassure.** Let the person know that 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’s appointments.** Is the person upset about going to the doctor or dentist? Here are some helpful hints: Emphasize the value of a checkup, rather than a test for a specific problem. Try to figure out if your relative is the type of person who does better with advance notice in order to prepare, or does better without being told ahead of time. Present the trip in a matter-of-fact manner as part of the day’s plans. Allow enough time so that you are not rushed. 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 HOW TO TALK WITH A PERSON WHO HAS DEMENTIA

People with dementia often find it hard to remember the meaning of words that you are using or to think of the words they want to say. You may both become frustrated. The following tips can help you communicate more effectively with a person who has dementia:

Home is the place
where I can remember.
Man with early Alzheimer’s disease

- It is understandable that you may feel angry; but showing your anger can make the 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 to 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 or her 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 you suggest a walk, get out the coats, open the door, and say “Time for a walk.” Set up needed supplies in advance for tasks such as bathing and getting dressed; 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 more agitated or frustrated, it may help more if you drop the issue rather than keep on 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 the behaviors that you see in your loved one may be very difficult, exhausting, and even frightening. When you feel frustrated, try to remember that these behaviors are part of the disease that has affected 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.

Alzheimer’s means learning to bend
without breaking.

A daughter

Social support is important for caregivers, whose own mental health can be affected by the stress and sadness of helping someone with severe dementia and agitation. There are a number of sources of help, including organizations, newsletters, books, and computer 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 comfort you and often have good ideas for dealing with day-to-day problems. You can locate the nearest support group by contacting the Alzheimer’s Association or sometimes community organizations such as a senior center or your local hospital.

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

Sometimes caregivers find it very difficult to arrange time to attend educational meetings or groups outside the home. In this case, you might want to try one of the telephone helplines, most of which are toll-free. These offer trained peer counselors who 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, email 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 individuals with dementia. At the end of this guide, we provide information on where to find all these resources.

MEDICATIONS

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 “burnout” and make it easier for a suffering person to respond to your efforts. The more severe the agitation, the more important it is to consider medication. It does not “cure” dementia or agitation, but can reduce the frequency and severity of agitated behavior.

Doctors who are experts in geriatrics, psychiatry, or neurology are familiar with all of the medications we will be discussing. It is important to understand that most of the research in this area has been done with one group of medications (the antipsychotics, described more fully below). However, doctors often need to use other types of medicine. For this reason, a survey was conducted by Expert Knowledge Systems to find out about the entire range of treatments that experts find helpful. Some trial-and-error is often involved before finding the right medication, dose, and schedule—every treatment plan is “custom-made.” Although the doctor can help call the shots, it is a good idea for you to learn as much as you can about the various choices available in terms of 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 fear that anti-agitation medicines will just sedate a person or make their confusion worse, or that they are shirking their responsibility by relying on medication. To the contrary, the careful use of medication can lessen agitation without unwanted sedation and make it more possible to care for and communicate with an ill person.

How are specific medications chosen for a person?

Experts choose different medications based on several factors:

- **Is the goal short-term or long-term?** The goal of short-term or acute treatment is to calm the person down quickly during a crisis. This often calls for sedation to make the person somewhat drowsy for a few hours. On the other hand, since agitation is often persistent, the goal may be to find a long-term treatment that can be used for many weeks or months without causing unwanted sedation or harmful side effects. However, it may take several weeks for such a treatment to begin working. This delay can require a fair amount of patience on the part of caregivers 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?** General medical conditions cause a person to be more vulnerable to side effects of medications. Older people are often already taking several medicines, and it is extremely important to avoid interactions if another drug is added. Also, particular diseases may make it difficult to use certain anti-agitation medications. For example, people with lung disease should avoid medicines that might slow down their

breathing, whereas those who fall or are unsteady on their feet should avoid medicines that might affect coordination.

- **What types of symptoms does the person with agitation have?** In choosing a medication, it is also important to consider the types of symptoms the person has. For example, some medicines might be best if the main problem is psychosis, whereas others would be more appropriate if the main problem is anxiety or depression.

What medication strategies are used for different types of agitation?

Many kinds of medication can be used to treat agitation, depending on the person's main problem. Doses are almost always lower than those used in younger persons, because our bodies eliminate drugs more slowly as we age and side effects are more likely. The experts' recommendations for treatment are outlined in the table below. Each type of medicine is discussed in detail in the sections that follow.

Medication Strategies	
Main problem	Usual choices to start with
Delirium from a sudden medical problem	Conventional antipsychotic
Psychosis	Antipsychotic. For long-term use, an atypical antipsychotic is preferred.
Aggression, anger	Antipsychotic for short-term use Divalproex or antipsychotic for long-term use
Insomnia	Trazodone Benzodiazepines sometimes for short-term use only
"Sundowning" (confusion in late afternoon or early evening)	Trazodone Sometimes an antipsychotic
Anxiety	Buspirone for long-term use Benzodiazepine for short-term use only
Depression	Antidepressants, especially selective serotonin reuptake inhibitors
Pain from arthritis if over-the-counter pain medicines don't work	Tricyclic and other antidepressants

Antipsychotics

Examples include:

- Conventional antipsychotics such as haloperidol (Haldol)
- Atypical antipsychotics such as risperidone (Risperdal), olanzapine (Zyprexa), and quetiapine (Seroquel); others are likely to be available in 1998.

Antipsychotic medications, also called neuroleptics, have been the mainstay for treating agitation for many years, both in clinical practice and in research studies. There are two kinds: *conventional antipsychotics*, which have been available for the past 40 years (11 conventional antipsychotics are on the market), and *atypical antipsychotics*, which have been widely used since the mid-1990s.

Antipsychotics are effective against delusions, hallucinations, aggression, and sun-downing. They act rapidly and can be sedating, which makes them useful in emergencies. Haloperidol can also be given by injection if the need is urgent. Conventional antipsychotics sometimes cause three kinds of neurological side effects: 1) muscle stiffness and tremor that resemble Parkinson's disease; 2) a restless feeling called akathisia that may make the person want to pace even more; and 3) involuntary movements of the mouth or hands, a condition called tardive dyskinesia, which may occur after high doses given for many months or years. A reasonable dose of haloperidol to treat agitation while minimizing side effects is about 1–2 mg/day, often given at bedtime.

The newer atypical antipsychotics represent a potential advance because they are less likely to cause neurological side effects. For this reason, many experts in our recent survey preferred to use atypical rather than conventional antipsychotics, especially for long-term treatment. Even though they cost more and are not always free of side effects, they may be preferable for many patients in the long run.

The atypical antipsychotics in widest use now are risperidone (Risperdal) and olanzapine (Zyprexa). Risperidone has been tested extensively in older patients with dementia and agitation. It can be as effective as conventional antipsychotics and, at a low dose, is usually free of neurological side effects. Possible side effects of risperidone are sedation and dizziness when standing. Side effects can be minimized by starting with a low dose, 1 mg or less per day. Small amounts can be given either by breaking a scored pill or using a liquid form. Olanzapine can be somewhat more sedating than risperidone, but is a useful alternative, especially for a person who has had muscle stiffness on risperidone, which occasionally happens, or for someone who has Parkinson's disease. The typical starting dose is a 2.5-mg pill at bedtime. Quetiapine (Seroquel) has just recently been introduced. This and other atypical antipsychotics which are expected to be available soon may also prove useful.

Antidepressants

The type of antidepressant most often recommended for older persons with dementia is a medication from the group known as selective serotonin reuptake inhibitors (SSRIs). Most experts prefer one of these two agents:

- sertraline (Zoloft)
- paroxetine (Paxil)

Other antidepressant choices to consider for an older person with dementia are listed below in alphabetical order:

- bupropion (Wellbutrin)

- desipramine (Norpramin, Pertofrane and others; a tricyclic)
- fluoxetine (Prozac, an SSRI)
- fluvoxamine (Luvox, an SSRI)
- nefazodone (Serzone)
- nortriptyline (Pamelor or Aventyl; a tricyclic)
- trazodone (Desyrel)
- venlafaxine (Effexor)

Clearly, there are many antidepressants to choose from. There is often a need to try several medications before finding the best one for an individual. It is important to be very patient, since it often takes several weeks to tell if a medicine is working. During the waiting period, you can sometimes help keep up a person's spirits with activities, a day program, or a support group.

Among the antidepressants, sertraline or paroxetine is often chosen first because these antidepressants have few side effects (occasionally insomnia or nausea) and are usually safe to combine with other medications an older person is likely to be taking. They are given once a day (usually in the morning). If these do not work, an alternative can be chosen, tailored to the needs of the individual. For example, bupropion and venlafaxine tend to be energizing and might be chosen for someone who is very withdrawn or apathetic. Nefazodone is relatively calming and might be a good choice for someone with a great deal of anxiety. The tricyclic antidepressants tend to have more troublesome side effects, such as dry mouth, constipation, and dizziness if a person stands up too quickly. However, when used by experienced doctors and carefully monitored, they are sometimes quite effective in severe depression.

People with depression can also have delusions, such as a fear that body organs are not working, that they have been abandoned by everyone, or that they have no more money (when in fact they have). Delusional depression can be life-threatening due to suicide, or because of refusal to eat and drink, which can cause severe weight loss and dehydration. Agitation and trouble sleeping are also often very prominent. Although these symptoms can be very upsetting to witness, there are effective treatments. Usually, the first strategy is to combine the antidepressant with an antipsychotic medication. If severe depression or delusional depression does not respond to medications, electroconvulsive therapy can be life-saving. Although there are many negative myths surrounding shock treatment, it is very safe when given by experts and is an important tool for the severely depressed person who is in extreme suffering.

Antidepressants can also be used in conditions other than depression. Some antidepressants, especially the SSRIs, can help with anxiety. Tricyclics and SSRIs are also used for pain relief in arthritis and certain types of nerve pain if over-the-counter medicines like Tylenol or Advil haven't worked. Trazodone, a relative of nefazodone, is sold as an antidepressant but is usually too sedating for this purpose; we discuss it later as a sleeping aid.

Divalproex (Depakote)

Divalproex is best known as a treatment for brain disorders, such as epilepsy and seizures, and as a mood stabilizer for bipolar disorder (manic-depressive illness). It can also help with behavioral symptoms in older persons with dementia, especially in a person showing aggression, anger, or hypersexual behavior. It is often combined with an antipsychotic. The side effects of divalproex are nausea and sedation, which can usually be controlled by starting at small doses, making gradual adjustments, and monitoring the level of medication in the bloodstream. A low to average final dose of divalproex is 250 mg two or three times a day.

Carbamazepine (Tegretol)

Carbamazepine is another antiseizure medication that is also sometimes used for agitation. It can lower blood cell counts, which need to be monitored.

Buspirone (BuSpar)

Buspirone is an anti-anxiety medication that is not habit-forming and does not cause sedation. Buspirone is an excellent choice for someone who is very nervous or worried but does not have psychotic delusions. It is sometimes helpful for someone who gets angry too easily. It is also very safe to combine with other medications that an older person may be taking for general medical problems. Side effects of headache, dizziness, or nausea can occur if the dose is too strong; once in a while it can also cause overstimulation. Buspirone works gradually, and the dose usually needs to be adjusted over 2 to 6 weeks before beneficial effects can be judged. A typical starting dose is 5 to 7.5 mg twice a day, whereas a final dose may be 15 to 30 mg twice a day.

Trazodone (Desyrel)

Trazodone is a relatively safe, non-habit-forming medication that is technically considered to be an antidepressant, but is actually used more often simply to help the individual get a good night's sleep. It is also a good short-term alternative treatment for anxiety or when a mild sedative is needed. It should be started in very small amounts at first and adjusted upward until the right dose is found, usually about 50 mg. To help with sleep it should be given about 1 hour before bedtime. Its effects usually last about 8 hours, so if it is being used to help with daytime agitation, it may need to be given two or three times a day. Its main side effect is drowsiness if the dose is too high. Other side effects include dizziness when standing up and, very rarely, painful erections of the penis in men. Nefazodone (Serzone), a new antidepressant related to trazodone, is sometimes used for similar purposes; it may have fewer side effects.

Benzodiazepines

Examples include:

- lorazepam (Ativan)
- zolpidem (Ambien)

- temazepam (Restoril)
- oxazepam (Serax)

Benzodiazepines are a group of about a dozen medications that cause sedation and can relieve anxiety. They are best used only in temporary situations—once in a while for sleep or for a daytime crisis of anxiety or agitation when someone needs to be calmed down quickly. In an emergency, benzodiazepines are sometimes combined with an antipsychotic; they can also be combined for a week or more with other medicines that may take longer to start working, such as divalproex.

The benzodiazepines listed above are preferred by experts for use in older people because they are cleared from the body relatively quickly. The effects of others, such as flurazepam (Dalmane) and clonazepam (Klonopin), can last 24 hours or longer; these longer-acting agents are usually best avoided because they may cause daytime sedation or falling. A typical dose of lorazepam is 0.5 mg; its effects last about 8 hours, so it is sometimes used two or three times over the course of a day for someone who is very agitated. Zolpidem, the effects of which last 6 to 8 hours, is usually given only to help sleep, at an average dose of 5 mg. Temazepam and oxazepam are good alternative choices that are cleared from the body relatively quickly. Benzodiazepines are habit-forming if used steadily for more than a few weeks; even single doses can cause unsteady gait and interfere with memory.

There is no such thing as a day
like any other day.
History professor with Alzheimer's disease

Because of the disadvantages of benzodiazepines, it is usually best to avoid using them for the long-term treatment of insomnia, anxiety, or agitation unless other choices have failed.

A FINAL WORD ABOUT AGITATION IN DEMENTIA

It is extremely painful to see a member of your family decline because of dementia, and especially difficult if agitation is also present. Remember that the behaviors are caused by a medical illness; that providing a calm, structured, safe, and caring environment can help; and that medications chosen carefully to address specific symptoms can alleviate distress and improve functioning. Research in treating agitation is only at the beginning. We have presented the best of current opinion, but much remains to be learned. The organizations listed below can help you find out about research studies of new treatments in which your loved one may be able to participate. Learn as much as you can about agitation and its treatment—your knowledge will make a difference in the quality of life for you and your affected family member.

RESOURCES

Nonprofit organizations and support groups

- Alzheimer's Association: 800-272-3900. The major self-help organization for people with Alzheimer's disease and their families. Over 200 local chapters sponsor support groups and seminars. Call for locations, and to find out about the telephone peer helpline. Booklets and reading lists are available through the Green-Field Library: 312-335-9602.
- American Federation for Aging Research: 212-752-2327. A leading national organization supporting medical research on aging and age-related diseases to promote healthier aging. It publishes *Lifelong*, a monthly newsletter for patients and families.
- American Association of Retired Persons (AARP): 202-434-2277, 800-424-3410. Makes available booklets on specific topics such as Coping and Caring, Nursing Home Life, and Staying at Home.
- National Citizens' Coalition for Nursing Home Reform: 202-332-2275. Makes available booklets on getting the best care in nursing homes and about regulations that protect nursing home residents.
- Children of Aging Parents: 215-945-6900
- Help for Incontinent People: 864-579-7900, 800-BLADDER
- Insurance Consumer Helpline: 800-942-4242
- National Hospice Organization: 703-243-5900, 800-658-8898

Government agencies

- Alzheimer's Disease Education and Referral Center (ADEAR): 800-438-4380
- Eldercare Locator, for long-distance help finding services: 800-677-1116
- Medicare Hotline: 800-638-6833
- Social Security Information: 800-772-1213

- Agency for Health Care Policy and Research, Publications Clearing House (Request a free copy of *Early Alzheimer's Disease: Patient and Family Guide*): 800-358-9295

Readings and other educational materials (many available through the Alzheimer's Association or ADEAR)

Books written from the patient's perspective

Davis R. *My journey into Alzheimer's disease*. Wheaton, IL: Tyndale House; 1989

Rose L. *Show me the way to go home*. Forest Knolls, CA: Elder Books; 1996

Henderson CS. *Musings*. Durham, NC: The caregiver—Newsletter of the Duke Family Support Program; Fall 1992. Reprints are available from Box 3600, DUMC, Durham, NC 27710.

Books written by and for caregivers

Doernberg M. *Stolen mind*. Chapel Hill, NC: Algonquin Press; 1989 (out of print; check your local library)

Dyer L. *In a tangled wood: an Alzheimer's journey*. College Station, TX: Texas A&M University Press, 1996 (Call 800-826-8911)

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*. 2nd revised ed. New York: Warner Books; 1992

National Institute on Aging. *Talking with your doctor: a guide for older people*. National Institutes of Health Publication No. 94-3452. (Call 800-222-2225 for a free copy)

Shanks L. *Your name is Hughes Hannibal Shanks: a caregiver's guide to Alzheimer's disease*. Lincoln, NE: University of Nebraska Press, 1996 (Call 800-755-1105)