OVERVIEW

Dementia—a group of symptoms that includes memory loss, confusion, and trouble with problem-solving that is severe enough to disrupt daily life—affects over 5 million Americans, particularly those age 65 and older. Many people living with dementia can develop agitation or psychosis. These symptoms may come and go or last for longer periods of time. They can be stressful and possibly dangerous for the people living with dementia and their caregivers. If these symptoms are not treated, families may have a harder time providing care and the person living with dementia may ultimately need long-term care. Treating agitation and psychosis can improve the quality of life for people living with dementia and provide some relief to their caregivers.

This guide provides information about the causes of agitation and psychosis in adults living with dementia and available treatment options. It can help patients and families begin the discussion with their doctor to make an informed decision about appropriate treatment.

The patient and caregiver guide is based on the practice guideline the American Psychiatric Association (APA) published in 2016 for psychiatrists and other health professionals. The complete guideline, The Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia, is available from APA Publishing, along with more information about how it was developed.

KEY TERMS

**Dementia**
A group of symptoms, including memory loss, confusion, and trouble with problem solving or finding words, that is severe enough to disrupt daily life due to a decline in mental function. Many conditions can cause dementia, but the most common cause is Alzheimer’s disease.

Dementia can cause other symptoms such as depression, anxiety, irritability, aggression, agitation, hallucinations, delusions, and sleep problems.

**Agitation**
A state of excessive physical movement, verbal aggression, or physical aggression to oneself or others that is associated with emotional distress.

**Psychosis**
A condition that includes symptoms such as delusions (firmly maintained and false beliefs), hallucinations (seeing or hearing things that are not there), and other disorganized thoughts, speech, and behaviors.
CAUSES OF AGITATION OR PSYCHOSIS

Changes in the brain may make it difficult for a person with dementia to express discomfort, pain, or basic needs. As a result, many situations can cause a person living with dementia to feel agitated. Some of the common ones include:

- problems with eyesight or hearing
- experiencing hunger, fatigue, pain, or discomfort
- recent medication changes, side effects, or drug interactions
- boredom, loneliness
- distractions and excess stimulation such as loud noises, TV
- change in environment
- difficulty carrying out simple tasks
- feeling rushed to complete tasks such as bathing, dressing, or other daily activities
- feeling a loss of privacy or modesty, or other loss of control
- sensing frustration, anxiety, or other emotional distress from others
- perceived threats

Symptoms of psychosis in people with dementia are often due to changes happening in the brain. They may also be caused by medical illness, or by medication changes, side effects, or interactions. It’s important to talk with a doctor about all the possible causes of these symptoms.

EVALUATION AND TREATMENT OF AGITATION AND PSYCHOSIS

See a Doctor for a Thorough Checkup
It is important to see a doctor for a thorough checkup. Agitation and psychosis may worsen if they are not addressed. The doctor will recommend appropriate treatment options based on the type of dementia, specific symptoms and severity, and the unique situation and preferences of both the person living with dementia and their caregivers.

Try Non-Medication Options First
Experts recommend starting with non-medication options for treating agitation or psychosis, except in cases of emergency. It is important to know that everyone responds differently to treatment. If one approach does not work, try another one. These non-medication options are not usually harmful, and may include having the caregiver:

- modify the environment, for example, reduce noise, or remove items that could be upsetting
- encourage positive behaviors
- involving the person in activities such as:
  - taking a walk
  - talking about memories or looking at photos
  - meditating
  - playing their favorite music
  - coloring pictures
  - playing with or petting a trained animal

It is important to continue to use non-medication approaches even if medication treatment is also being used. More information and tips for managing the symptoms of dementia are included under the Additional Resources section. Caregivers can learn to understand these symptoms better and improve communication skills with the person living with dementia. By learning how to care for and cope with the symptoms of agitation and psychosis, families can reduce their sense of burden and improve their own well-being.
**Consider Antipsychotic Medications**
Medication options to treat agitation or psychosis may involve using antipsychotics. Common antipsychotic medications include risperidone, olanzapine, aripiprazole, quetiapine, and haloperidol. The decision to use these medications should be made carefully and in consultation with a doctor. Antipsychotic medications should only be used in cases of emergency or when agitation or symptoms of psychosis are severe, dangerous, or cause significant distress.

How effective antipsychotic medications are may vary depending on things such as the type of dementia, severity of symptoms, and other unique situations. On average, the benefit of antipsychotic medications in clinical studies is small. For some individuals, they may reduce distress, make it easier for caregivers to provide care, and improve safety and quality of life.

**Review Possible Side Effects of Medication with the Doctor**
Like all prescription medications, antipsychotics have a risk of side effects that can range from mild to severe. Drowsiness is very common with antipsychotic treatment. Some people who take an antipsychotic medication experience weight gain, lightheadedness, and changes in walking. Although rare, older adults may have an increased chance of having more severe side effects such as a stroke or dying. The FDA has placed a warning on the labeling of all antipsychotic medications that describes this risk. Although younger individuals who take antipsychotic medication have an increased risk of developing diabetes or changes in blood lipids, close monitoring is important in individuals of all ages. The doctor will also check for these side effects.

**Discuss Benefits and Risks of Medication with the Doctor**
People living with dementia and caregivers should discuss the potential risks and benefits of any antipsychotic medication with their doctor. This will help them make an informed decision about prescription medication use. Be sure to communicate to the doctor any previous side effects from a specific medication, as well as preferred treatment choices. It is important to know that everyone responds to medications differently. If one medicine does not work, the doctor may suggest trying another one. It is also important to understand that treating agitation or psychosis with medications involves coordination among care providers, including pharmacists. This helps prevent harmful drug interactions or impacting on other chronic conditions.

**WHAT TO DO WHEN USING AN ANTIPSYCHOTIC MEDICATION**

**Ask the Doctor about Starting at a Low Dose**
For older people with dementia, a common starting dose is one-third to one-half the dose that is used with a younger adult, or the smallest tablet available. Doses should be increased slowly to the lowest amount that relieves symptoms.

**Work with the Doctor to Monitor Response and Side Effects**
Talk to the doctor regularly to see if symptoms have improved and if there are any side effects. It may be helpful to write down and share information with the doctor about any responses or side effects to the prescribed medication, or changes in other medications or medical conditions. If there are side effects, discuss with the doctor whether to continue the medication, decrease the amount, or stop taking it. (Sample symptom tracker: [http://alzlive.com/wp-content/uploads/2015/08/Biography_Based_Care-Symptom_Tracker.pdf](http://alzlive.com/wp-content/uploads/2015/08/Biography_Based_Care-Symptom_Tracker.pdf))

**Talk to the Doctor about Checking Response at Four Weeks**
If the symptoms have not changed after taking an adequate amount of the medication for four weeks, a doctor should lower the dose and stop the medication to avoid potential harms. If severe, dangerous, or distressing symptoms continue, talk to the doctor about what to do next.
Ask the Doctor about Stopping the Medication within Four Months

To reduce potential harms from the antipsychotic medication, the doctor should try to slowly stop the medication within four months or sooner, if appropriate. The person living with dementia should see the doctor each month and for at least four months after the medication is stopped. If the symptoms return while decreasing or stopping the medication, talk with the doctor about what to do next, which may include continuing the medication or other treatment options.

OTHER IMPORTANT INFORMATION ABOUT USING ANTIPSYCHOTIC MEDICATIONS

Haloperidol may be appropriate for short-term use in emergencies, but not as a first line treatment. Haloperidol can be less effective than other antipsychotic medications, and though unlikely, risks, such as death, are greater.

Some antipsychotic medications are available in a long-acting form that a doctor or nurse injects with a needle. Due to its potential harm compared to pills, long-acting antipsychotic medication should only be used if the doctor ensures that it is needed to treat a psychotic disorder other than dementia.

APA would like to thank the Alzheimer’s Association for their thoughtful input in the development of this guide.

ADDITIONAL RESOURCES

American Psychiatric Association
Help With Alzheimer’s Disease: https://www.psychiatry.org/patients-families/alzheimers

Alzheimer’s Association
Caregiver Center: http://www.alz.org/care/overview.asp
Behavior Treatments: https://www.alz.org/alzheimers_disease_treatments_for_behavior.asp

National Institute on Aging: Alzheimer’s Disease & Related Dementias
Overview of Alzheimer’s and Dementia: https://www.nia.nih.gov/alzheimers
Treatment: https://www.nia.nih.gov/health/how-alzheimers-disease-treated
Information for Caregivers: https://www.nia.nih.gov/health/alzheimers/caregiving
Medication Tracking Sheet: https://www.nia.nih.gov/health/tracking-your-medications-worksheet

Mayo Clinic
Dementia Overview: http://www.mayoclinic.org/diseases-conditions/dementia/home/ovc-20198502

Family Caregiver Alliance: National Center on Caregiving
https://www.caregiver.org/

This Patient and Caregiver Guide, including all text, graphics, images and any other material contained herein, is for informational purposes only and is not a substitute for, is not designed to, and does not provide medical advice, diagnosis or treatment. You should always seek the advice of a qualified health provider regarding your questions about any medical condition. Do not ever disregard professional medical advice or delay in seeking it because of something you have read in this Patient and Caregiver Guide. The American Psychiatric Association does not recommend nor endorse any specific products, procedures, opinions or other information that may be mentioned in this Patient and Caregiver Guide. Reliance on any information contained in this Patient and Caregiver Guide is solely at the reader’s own risk.