

FAST FACTS: What You Need to Know About Antipsychotic Drugs for Persons Living with Dementia

The AHCA/NCAL Quality Initiative



What is an antipsychotic drug?

An **antipsychotic** (an-tie-sy-COT-ick) drug is a medicine that works in the brain, which may help to block certain chemicals that can cause symptoms of psychosis, such as hallucinations or delusions.

- Hallucinations are when a person sees or hears things that are not there.
- Delusions are when a person believes something that isn't true, even after being told.

Some people with some mental illnesses like schizophrenia and bipolar disorder often have these symptoms.

What are common antipsychotics?

- Haldol
- Quetiapine (Seroquel)
- Olanzapine (Zyprexa)
- Aripiprazole (Abilify)
- Risperidone (Risperdal)

Why are these drugs used in people with Dementia?

These drugs can help for some people with dementia who do have psychosis. However, most of the time these drugs are used when a person acts in way that is challenging or disturbing to others, such as

- hitting, yelling, screaming
- refusing care, walking around
- crying, banging, throwing things

Some people think that these drugs may help with these behaviors however; studies show that many of these behaviors in people with dementia are normal reactions to something they find scary, upsetting or uncomfortable. Or, their actions may also be telling us that they need something such as:

- food because they are hungry,
- water or juice to drink because they are thirsty,
- to take a nap because they are tired,
- to go to the bathroom, or
- something to do because they are bored.

In these cases, drugs will not help.

Do these drugs work in people with dementia?

For people with dementia who have hallucinations or delusions, these drugs can help. However, most people with dementia don't have hallucinations or delusions. For many people, these drugs slow them down, making them drowsy or groggy. These drugs don't get to the heart of the reason for the person's actions. Scientific studies show that for only a small number of people with dementia these drugs will help a little bit. Overall, most people do not get better. Of those who get better, it is those with psychosis and hallucination.

What can these drugs NOT do?

These drugs do not help:

- Stop yelling or repeating questions over and over;
- Calm being restless, fidgety or uneasy,
- Stop memory problems;
- Persons do more for themselves;
- Persons interact better with others; or
- Stop inappropriate things being said.

Why am I hearing so much about them?

Recent scientific studies from both universities and government agencies have found:

1. That these drugs are often used too much in people with dementia
2. That these drugs do not work as well as people first believed in people with dementia.

What are the risks?

People with dementia who are given these drugs are more likely to:

- be unsteady when they walk
- fall
- break their bones
- have incontinence ("pee in their pants")
- have a stroke
- die sooner

Because of these dangers, the US Food and Drug Administration (FDA) requires a warning on the label of all antipsychotic drugs. Such "black box" warnings are only required for drugs with serious risks. The warning includes the following:





Warning: Increased Mortality in Elderly Patients with Dementia-Related Psychosis. Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. [Name of Antipsychotic] is not approved for the treatment of patients with dementia-related psychosis

Is it safe to stop these drugs?

Studies in nursing homes show that it is very safe to try stopping these drugs in people who:

- are taking a low dose;
- did not have any actions recently; or
- did not have hallucinations before starting the drugs.

In studies of people already on an antipsychotic drug that was then replaced with a fake pill, doctors and nurses could not tell the difference between who stopped the drug and who took the drug. This shows that stopping these drugs is safe.

Many experts suggest trying a lower dose or stopping these drugs because

- in nursing homes, staff watch to see if there is a reason to keep using these drugs;
- many of the actions these drugs are used for are about unmet needs and cannot be fixed by drugs; and
- about one out of three people will still act in challenging ways, whether the drug is continued or not.

Why do people with dementia behave in ways that can be challenging?

They may have a need they cannot express or be in a situation they don't understand. For example, when it's time to get undressed for bed or a bath, some people with dementia may hit or try to stop their care giver. This can be because they don't understand why someone is taking off their clothes. A person with dementia can't always tell us how they feel. They may get upset when they need to go to the bathroom. They may get angry when they are tired or hungry. Skilled care givers do their best to predict the needs of people with dementia. Sometimes, they can take steps to meet those needs and keep the person from getting upset. Skilled care givers look at what is going on

physically, emotionally, and environmentally that might be causing the person to react.

- Are they cold, hungry, tired, thirsty, or in pain?
- Are they bored; scared, stressed out, upset by too much noise or another person's actions?
- Are they missing their family or friends?
- Do they find a task they are trying to do, like dressing or bathing, too hard?

These kinds of things can all upset a person. However, drugs do not help with these kinds of needs.

What should I do?

If your loved one is already taking these drugs, ask:

- What type of drug is my loved one on?
- What caused the drug to be prescribed?
- How has the care team tried to help solve the problem without drugs?
- What is the plan to decrease or stop the drug?

If your loved one is not currently on an antipsychotic, BEFORE any are prescribed, ask:

- What is causing the drug to be prescribed?
- What has the care team tried to respond to my loved one's challenging behaviors?
- How will they track the behaviors once the drug is started?
- What is the plan to decrease or stop the drug?

How can I help?

Staff will never know all that you know! You can help by providing answers to questions such as:

- How does your family member express themselves when they are scared, angry, anxious, and hungry?
- What, in the past, has comforted them?
- What is their typical daily routine?
- Are there any behaviors that you have found more difficult to respond to than others?
- What have you tried to prevent them?
- Stay involved in your loved ones care and attend care plan meetings.

DISCLAIMER: The AHCA/NCAL quality programs' contents, including their goals and standards, represent some preferred practices, but do not represent minimum standards or expected norms for skilled nursing and/or assisted living providers. As always, the provider is responsible for making clinical decisions and providing care that is best for each individual person.



For more information, visit
qualityinitiative.ahcancal.org

