

## **FAST FACTS:**

# **What You Need to Know About Antipsychotic Drugs for Persons Living with Dementia**

## **What is an antipsychotic drug?**

An antipsychotic drug is a medicine that works in the brain. The drug may help to block certain chemicals that can cause symptoms of psychosis, such as hallucinations or delusions.

- A person who is hallucinating sees or hears things that are not there.
- A delusion is a false belief or opinion in spite of strong evidence to the contrary.

Some people with mental illnesses such as schizophrenia and bipolar disorder often have these symptoms.

## **What are common antipsychotic drugs?**

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

## **Why are these drugs used in people with dementia?**

These drugs can help some people with dementia who have psychosis. However, most of the time these drugs do not help when a person acts in a way that is challenging or disturbing to others, such as:

- Hitting, yelling, screaming;
- Refusing care, walking around;
- Crying, banging, throwing things.

Some people think these drugs may help with these challenging behaviors. However, studies show that many of these behaviors in people with

dementia are actually behavioral expressions of distress caused by something they find scary, upsetting or uncomfortable. 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;
- Rest because they are tired;
- To go to the bathroom; or
- Something to do because they are bored.

In these cases, drugs will not help, but addressing the cause of the behavior may.

## **Do these drugs work in people with dementia?**

For people with dementia who have hallucinations or delusions, these drugs may help. However, most people with dementia do not have hallucinations or delusions.

Antipsychotic drugs commonly slow people down, making them drowsy or groggy. These drugs may cause many other negative side effects. They do not get to the main cause for the person's actions or behaviors. Scientific studies show that these drugs only help a small number of people with dementia, and then provide only minor relief. Overall, most people do not get better. Those who improve have psychosis and hallucinations.

## What can these drugs NOT do?

These drugs do not:

- Stop the person from yelling or repeating questions;
- Stop the feeling of restlessness or uneasiness;
- Stop memory problems;
- Allow a person to do more for himself or herself;
- Help the person interact better with others; or
- Stop him or her from saying inappropriate things.

## Why am I hearing so much about them?

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

- These drugs are used too much in people with dementia; and
- These drugs do not work as well as first believed in people with dementia.

## What are the risks?

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

- Be unsteady when they walk;
- Fall, which can cause injury;
- Break their bones;
- Have problems with bowel and bladder control;
- Have a stroke;
- Die sooner.

Because of these dangers, the U.S. Food and Drug Administration (FDA) has issued a black box warning about possible serious risks of all antipsychotic drugs. The death rate is greater (1.6 to 1.7 times) for individuals taking antipsychotic drugs than in those not taking them.

## Is it safe to stop these drugs?

With the involvement of an interdisciplinary team (e.g., nursing, direct caregivers, family, physician, pharmacist), it is very safe to gradually reduce the dosage and eventually stop these drugs. Good candidates for gradual dosage reduction include people who:

- Are taking a low dose;
- Have not recently had challenging actions or behaviors; or
- Did not have hallucinations before starting the drugs.

Many experts suggest trying to gradually decrease the dose and eventually stop these drugs because:

- In long-term care settings, staff members watch to see if there is a reason for the person to keep using these drugs;
- Many of the actions or behaviors these drugs are used for relate to unmet needs of the person with dementia that cannot be fixed by these drugs;
- Approximately one of three people will still act in challenging ways, whether or not the drug is continued; and
- Hallucinations or delusions that are not frightening or cause distress may not require this type of treatment.

## Gradual dose reduction before stopping

For people on higher doses, slowly reduce the dose before stopping it.

- The best time to reduce the dose is when the person is stable with few or no challenging behaviors.
- The prescriber or pharmacist will guide you in how best to reduce the dose. An example might be lowering the dose by 25 percent every few weeks until stopped.

- If challenging actions or behaviors return when the dose is decreased, a temporary increase in the dose might be needed. It may be possible to reduce the dose again, but more gradually, when the person is once again stable.
- Sometimes the side effects of the drug or the withdrawal symptoms look just like the behavior or action that was treated in the first place.

## 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 do not understand. For example, when it is time to get undressed for bed or a bath, some people with dementia may hit or try to stop their caregiver. This can be because they do not understand why someone is taking off their clothes. People with dementia cannot 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 caregivers do their best to predict the needs of people with dementia. They can sometimes take steps to meet those needs and keep the person from getting upset. Skilled caregivers look at what is going on physically, emotionally and environmentally that might be causing the person to react. For example:

- Is the person cold, hungry, tired or thirsty?
- Does he or she have a health condition that causes pain?
- Is the person bored, scared, stressed or upset by too much noise or another person's actions?
- Does the person miss family or friends?
- Is he or she trying to do a task, such as dressing or bathing, that is too hard?

All these things can upset a person. However, drugs do not help with these needs.

## What should I do?

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

- What drug is my loved one taking?
- What led to prescribing the drug and what is the specific goal of therapy?
- How has the care team tried to help solve the problem without drugs?
- What is the plan for decreasing or stopping the drug?

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

- Specifically, why is the drug being prescribed?
- What has the care team done to respond to my loved one's distress?
- 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 about your loved one. You can help by providing answers to questions such as:

- How does your family member express being scared, angry, anxious and hungry?
- What, in the past, has comforted the person?
- What is your loved one's typical daily routine?
- Have you found it hard to respond to certain behaviors? What are they?
- What have you tried to prevent them?

Stay involved in your loved one's care and attend care plan meetings.

DISCLAIMER: This brochure is provided by the Oregon Partnership to Improve Dementia Care (the partnership), which includes the Oregon Department of Human Services, Oregon Health Care Association, Acumentra Health, LeadingAge Oregon, Oregon Patient Safety Commission, Making Oregon Vital for Elders, Oregon Long-Term Care Ombudsman and geriatric consultant pharmacists.

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