Antipsychotic (An-tie-sy-COT-ick) Medicines for People with Dementia

When you have a loved one with dementia, it can be hard to make choices about their care. This hand-out can help you decide about using certain medicines for them.

What is dementia* (de-MEN-shuh)?

Dementia is an illness that makes it harder and harder for a person to remember things and live normally. There are many kinds of dementia. Alzheimer's (ALTZ-hi-merz) is one kind. People with dementia may also:

- See or hear things that are not there. These are called hallucinations* (huh-loo-sin-AY-shuns).
- Believe something that isn't true, even when told otherwise. This is called a delusion* (duh-LOO-zhun).
- Get angry for no clear reason, or for a small problem.

These things can be very upsetting for people with dementia and their caregivers. It is important to comfort and support people with dementia. But sometimes medicines might be used.

What are antipsychotic (an-tie-sy-COT-ick) medicines*?

These medicines can help when people see or hear things, or believe things that are not true. But they can also have side effects (things that come from taking a medicine but are not part of the treatment). These medicines may cause a small increase in the risk of death. So it's important to only use them when needed. And only if they help. Other ways to handle problems with dementia should be tried first.

What can these medicines help?

Antipsychotic medicines can help:

- **Aggressive behavior**, like hitting, kicking, or biting.
- Hallucinations, like hearing voices when there are none, or seeing people in the room who aren't there.
- **Delusions**, like being suspicious (suh-SPI-shus) or thinking people are trying to hurt them. This is called being paranoid (PAIR-uh-noyd).
- Other things that can cause danger to the person or other people, or make it very hard to take care of the person.

What will these medicines NOT help?

Antipsychotic medicines do <u>not</u> help these problems:

- Not being social—when a person doesn't want to be friendly to others
- Not taking care of their self
- Memory problems
- Not paying attention or caring about what is going on around them
- Yelling or repeating questions over and over
- **Being restless**—when it's hard for a person to sit still

There may be other medicines or ways to help. So talk to the health care team.

What are the possible benefits of antipsychotic medicines?

They may help aggressive behavior, hallucinations, or delusions. This can make a person with dementia feel better. It might also make it safer for the person or others.

*Words to Know

Antipsychotic medicine – helps when people see or hear things, or believe things that are not true. Delusion – believing something that is not true, even when told otherwise.

elusion – believing something that is not true, even when told otherwise.

Dementia – an illness that makes it harder and harder for a person to remember things and live normally. **Hallucination** – seeing or hearing things that are not there.

What are the possible side effects of antipsychotic medicines?

They can cause a small increase in some side effects in people with dementia. Here is information about this:

- **Death:** Research shows that if 100 people with dementia take an antipsychotic medicine, 1 of them may die sooner because of the medicine. The chance of dying is small. If someone dies, it is hard to tell if the antipsychotic medicine had anything to do with it. There is no way to tell who might die while taking this medicine.
- **Stroke:** Research shows that if 100 people take an antipsychotic medicine, 1 could have a stroke because of the medicine. Some kinds of antipsychotic medicines might have a lower risk for stroke. But we don't know for sure.
- Movement Side Effects: In some people, these medicines can affect the part of the brain that controls how muscles move. The chance of this is different for each kind of antipsychotic medicine. It doesn't happen as much with low doses. Most of the time, these go away if the medicine is stopped, or the dose is lowered. Sometimes a different kind of medicine can be used. Here are some movement side effects to watch for. Tell the doctor right away if you see:
 - ✓ The person's muscles getting tight, like in Parkinson's Disease. This is Parkinsonism (PARK-in-sun-izm). It can make their steps short so they shuffle when they walk. Their hands or arms may shake. This is called a tremor.

- Restlessness or needing to walk around a lot. Sometimes their face can twitch. Rarely, a person can get very stiff and ill, with a very high fever. If this happens, call a doctor or take the person to the emergency room right away!
- Things that make overall health worse, like gaining weight, high blood sugar, and high cholesterol. Some antipsychotic medicines cause these more than others. It might be okay to try a different kind.
- Very low blood pressure when a person stands up quickly. It can make them dizzy or fall.
- **Swelling**, usually around the ankles.
- Changes in Thinking:
 - ✓ Being sleepy or groggy because of a drug. This is called sedation (suh-DAY-shun).
 - Confusion This can be part of dementia. But antipsychotic and other medicines can sometimes make this worse.
- Other Side Effects:
 - ✓ Constipation (con-sti-PAY-shun) (trouble pooping)
 - Problems urinating (YUR-in-ate-ing) (trouble peeing)
 - ✓ Falling down

How do we know if antipsychotic medicines are helping?

- Get a clear picture of the problems.
 - ✓ Before the medicine starts, write down exactly what problems are happening, and how often.
 - ✓ Do this every week after the medicine starts.
 - ✓ If the problems are not as bad or don't happen as often, the medicine might be helping. But these problems can get better or worse, whether or not medicine is given.
 - ✓ After being on the medicine awhile, a person may have less of the problems. Or the problem may not get better. Talk to the person prescribing the medicine about a lower dose or stopping the medicine.

• Watch for Side Effects.

- ✓ You and the health care team should watch and check for things like:
 - Odd movements
 - Tight muscles
 - Shaking
 - Trouble eating
 - Choking
 - Dizziness
 - Falling
 - Sleepiness
 - Confusion
 - Swelling in the legs
 - Trouble pooping or peeing
 - High or very low blood pressure
 - High blood sugar
 - High cholesterol
- ✓ If these happen, talk to the doctor or health care team. If it looks like the medicine is causing a problem, things can be tried to help, like:
 - Lowering the dose.
 - Changing to a different kind.
 - Stopping it.

• Talk to the person's doctor and the rest of the health care team.

How do I decide if an antipsychotic medicine is right for my loved one?

- First, check for other things that might be causing problems. Talk to the doctor or health care team to help figure this out. They might have other ways to help problem behaviors. Here are some things that can cause aggressive behavior, hallucinations, or delusions.
 - ✓ Medicines, especially new ones
 - ✓ Health problems
 - ✓ Constipation
 - Dehydration (not enough water in the body)
 - ✓ Pain
 - ✓ Mouth sores from dentures or other things
 - ✓ Trouble seeing or hearing
 - ✓ Depression
 - \checkmark Stress or fear
 - ✓ Being bored
- Making the Choice: Sometimes, no matter what you do, a person with dementia may be aggressive or have bad hallucinations or delusions. Medicine might help if the person is acting dangerous or is very upset, and nothing else is working. It may help the person feel better, even if there are risks. Think about things like:
 - ✓ What would the person have wanted before they got dementia?
 - ✓ What would they want if they knew they were biting, hitting, or kicking people?
 - ✓ If the person is having scary hallucinations or seeing people who aren't there, would they want it to stop if a medicine might help?

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Many people would want to stop these things if possible, even if there are risks.

Deciding to use an antipsychotic medicine is hard. There are risks. Not everyone is helped. But many people can take them and not get side effects.

We can't cure dementia. When it is getting worse, you can think about whether using an antipsychotic medicine makes a person's comfort and quality of life better, even if there are risks.

What are the names of antipsychotic medicines?

There are 5 kinds that research shows might help people with dementia who act in ways that make it hard to take care of them. Here is a list, and an example brand name:

Name	Example
Aripiprazole (air-uh-PIP-ruh-zol)	Abilify®
Haloperidol (hal-oh-PEAR-uh-dol)	Haldol®
Risperidone (ri-SPARE-uh-dohn)	Risperdal®
Olanzapine (oh-LAN-zuh-peen)	Zyprexa®
Quetiapine (kwe-TIE-uh-peen)	Seroquel®
Brexpiprazole (brek-SPIP-rə-zohl)	Rexulti®

Questions You Want to Ask

Notes:

Name of Antipsychotic Medicine:

Strength of Medicine:

How often it is given:

Watch for these things. If you see them, write when it happened, and how often. Tell the health care team.

- Odd movements ______
- Tight muscles ______
- Shaking _____
- Trouble eating ______
- Choking ______
- Dizziness
- Falling _____
- Sleepiness _____
- Confusion
- Swelling in the legs _____
- Trouble pooping or peeing _____

Other things: _____