

How Antipsychotic Medications are Used to Help People with Dementia

A Guide for Residents, Families, and Caregivers



Antipsychotic medications are used to treat a variety of different mental health conditions. They may be used to treat people with dementia when an individual has certain responsive behaviours and not responding to non-medication approaches to care. In most cases, antipsychotic medications should not be the first choice for treatment of responsive behaviours but instead the care team should focus on creating a supportive environment, and investigating and satisfying the unmet needs of the person with dementia. As a member of the care team, you have an important role to play in helping the health care providers decide whether this treatment is appropriate care for your family member or friend. This guide will help you learn more about how antipsychotic medications are used to help people with dementia.

Dementia and Responsive Behaviours

What is Dementia?

Dementia is the general name for a set of symptoms that are caused by physical changes that affect the brain. The most common kind of dementia is Alzheimer's disease, but there are several other kinds, such as Lewy Body dementia, frontotemporal dementia, and vascular dementia. People with dementia have trouble with memory, thinking, problem-solving and communicating. These problems make it hard for them to do day-to-day activities.

A person with dementia might also experience changes in their mood or behaviour, such as:







- Seeing or believing things that are not real
- Being confused and scared
- Feeling agitated, depressed, or irritable
- Lacking interest in activities

These experiences can be a common part of the way the disease develops. They are often a response to the way the person with dementia feels, or they may be a reaction to a change in their environment.

Some of these responsive behaviours can be upsetting for the person with dementia and for others. Health care providers are trained to manage these behaviours. As a close friend or family member you can help the care team to better understand what might be causing these behaviours.

What Are the Behavioural and Psychological Symptoms of Dementia? (i.e. responsive behaviours)

Some common responsive behaviours include:

| | | |
|--|---|--|
|  Psychosis <ul style="list-style-type: none">• Delusions (false beliefs)• Hallucinations (hearing/seeing things that aren't there) |  Reactions <ul style="list-style-type: none">• Defensiveness• Resistance to care• Severe verbal reactions• Severe physical reactions |  Agitation <ul style="list-style-type: none">• Dressing or undressing• Pacing• Repetitive actions• Restlessness/anxiety |
|  Depression <ul style="list-style-type: none">• Anxiety• Guilty thoughts• Hopelessness• Irritability• Sadness/tearfulness• Suicidal thoughts |  Apathy <ul style="list-style-type: none">• Lack of motivation• Lack of interest• Withdrawing from others |  Mania <ul style="list-style-type: none">• Intense excitement• Irritability• Fast speech |

Other: • Hiding or collecting things • Getting lost • Disinhibition (e.g., sexual)

Treating Dementia

How is Dementia Treated?

For now, there is no cure for dementia and no way to stop it from getting worse over time. Some medications may help manage symptoms like hallucinations, delusions, severe agitation and severe physical reactions when they are very upsetting or dangerous to the individual with dementia or to others. Other medications help with depression or anxiety.

Even if a doctor or nurse practitioner prescribes medications, many non-medication approaches to care can help manage responsive behaviours caused by dementia. The care team will involve the person with dementia and their family or friends to find the approaches they think will work best.

Creating a Supportive Environment

As a first step, the care team will look for ways to manage the responsive behaviours without using medication. The most effective ways focus on creating a supportive environment, and investigating and satisfying the unmet needs of the person with dementia. The care team will try to:

- Understand all they can about the person
- Understand what makes the person feel calm and safe
- Understand what may be causing the responsive behaviours
- Set up a safe and comfortable environment, and routines that match the person's habits and preferences
- Remove loud and distracting things or events
- Treat the person with respect and compassion
- Communicate with simple words and phrases
- Offer therapies and recreational activities that are meaningful and enjoyable
- Understand how responsive behaviours can change at different times of the day
- Remember that some responsive behaviours are a regular reaction to things like frustration or sadness, and may not be a symptom related to their dementia

You Can Help

Talk with the care team about:

- What helps make the person feel calmer and happier, their hobbies, their likes and dislikes, and culturally or socially important routines
- Responsive behaviours that are upsetting or unsafe for the person with dementia or for other residents or family members
- How often the responsive behaviours are happening
- Conditions or triggers that cause these responsive behaviours
- Changes in the person's behaviour or anything different or unusual about their behaviour

Approaches for Managing Responsive Behaviours

Possible Solutions to Specific Responsive Behaviours

The care team may use a guide like the one below to help them understand and manage responsive behaviours. The first set of responsive behaviours below come from the Dementia Observation System (DOS), a tool that some health care providers use to assess a person’s behaviour. Overall the care team should focus on creating a supportive environment, and investigating and satisfying the unmet needs of the person with dementia.

| Responsive Behaviour | | Possible Solutions |
|----------------------|--|--|
| DOS | Noisy | <ul style="list-style-type: none"> Distract*, engage Use music that the person likes, nature sounds, recordings of family members |
| | Restless | <ul style="list-style-type: none"> Distract*, engage Offer places to rest, physical exercise, outdoor activities |
| | Exit Seeking | <ul style="list-style-type: none"> Distract*, engage Adapt the environment to reduce exit-seeking Provide physical exercise, outdoor activities Register the person with MedicAlert and Alzheimer’s Society Safety Home program so their contact information will be on a bracelet or necklace |
| | Verbal reactions | <ul style="list-style-type: none"> Distract*, engage Use music that the person likes, nature sounds, tapes of family members |
| | Physical reactions | <ul style="list-style-type: none"> Distract*, keep calm, remain warm and supportive Know when to give the person some space and try to approach them later |
| Other | Delusion/hallucination | <ul style="list-style-type: none"> Understand that something has upset them and don’t argue about the false belief Focus efforts on how the person feels, not the things they say Offer distraction |
| | Agitated/irritated | <ul style="list-style-type: none"> Calm, soothe, distract* Use music the person likes, aromatherapy, pet therapy, physical exercise, outdoor activities |
| | Resistant to care | <ul style="list-style-type: none"> Try to understand the cause of the person’s feelings, approach them slowly Identify the cause of the resistance, change the routine and ways of doing things |
| | Repetitive questions/mannerisms | <ul style="list-style-type: none"> Reassure, address the possible cause, distract* Put the answer to the same repetitive question on a piece of paper or card and ask the person to read the card instead |
| | Collecting | <ul style="list-style-type: none"> Ensure the person’s environment remains safe Be compassionate |
| | Disinhibition <small>(e.g., disrobing, masturbation in public, hyper sexuality)</small> | <ul style="list-style-type: none"> Distract*, re-direct them to more appropriate behaviour or a more appropriate location for the behaviour |

* When distracting, make sure the activity has a meaning or purpose (based on the person’s preferences and history) and ask questions like “I need your help to....” or “do you think you can help me with this”.

Antipsychotics and Dementia: An Introduction

How is the Choice Made to Use Antipsychotics?

The care team will try many approaches to care for the person with dementia without using medications. Sometimes these approaches don't work or the responsive behaviours get worse. If these responsive behaviours are very upsetting or dangerous to the person with dementia or to others, the care team might use medications, including antipsychotics. Before they prescribe antipsychotic medications the care team will review:

- Any physical health, hearing, or vision problems that might be causing them pain, discomfort, or frustration
- Medications they are taking to determine whether these may be making the symptoms worse
- Factors like the physical space, level of noise or activity, and changes to the person's routine
- Relationships with caregivers, family, or friends
- Any risk of harm to the person or others
- If the responsive behaviours are likely or unlikely to respond to antipsychotics

| Common Antipsychotics | |
|-----------------------|---|
| Drug Names | Brand Name |
| Risperidone | Risperdal [®] |
| Olanzapine | Zyprexa [®] |
| Aripiprazole | Abilify [®] |
| Quetiapine | Seroquel [®] |
| Haloperidol | Haldol [®] |
| Loxapine | Loxapac [®] , Xylac [®] |

Symptoms Likely or Unlikely to Respond to Antipsychotics

Likely to Respond to Antipsychotics

Antipsychotics **may** help to manage symptoms or responsive behaviours like:

- Hallucinations (distressed by hearing voices or seeing people who are not there)
- Delusions (feeling suspicious or paranoid that people are trying to hurt them)
- Severe agitation (extreme irritability, screaming)
- Severe physical reactions (shouting, hitting, kicking, or biting)

Unlikely to Respond to Antipsychotics

Antipsychotics **do not help** to manage symptoms or responsive behaviours like:

- Unsocial behaviour towards other people
- Apathy (no interest in what is happening)
- Disinhibition (like taking off clothes or sexual advances towards other people)
- Hiding or collecting things
- Repeating actions or words/chanting
- Resistance to a specific person
- Wandering or being restless
- Inability to sleep

You can help

- When adding an antipsychotic medication, you can make notes about:
 - The name and dose of the antipsychotic medication(s)
 - Symptoms that the medication is supposed to help
 - Possible side effects of the medication
 - When the medication was started and stopped
 - Other approaches to care being used to manage the symptoms
- Watch for side effects and communicate with the care team if you are concerned
- Watch the responsive behaviours to see if they get better, worse, or don't change
- Talk with the care team periodically about whether the antipsychotic should be continued

Antipsychotics: What to Expect

How Do We Know If Antipsychotics are Helping?

At the start, the care team will give the person with dementia the lowest possible dose of the antipsychotic and will monitor them carefully. They may change the dose or stop the medication if the responsive behaviour does not get better, if the side effects are bad, or if the behaviour is more manageable. If the antipsychotics are not working, the care team will consider using other types of medication.

Dementia is a progressive disease. That means that **most responsive behaviours will change over time**. For this reason, the care team will review the effects of antipsychotics from time to time to decide if they should be continued or not. If the care team has not reassessed the antipsychotic medication, ask to prompt this review. Research shows that antipsychotics may help about one person out of every five who takes them for about 12 weeks.

Side Effects

Some of the **more common** side effects are:

- Feeling sleepy or groggy
- Confusion
- Weight gain
- High blood sugar
- High cholesterol
- Dizziness caused by low blood pressure
- Constipation
- Swelling, usually around the ankles
- Problems urinating (more common in older men)
- Tight muscles that make the person shuffle or take short steps

Some of the **less common** side effects are:

- Shaking in the hands or arms
- Restlessness or needing to walk around a lot
- Twitching face
- Stroke
- Death

Do Antipsychotics Help or Harm?

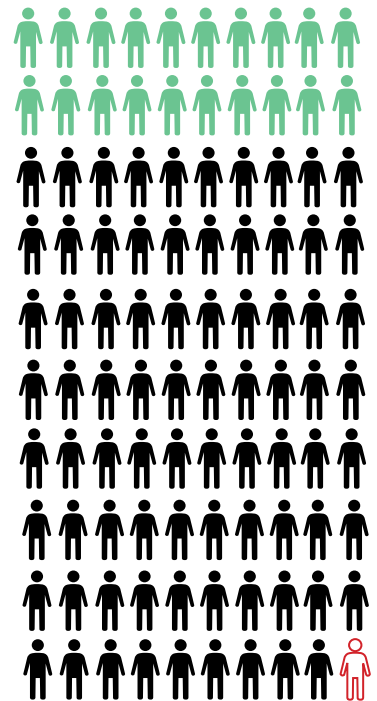
How can antipsychotics help?




The care team might recommend antipsychotics for people with dementia to try to reduce or control symptoms of psychosis, such as delusions (distressing false beliefs) and hallucinations (seeing or hearing something that is not there that is causing distress), and sometimes for severe agitation or severe physical reactions. They can help to calm and clear confusion in a person with acute psychosis within hours or days, but may take several weeks to reach their full effect. When a person feels calmer, some of the other approaches to manage behaviour might work better.

How can antipsychotics harm?

Antipsychotics may make some symptoms better, but make others worse. Every medication causes different kinds of side effects. Some side effects are more serious if the person takes higher doses of the medication. Some side effects get better after taking the medication for a while. Sometimes, it's hard to tell the difference between a side effect of the medicine and a symptom of dementia. For these reasons, antipsychotic medications must be regularly reassessed and removed if found to be harmful.

By the Numbers



-  : Likely to be helped by antipsychotics
-  : Likely to have **no benefit** from using antipsychotics
-  : Likely to have a stroke or die*

*There is research to show that for every 100 people with dementia who take antipsychotics one person is likely to have a stroke or die (mostly related to heart failure, sudden death, pneumonia). However, it is hard to tell if the antipsychotic medicine was the cause, because those with dementia are often at high risk even when not taking an antipsychotic.

For More Information

Please visit <https://cep.health/dementia> for other resources, or visit the websites of the organizations below for more information and support:

Alzheimer Society of Canada. About Dementia

<http://www.alzheimer.ca/en/About-dementia>

The Butterfly Approach

<http://www.dementiacarematters.com/pdf/modern.pdf>

CAMH. Antipsychotic medication

http://www.camh.ca/en/hospital/health_information/a_z_mental_health_and_addiction_information/antipsychotic_medication/Pages/antipsychotic_medication.aspx

Choosing Wisely Canada. Treating disruptive behaviour in people with dementia.

<http://www.choosingwiselycanada.org/materials/treating-disruptive-behaviour-in-people-with-dementia-antipsychotic-drugs-are-usually-not-the-best-choice/>

Eden Alternative

<http://www.edenalt.org/>

Family Councils' Ontario.

<http://www.fco.ngo/>

Health Quality Ontario. Tools and Resources for Patients, Families and Caregivers.

<http://www.hqontario.ca/Patient-Engagement/Tools-and-Resources/Patients-Families-and-Caregivers>

Ontario Association of Residents' Councils.

<http://www.ontarc.com/>

Pioneer Network

<http://www.pioneernetwork.net/>

References

Additional references can be found in Centre for Effective Practice (CEP)'s Discussion Guide for providers at effectivepractice.org/dementia. This resource for residents, families, and caregivers was developed from feedback given by our long-term care stakeholder organizations, providers, and residents, who identified a need for a resource that supports consistent language and approaches for antipsychotic use for dementia across the care team. This resource was adapted, with permission, from work at the University of Iowa and Health Literacy Iowa, and CEP's Use of Antipsychotics in Behavioural and Psychological Symptoms of Dementia Discussion Guide. CEP is grateful to the providers, residents, family members, and caregivers that provided feedback throughout the development process of this resource.

- [1] **Alzheimer Society Canada. What is dementia?** <http://www.alzheimer.ca/en/About-dementia/What-is-dementia> (accessed February 2016).
- [2] **Alzheimer Society Ontario. Shifting focus: a guide to understanding dementia behaviour. 2013.** <http://brainxchange.ca/Public/Files/Behaviour/ShiftingFocusBooklet.aspx> (accessed February 2016).


Adapted from:

University of Iowa and Health Literacy Iowa. (2013). Antipsychotic Medicines for People with Dementia. For more information please see: <https://igec.uiowa.edu/ia-adapt>

Centre for Effective Practice. (2016). Use of Antipsychotics in Behavioural and Psychological Symptoms of Dementia (BPSD) Discussion Guide: Long-Term Care (LTC Edition). For more information please see: <https://cep.health/dementia>

This Tool was developed by Centre for Effective Practice (CEP) with input and review from our Academic Detailing Service Team. In addition, target end-users and other relevant stakeholders provided input during the development process. This Tool was funded by the Province of Ontario as part of CEP's Academic Detailing Service. For more information on the Academic Detailing Service, our Team and/or the development process please visit effectivepractice.org/academicdetailing

This Tool was developed for individuals as a guide only and does not constitute medical or other professional advice. Physicians, Nurse Practitioners, Pharmacists and other health care professionals are required to exercise their own clinical judgment in clinical decision-making. Neither the Centre for Effective Practice ("CEP"), nor any of their respective agents, appointees, directors, officers, employees, contractors, members or volunteers: (i) are providing medical, diagnostic or treatment services through this Tool; (ii) to the extent permitted by applicable law, accept any responsibility for the use or misuse of this Tool by any individual including, but not limited to, patients' family members or entity, including for any loss, damage or injury (including death) arising from or in connection with the use of this Tool, in whole or in part; or (iii) give or make any representation, warranty or endorsement of any external sources referenced in this Tool (whether specifically named or not) that are owned or operated by third parties, including any information or advice contained therein.

 How Antipsychotic Medications are Used to Help People with Dementia: A Guide for Residents, Families, and Caregivers is a product of the Centre for Effective Practice. Permission to use, copy and distribute this material for all non-commercial and research purposes is granted, provided the above disclaimer, this paragraph and the following paragraphs, and appropriate citations appear in all copies, modifications, and distributions. Use of How Antipsychotic Medications are Used to Help People with Dementia: A Guide for Residents, Families, and Caregivers for commercial purposes or any modifications of the tool are subject to charge and use must be negotiated with the Centre for Effective Practice (info@cep.health).

For statistical and bibliographic purposes, please notify the Centre for Effective Practice (info@cep.health) of any use or reprinting of the tool. Please use the below citation when referencing the tool:

Reprinted with Permission from Centre for Effective Practice. (February 2019). How Antipsychotic Medications are Used to Help People with Dementia

Developed by:  Centre for Effective Practice

 Ontario Association of Residents' Councils

In collaboration with:

Canadian Foundation for **Healthcare Improvement**
Fondation canadienne pour l'**amélioration des services de santé**