

For the Person Living  
With Dementia,

*All Behavior Is*

*Communication*

Consider people living with dementia have been prescribed antipsychotics to control their behavior when they have become distressed. Antipsychotics can be dangerous to these people, even resulting in death. The cause of the distress behind this behavior and other behaviors that may seem odd is often the inability to communicate about an underlying issue such as being in pain, hungry, lonely, or bored. In this guide, we offer tips for figuring out what may be the real problem—what the person, who due to dementia is having a hard time communicating, is trying to say—and then helping the person feel better without a dangerous drug.

**Note:** In this guide, we use the word “distress” rather than “agitation.” The former implies peril, which should be addressed. The latter implies misbehaving or acting up, which some people might say is best ignored. Do not ignore the behaviors of someone living with dementia; respond to them.

## Contents

[Responding to a Person Living With Dementia  
Who Is in Distress](#)

[Behavioral and Psychological Symptoms of Dementia](#)

[Possible Meanings of the Behavior](#)

[More on Pain](#)

[Helping With Daily Care Activities](#)

[Why Antipsychotics Are Not the Answer](#)

[Sources and Suggestions for Further Reading](#)

[Note](#)



# Responding to a Person Living With Dementia Who Is in Distress

## 1 Regain your composure.

DO

- Do take a deep breath.
- Do approach the person from the front.
- Do identify yourself.
- Do smile.
- Do go to their eye level.
- Do make eye contact.

DON'T

- Don't touch the person until they've calmed down.
- Don't scold.
- Don't laugh at them.



## 2 Find out what is causing the distress.

DO

- Do acknowledge that the person is distressed.
- Do say, "I will keep you safe."
- Do check for medical issues first.
- Do assess for pain.
- Do speak slowly and clearly.
- Do word questions in a way that they can be answered with "yes" or "no."
- Do repeat a question if necessary.
- Do listen.
- Do pay attention to facial expressions and other non-verbal clues.
- Do reinforce your "yes" answers with a head nod and your "No" answers with a headshake.
- Do remain patient.

DON'T

- Don't ask more than one question in a row.
- Don't talk loudly.
- Don't argue or try to correct them.
- Don't use "elderspeak" (baby talk).

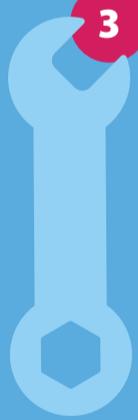


## 3 Modify the cause of the distress.

If it is a medical issue, address it.

For non-medical issues, try other things.  
For example:

- If the person is hungry, provide a snack.
- If the television is bothering the person, turn it off.
- Divert their attention by asking them to help you do something, such as folding washcloths.



## 4 If what you tried doesn't work, keep trying.

- Try again later.
- Have someone else try.
- Try something else.
- Know that a strategy that works one day may not work the next day for the same person.



# Behavioral and Psychological Symptoms of Dementia

**Note:** Many of the symptoms listed may be signals that the person is in pain.

🕒 The clock indicates behaviors that may start in the early evening and could continue throughout the night—“sundowning” symptoms.

- Activity level, change in
- Aggression (hitting, biting, etc.) 🕒
- Anxiety 🕒
- Apathy
- Appetite changes
- Arguing
- Breaking things
- Breathing in a labored manner
- Breathing rapidly
- Calling for help
- Combativeness
- Confusion, increased 🕒
- Crying out
- Delusion (false belief, disconnect from reality)
- Depression
- Drowsiness 🕒
- Exit seeking 🕒
- Eyes squeezed shut
- Fidgeting
- Fire alarm pulling
- Getting up without help
- Grabbing
- High-pitched noises
- Hitting
- Hoarding
- Holding a body part
- Inconsolability
- Irritability
- Kicking
- Moaning
- Moving abnormally
- Name calling
- Pinching
- Pushing, pulling
- Rejection of/resistance to care
- Repeating phrases
- Resistance to movement
- Restlessness 🕒
- Rubbing a body part
- Sexual behaviors that are disinhibited
- Shadowing (following someone around) 🕒
- Sleep disturbances 🕒
- Sleepiness
- Tearfulness
- Throwing food
- Toileting inappropriately
- Wailing 🕒
- Wandering 🕒
- Wincing, grimacing
- Withdrawing
- Yelling 🕒

[\(return to contents\)](#)

# Possible Meanings of the Behavior

## The most concerning:

- Anxiety
- Exhaustion
- Fear
- Pain

## Others:

- Boredom
- Clothes that are too tight
- Cold
- Confusion about what is being said
- Dislike of a person present
- Dislike of what is being requested (e.g., to get out of bed, to be showered)
- Hearing issue (e.g., a new hearing aid battery is needed or wax has built up in the ears)
- Hot
- Hunger
- Illness
- Loneliness
- Overstimulated (e.g., bothered by noise)
- Soiled
- Thirst
- Uncomfortable position (a need to be repositioned)
- Wet

[\(return to contents\)](#)

## More on Pain

Pain is often not treated in people living with dementia because they have difficulty communicating that they are in pain. The irony is that pain negatively impacts the mental processes.

Some things to keep in mind:

- The person might have a **“pain signature”**—a way they typically indicate that they are in pain. If you have a chance to speak with someone who is visiting the person, ask how pain has been expressed in the past.
- When it comes to their pain, **the person is the expert** and is trying to tell you what they need. If they are having trouble talking, watch their facial expressions and other nonverbal clues.
- The Hartford Institute for Geriatric Nursing has a short [guide](#) about **“Assessing Pain in Older Adults with Dementia.”**
- **Pain relief drugs** are important tools. But antipsychotics and other psychotropic drugs do not relieve pain. (In fact, psychotropics may sedate the person to the point in which it is more difficult to communicate that they are in pain.)
- Even if you are not able to eliminate the pain completely, you may be able to **ease** it and figure out a way to prevent it in the future.
- When a person becomes an older adult, there are **many ways they might be in pain**, and the person can be experiencing more than one type of pain at the same time. Here are some of the reasons an older adult may be in pain:

### The most common:

- Arthritis
- Constipation
- Dental problems such as abscesses, cavities, and ill-fitting dentures
- Injuries from the past

### Others:

- Acid reflux
- Bunions
- Cancer and cancer treatments
- Circulation issues
- Diabetic neuropathy
- Falls, injuries from
- Gout
- Heart disease
- Hemorrhoids
- Irritable bowel
- Osteoporosis
- Pressure ulcers
- Skin that is fragile
- Spinal stenosis
- Stomach issues
- Surgery, after-effects of previous surgeries
- Urinary retention
- Urinary tract infections

## Helping With Daily Care Activities

You may find yourself helping a person living with dementia with activities such as getting out of bed, getting dressed, brushing teeth, and bathing. Keep in mind that it is during personal care tasks—particularly bathing—that a person living with dementia is most likely to become distressed. What may not seem a big deal to someone else—like getting water in the ears or eyes—can confuse someone with dementia and make them very upset.

Some things to keep in mind during these activities:

- Speak in short, simple sentences.
- Word questions in a way that they can be answered with “yes” or “no.”
- Keep instructions very simple.
- Repeat instructions.
- Describe what you are doing.
- Don’t rush the person.
- Avoid negative words like “don’t” and “no.”  
It’s better to say, for example, “try to hold the toothbrush this way” rather than “don’t hold the toothbrush like that.”
- Don’t use elderspeak, which has been shown to make people with dementia even more resistant to care activities (an example: “Are we ready for our shower, Sweetie?”).

And for bathing in particular:

- Don’t rub the skin when washing and drying. Pat it gently.
- Cover the person as much as you can. It will help keep them warm, and it respects that the person likely is uncomfortable with someone other than a significant other seeing them naked. A bath poncho, if available, can be lifted and you can place the washcloth underneath it.
- Use a handheld showerhead when possible so that you can start at the feet and slowly work upward. This is less threatening than starting with the water on the head.
- Use towels that are warm from the dryer after bathing; warm towels provide comfort.
- Use rinseless soap, which will expedite the bathing process and, thus, minimize the person’s distress.

If the person becomes very upset during the care activity:

- Stop the activity.
- Step away from the person so they have some space.
- Apologize even though you didn’t mean any harm—it may help defuse the situation.

[\(return to contents\)](#)



## Sources and Suggestions for Further Reading

Please see the [Consumer Voice website](#) for information on alternatives to antipsychotics, the sources of the information in this guide, and suggestions for further reading.

### Note

This guide should not be considered a replacement for more detailed material taught in gerontology, geriatric psychiatry, or pharmacology courses.



**Changing the Culture of Care**

**A CONSUMER EDUCATION CAMPAIGN**

The National Consumer Voice for Quality Long-Term Care & AARP Foundation

[\(return to contents\)](#)