



## Engaging Staff in Individualizing Care

### Tip Sheet Reducing *Off Label* Use of Antipsychotic Medications by Engaging Staff in Individualizing Care to Alleviate Resident Distress

#### WHAT IT IS

*Off label use* of antipsychotic medications means *uses* the medications were not designed and approved for by the FDA. In approving medications, the FDA considers the benefits and risks. Use of antipsychotic medications for people with dementia is an *off label* use because the medications have not demonstrated significant beneficial impact on the behaviors for which they are prescribed, and their sedative increases the risk of mortality and serious health complications.

The medications are often prescribed for people with dementia to “control behaviors.” Yet stopping a “behavior” through sedation prevents staff from learning the root cause of the person’s actions. Behavior is a form of communication for people with dementia who may no longer be able to verbalize why they are distressed or what they need. A resident who is hitting or kicking a caregiver during a shower is using actions to say, “**stop!**” Antipsychotic medications are often used when these actions are considered behaviors to be controlled instead of communication to be understood and followed. This *off label* use sedates the person without understanding what caused the person’s distress or what need the person was trying to express.

The CMS Partnership to Improve Dementia Care encourages person-centered approaches to reduce *off label* use of antipsychotics for people with dementia. Engaging staff in individualizing care to alleviate resident distress means involving staff closest to the resident in identifying the root cause of the person’s distress and meeting the person’s need. For example if a resident is distressed by the current bathing experience, or the morning wake up routine, the consistently assigned CNAs adjust the experience to one more comfortable for the person, alleviating the resident’s distress.

## **WHY IT IS IMPORTANT**

The two reasons to reduce *off label* use of antipsychotic medications are:

1. They usually do more harm than good
2. They stop the behavior instead of understanding its meaning

Antipsychotic medications rarely benefit people with dementia. Their sedative effect increases risk of serious harm and masks the needs residents are expressed through their behavioral communication. Except when used on a short-term basis in response to an acute condition, often the dangers of these medications far outweigh the benefits. Research indicates major adverse outcomes with antipsychotics over a 6-12 week period (Schneider et al 2005, Ballard et al 2009) including gait disturbance, increased respiratory infections, edema, accelerated cognitive decline, and higher risk for stroke and death. These risks increase over longer periods of drug use, while benefits diminish.

The FDA approved antipsychotic medications for use with people with serious mental illness diagnosis, including: schizophrenia, bi-polar disorder, irritability associated with autistic disorder, treatment of resistant depression, major depression, and Tourette. Dementia is not a diagnosis listed for their use. Common off label uses are associated with residents with dementia who are seen as having behaviors difficult to handle such as agitation, violent episodes, or wandering, repetitive behaviors. Recent studies have shown off label use for these behaviors to be largely ineffective.

People with dementia use their actions to communicate when words fail them. If their actions are controlled, their attempt to communicate their needs is thwarted, and their needs remain unmet. Al Power, MD, explains that in order to know what a person with dementia is communicating through their actions, we need to put ourselves in their place and see how they are experiencing the situation. A person with short term memory loss who doesn't recognize the CNA who wakes her in the morning may push "the stranger" away and feel frightened or confused by a stranger coming into her room.

There are many instances in which the behaviors are caused by environmental factors. A resident's yelling might seem to have no rhyme or reason until staff realize the person is talking back to an overhead page. Once we understand the resident's experience, their actions no longer seem abnormal.

Distress is often discomfort with care or the environment. Instead of antipsychotics to sedate residents in instances of “resistance to care,” individualize care to alleviate distress. Rushing naturally late sleepers through an early morning causes distress that is better prevented by following the person’s natural morning wake-up rhythm than sedating with antipsychotic medications. In reducing medications by making care and the environment more comfortable, we are better meeting residents’ needs.

## **HOW TO DO IT**

The four foundational practices provide the capacity to prevent and alleviate distress. Consistent assignment so that the staff really know each resident is crucial in any effort to reduce the use of medication. Some times the signs are so subtle that unless the caregiver has deep tacit knowledge of the resident the clues might be lost. In care plan meetings, and in shift and QI huddles CNAs pass on this information.

***Begin by understanding that all behavior is communication.*** Critical thinking requires questioning our assumptions and imagining different options. In rethinking use of antipsychotic medications, we question our assumption that behaviors are random and without cause. In fact most behaviors in people with dementia are not random and can be directly linked to their need for something to happen or to stop happening. For the resident with dementia who may not have the ability to tell you that something is not working for them, their behavior – biting, pinching, kicking, or hitting - is saying **stop** in the only manner left to them for saying it. Calling out or repetitive actions are “self-referred” or “attention seeking” behaviors that say **look at me**. These are clearly behavioral distress signals telling you to do something different.

### ∞ **Potential starting points:**

- **Start with PRNs and “resistance to care”:** The only immediate effect of an antipsychotic is its sedative effect. So, antipsychotics used PRN are used as a sedative. Get to the root cause to see if there is a more effective intervention. For a resident currently prescribed an antipsychotic for PRN use, look at situations in which it has been used or is considered for use to determine what is distressful about the situation for the resident. If the resident is “resisting” care, how can something more comfortable for the resident be done that stops whatever the person is resisting?

- **Review any recently started antipsychotics, including those started in the hospital:** Hospital stays are disorienting in ways that can easily stimulate distressed behaviors. With your ability to individualize according to each person's routine, residents will not experience the same disorientation and distress. As new prescriptions, they may not yet be at full effect and are easier to do a gradual dose reduction for. Given that they carry such risk, eliminating them will also eliminate the risks caused by their sedative effect.
  - **Multiple antipsychotics:** Find out what prompted each new prescription. Look for patterns. Get to the root causes. Note what calms the person and what is a less distressing way to handle a situation.
- ∞ **Use QI huddles:** Discuss individual residents. Start with information about the person's life story, family, work, what they were like when they first came in, their customary routines. Look at situations that are cause for concern. Prompt critical thinking by asking why the person reacted that way, what caused the reaction, what made it better. Note patterns, recognize triggers and early warning signs, and develop ways to prevent distressing situations.
- ∞ **Establish a QAPI (Quality Assurance & Performance Improvement) Performance Improvement Project (PIP):** Have all departments and shifts involved. Decide on a process and meet regularly as you undertake it. Focusing on one resident at a time, find out what the person needs to be free of distress and figure out how to make it happen. Learn and honor their customary routines. Work on individual solutions and group solutions. For instance if one resident benefits from midnight snacking, perhaps others will also benefit from having a wider range of food at a wider range of times. Pilot test in one neighborhood/unit and use daily and QI huddles.
- ∞ **Use an interdisciplinary approach:** Work across departments and shifts to honor residents' customary routines. Examples of the wide range of interdepartmental solutions include: flexible dining, eliminating alarms, consistent familiar staff for help in bathing, dining, and other personal assistance, asking more frequently about pain, hunger, thirst, being around pets, individualized music from personal ipods, outings and access to outdoors, removing clutter, stimulation, and noise.

- ∞ **Partner with families.** Explain what you are doing and why. Keep them fully informed as you discover causes and determine effective interventions. Use families' knowledge of the resident and what has worked for them and invite their participation in problem-solving. Seek their ideas about approaches that are most comfortable and least distressing. Obtain their input in getting to know the resident better, both who they are and who they were.
- ∞ **Integrate with assessment and care planning:** Connect your QI huddles or PIP process with your assessment and care planning process. Note new interventions in communication books, care plans, and CNA assignment sheets.
- ∞ **Involve Medical Staff.** Share your approach with your medical director and attending physicians so they are an educated and active in this process, including speaking to hesitant families. Often antipsychotic medications are ordered by physicians in response to calls the doctors get from nurses reporting on a resident's behavior. Set up a process so that before nurses call physicians, they are able to get help to identify the root cause and alleviate it. Implement processes included in **Interact2** such as Change of Condition decision support tools and SBAR in order to improve communication between nurses and physicians. Some behaviors like repetitive motions can be annoying but our own annoyance is something for us to deal with; medication has too many risks.

## **RESOURCES**

Pioneer Network [www.PioneerNetwork.net](http://www.PioneerNetwork.net)

- ∞ Pioneer Network's website provides links to many affiliate resource organizations.
- ∞ Pioneer Network National Learning Collaborative Webinars, available for a fee for five on-demand viewings of each webinar, include:
  - Webinar 7 – Operationalizing Customary Routines
  - Webinars 9 - Individualizing Care and Environments: Non-pharmacologic Interventions Instead of Anti-Psychotic Medications
  - Webinar 10 - Promoting Mental Health Through Team-based Individualized Assessment and Care Planning
  - Webinar 12 – It Takes a Team to Provide High Quality Individualized Care

All 12 webinars are also available for purchase as a set of discs, at a discounted rate. To purchase viewings of one or more of the webinars, or the entire package of 12 webinars, go to [www.PioneerNetwork.net](http://www.PioneerNetwork.net).

- ∞ This tip sheet is from the Pioneer Network Starter Toolkit: Engaging Staff in Individualizing Care. The entire toolkit, with additional tip sheets, starter exercise and resources, is available at [www.pioneernetwork.net/Providers/StarterToolkit](http://www.pioneernetwork.net/Providers/StarterToolkit).

**Advancing Excellence in America's Nursing Homes** [www.nhqualitycampaign.org](http://www.nhqualitycampaign.org)

Data collection can help determine whether the changes being made are working, and continue to work. The Advancing Excellence in America's Nursing Homes campaign has the tools and excel sheets for collecting data on consistent assignment (are we REALLY doing this?) and on Person Centered Care (are the wishes and preferences of the residents actually being delivered, and are the direct care workers attending and participating in the care plan meetings?), as well as other organizational and clinical goals. [www.nhqualitycampaign.org](http://www.nhqualitycampaign.org)

**B&F Consulting** [www.BandFConsultingInc.com](http://www.BandFConsultingInc.com)

Short videos available under free resources at [www.BandFConsultingInc.com](http://www.BandFConsultingInc.com)

Tools to aid communication and decision-making are available at [www.interact2.net](http://www.interact2.net)

Use the MDS Care Area Assessment (CAA) tools to guide you through the assessment or root cause analysis

*Dementia Beyond Drugs* by Allen Power, MD at <http://www.alpower.net>