

# **Eliminating Off-Label Use of Antipsychotics**

## **A 10 Step Guide for Nursing Homes**

Developed by B&F Consulting

for

### **LEADER's Project to Improve Dementia Care**

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### OVERVIEW

This step-by-step guide explains how to eliminate off-label use of antipsychotic medications for people with dementia. The guide draws from the experiences of staff at four New Orleans area nursing homes with high rates of off-label antipsychotic use who successfully reduced antipsychotics using a method developed by B&F Consulting for LEADER's Project to Improve Dementia Care.

### WHY ELIMINATE OFF-LABEL USE OF ANTIPSYCHOTIC MEDICATIONS?

Antipsychotic medications were designed, tested, and approved for use by people with serious mental illness. They work by blocking dopamine, which is elevated with schizophrenia. Dopamine affects motor skills, cognitive abilities, and engagement.

A side effect of antipsychotics is sedation. For decades, it has been common medical practice to prescribe antipsychotic medications to sedate people with dementia, including people living at home and in nursing homes, in response to dementia-related behaviors. These behaviors, previously characterized as "psychotic," are now understood to be how people with dementia communicate needs when they have lost their language abilities. The behaviors do not come from elevated dopamine levels. In fact, use of the antipsychotics for people with dementia brings dopamine levels below normal, and contributes to declines in their balance, memory, and mood.

Dangers from lowered dopamine levels and increased mortality due to sedation, led the FDA, in 2008, to issue a "black-box" warning (its strongest warning) against use of antipsychotics for people with dementia. In 2012, CMS launched a Partnership to Improve Dementia Care to eliminate this off-label use of antipsychotics. In 2013 CMS issued new surveyor guidance (Appendix A) to address off-label use of antipsychotics under **F 309 - Quality of Care** and **F 329 - Unnecessary Drugs**. In February 2015, CMS made the quality measure on off-label use of antipsychotics part of the 5 Star system.

As the standard of practice is changing, nursing home practitioners are challenged to learn new approaches to alleviate residents' distressed behaviors. With hospital, community, and geri-psych doctors still prescribing antipsychotics for people with dementia, nursing homes are singularly being held accountable for eliminating this off-label use. Nursing homes are in the best position to pioneer these new practices because they can get to know residents over time, by tracking and trending their behaviors to determine why they are distressed and how to relieve their distress.

LEADER, on behalf of Louisiana's Partnership to Improve Dementia Care, used Civil Monetary Penalties funds to contract with B&F Consulting to develop a method to reduce off-label antipsychotics by working with pilot nursing homes in the New Orleans area. The homes started with high rates and successfully reduced antipsychotics. This guide brings the lessons from the pilot homes to all nursing homes in Louisiana.

## **METHOD**

The method is designed to develop a sustainable quality improvement system for nursing homes to track, analyze, and eliminate their off-label use of antipsychotics. The method uses CASPER data from the quality measure reports to identify residents receiving antipsychotics off-label and then engages staff closest to the residents in daily observation, communication, and problem-solving to identify, alleviate, and prevent causes of residents' distress through individualized approaches to daily care. The method aligns with QAPI (Quality Assurance and Performance Improvement) and can be formalized as a performance improvement project (PIP).

The method includes the following steps:

- 1. Establish A Leadership Team**
- 2. Review CMS Survey Guidance to Understand Why and How**
- 3. Analyze the MDS CASPER Resident Level Quality Measure Report to Determine Your Target Population**
- 4. Triage: Review Why Each Resident is Receiving Antipsychotics and Take Care of Easy-to-Act-On Situations**
- 5. Training: Why and How to Reduce Antipsychotics**
- 6. QI Closest to the Resident: Track and Trend and Care Plan**
- 7. Engage Physicians, Prescribers, and Your Consultant Pharmacist**
- 8. Engage Families**
- 9. Update your policies, procedures and forms**
- 10. Sustain and Spread**

### **Step 1 - Establish a leadership team for the effort**

The team that coordinates the effort needs to include decision-makers, both clinical leaders and leaders who have direct responsibilities for daily care. This includes the DoN and unit-based nurse managers, MDS coordinator, social work and activities staff. Choose a team leader who has a clinical role, is able to use the MDS CASPER data, is knowledgeable about dementia care, and is a creative, engaging implementer with the authority to carry out interventions.

Assemble a team that will be able to lead the rollout of elimination of off-label antipsychotic use to the whole organization. Use a layered process, starting with the

leadership team's self-education, analysis of the data, and early action to address obvious and easy situations. In this initial stage, the leadership team needs to begin introducing the change in practice to the staff working directly with any residents who are being reviewed for antipsychotic drug reduction. As the leadership team develops experience and insight from this initial stage, it will be ready to support full staff engagement.

While the team will continue to provide oversight, ***the locus of the work will shift to be with the staff closest to the residents***. As staff tune in individually in their daily care and interaction, they will identify causes and early warning signs of distress. Through quick huddles, they can then share with co-workers strategies and approaches to alleviate and prevent the distress. Staff working most immediately with residents need the full support of the rest of the care team to be able to make the adjustments in care to accommodate each resident's routines and in-the-moment needs.

The team that coordinates this effort needs a direct pipeline to the staff closest to the residents and regular interaction, through rounds and huddles, to support the staff in making these adaptations.

## **Step 2 – Prepare: Review CMS Survey Guidance to Understand Why and How**

Review the May 24, 2013 CMS issuance (S&C: 13-35-NH) which instructs surveyors on how to survey for compliance with use of antipsychotic medications for people with dementia related to **F 309 - Quality of Care** and **F 329 - Unnecessary Drugs**.

Everything new is in red ink. The document isn't page-numbered so find key areas by heading. The two non-compliance examples give your team good places to start – residents with dementia receiving antipsychotics due to distress during bathing and residents whose antipsychotic was starting during a hospital stay.

The Indications for Use are broader than the Quality Measure triggers and include some acceptable uses that still trigger on the Resident Level Quality Measure Report.

- ***F 309 Level 4 Severity Non-compliance Example***, describes a resident distressed during bathing
- ***F 329 Antipsychotics*** lists medications and Indications for Use.
  - ***A. Conditions Other than Dementia***
  - ***B. Behavioral or Psychological Symptoms of Dementia***
    - ***Inadequate Indications***
    - ***Acute Situations/Emergency*** – review within 7 days
    - ***New Admissions*** – review at admission and within 14 days
- ***F 329 Level 4 Severity Non-compliance Example***, describes a resident

whose antipsychotic was started in the hospital in response to delirium that resolved, and was continued, unaddressed, during the nursing home stay.

### **Step 3 – Analyze the MDS CASPER Resident Level Quality Measure Report to Determine Your Target Population**

The starting point is to orient the team to the CASPER report, which uses MDS data to identify residents who are triggering for a number of quality measures, including off-label use of antipsychotics. By working with the CASPER report, which is automatically updated each week, the leadership team has an on-going mechanism for monitoring your home's antipsychotic medication use.

Reviewing the CASPER Resident Level Quality Measure Report gives you your target population. It marks with an **X** each short-stay and long-stay resident who triggers the quality measures for antipsychotic drug use. A resident receiving antipsychotics **triggers for off-label use, unless the person has *Schizophrenia, Huntington disease, or Tourette's Disorder***. This quality measure data draws from the most recent MDS completed for each resident and its accuracy is dependent on how accurate and up to date the MDS is.

#### **To get the MDS CASPER Resident Level Quality Measure Report:**

- Log in to the CMS system as you normally would to work with the MDS
- Log on to **CASPER reporting** with your same log in information
- On the page "Welcome to CASPER" in the upper right hand corner, click for **reports**
- At the bottom of the list, click on "**MDS 3.0 Resident Level Quality Measure Report**"
- For start and end date, select your most recent month so that the resident census is up to date
- On the right hand side of the screen, click on Save and Submit
- Allow 5-10 minutes for the information to come up on the screen. Then Print.

#### **Review the Resident Level Quality Measure Report:**

The Report lists every active resident and 18 Columns of Quality Measures.

- The left hand column lists names of all active residents.
- Find the columns labeled Antipsych Meds (S) for short-term residents and Antipsych Meds (L) for long-term residents (see arrows in the form above)
- Look for an **X** in the Antipsych Meds columns and match the **X** to the name in the left hand column.
- Review each resident with an **X** to determine which triggered residents might actually have a serious mental illness but do not have the needed documentation

of their diagnosis, and which residents are receiving antipsychotic medications without having a serious mental illness, and therefore for off-label uses.

**CASPER Report**  
**MDS 3.0 Resident Level Quality Measure Report**

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Facility ID: [REDACTED] Report Period: 08/01/11 - 12/01/11  
 Facility Name: [REDACTED] Run Date: 03/04/13  
 CCN: [REDACTED] Report Version Number: 2.00  
 City/State: [REDACTED]  
 Data was calculated on: 02/08/2013

Note: S = short stay, L = long stay, X = triggered, b = not triggered or excluded,  
 C = complete; data available for all days selected, I = incomplete; data not available for all days selected

Resident Name	Resident ID	A0310A/B/F	SR Mod/Severe Pain (S)	SR Mod/Severe Pain (L)	Hi-risk Pres Ulcer (L)	New/worse Pres Ulcer (S)	Phys restraints (L)	Falls (L)	Falls w/Maj Injury (L)	Antipsych Med (S)	Antipsych Med (L)	Antianxiety/Hypnotic (L)	Behav Sx Affect Others (L)	Depress Sx (L)	UTI (L)	Cath Insert/Left Bladder (L)	Lo-Risk Lose B&B Con (L)	Excuses Wt Loss (L)	Incr ADL Help (L)	Quality Measure Count
Data			C	C	C	C	C	C	C	I	I	C	C	C	C	C	C	C	C	
<b>Active Residents</b>																				
[REDACTED]	21412697	99/02/99	X	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	1
<b>Discharged Residents</b>																				
[REDACTED]	20103901	99/99/10	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	0
[REDACTED]	12745306	99/99/10	b	b	b	b	b	X	b	b	b	b	b	b	b	b	b	b	b	1
[REDACTED]	9885	99/99/10	X	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	1
[REDACTED]	17048605	99/99/10	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	b	0

This report may contain privacy protected data and should not be released to the public.

**First, eliminate coding errors.** When residents DO have long term serious mental illness for which antipsychotic medications are the appropriate treatment, but that diagnosis is not properly recorded, this is a coding error.

Sources of information to determine the presence of a life-long mental illness include PASARR, the ICD-9 code with the billing diagnosis for each antipsychotic medication, and the resident's medical record and history.

A key indicator is whether the medication has been given since young adulthood, or was started much later in life. Most serious mental illness manifests in younger life. Therefore, if an antipsychotic medication has been started later in life for an older person with dementia, it is likely that the person does not have a late-life onset of mental illness. **However, many people who have had life-long mental illness do not necessarily provide that information to the nursing home on admission.**

For those who actually have a mental illness for which the medications were designed, correct the coding error so they no longer trigger by going to the **MDS Section I on Active Disease Diagnosis** and checking off under **Psychiatric/Mood Disorder box I6000 for Schizophrenia** (see arrow in form below)

	Section I	Active Diagnoses
	<b>Active Diagnoses in the last 7 days - Check all that apply</b>	
	Diagnoses listed in parentheses are provided as examples and should not be considered as all-inclusive lists	
	<b>Neurological - Continued</b>	
	<input type="checkbox"/>	I4900. Hemiplegia or Hemiparesis
	<input type="checkbox"/>	I5000. Paraplegia
	<input type="checkbox"/>	I5100. Quadriplegia
	<input type="checkbox"/>	I5200. Multiple Sclerosis (MS)
	<input type="checkbox"/>	I5250. Huntington's Disease
	<input type="checkbox"/>	I5300. Parkinson's Disease
	<input type="checkbox"/>	I5350. Tourette's Syndrome
	<input type="checkbox"/>	I5400. Seizure Disorder or Epilepsy
	<input type="checkbox"/>	I5500. Traumatic Brain Injury (TBI)
	<b>Nutritional</b>	
	<input type="checkbox"/>	I5600. Malnutrition (protein or calorie) or at risk for malnutrition
	<b>Psychiatric/Mood Disorder</b>	
	<input type="checkbox"/>	I5700. Anxiety Disorder
	<input type="checkbox"/>	I5800. Depression (other than bipolar)
	<input type="checkbox"/>	I5900. Manic Depression (bipolar disease)
	<input type="checkbox"/>	I5950. Psychotic Disorder (other than schizophrenia)
→	<input type="checkbox"/>	I6000. Schizophrenia (e.g., schizoaffective and schizophreniform disorders)
	<input type="checkbox"/>	I6100. Post Traumatic Stress Disorder (PTSD)

**Note:** Residents that receive antipsychotic medication to treat a mental illness other than schizophrenia, Huntington's or Tourette's will still trigger on the quality measures. Make sure the medication they are receiving is designed to treat the disease they have, and not being used in response to behaviors.

Make sure that the proper diagnosis is also documented in MAR, the care plan, and the medical record. The diagnosis must match the ICD-9 code used by the pharmacist to indicate the diagnosis for use of the medication for billing, and it must match the recommended uses for the medication. The presence of the illness must be supported in the documentation. For example, someone with a diagnosis of bipolar would have indications of both ends of the mood swing in the nurses' and CNA's notes.

- **Determine Your Target Population for Antipsychotic Medication Reduction**  
**Residents who do not have mental illness** are your target for discontinuation of the antipsychotics.

**Step 4 – Triage: Review Why Each Resident is Receiving Antipsychotics and Take Care of Easy-to-Act-On Situations**

Now you have a list of people who need to have their antipsychotic medications discontinued. Before you can make an action plan, you need more information. At this stage in the process, find out when and why the antipsychotic medication started.

In this first layer of review, gather enough basic information to determine if there are easy ways to address the situation for this person or if it is more complicated. **You can then target the easy situations to resolve first. More complex situations can then be handled one at a time from the easiest to the hardest.**

➤ **Start with Low Burden – High Benefit**

**Starting with the easiest situations gives you benefit without much burden, and allows you to learn the basics without the distraction of complexity.**

*An example of an easy situation is a resident who was just started on an antipsychotic during a short hospital stay and had no prior history of mental illness. The medication hasn't been in use for very long and the behaviors that prompted the hospital to prescribe the medication were likely attributable to the disorientation of the hospital setting or of the medical condition and treatment.*

*When the resident returns from the hospital, staff are likely to notice how the person is sedated and unable to perform activities of daily level at the pre-hospitalization level. The sedation has the effect of deconditioning the person, who is already debilitated from the hospital stay and the conditions that prompted it. As the antipsychotic is discontinued and its sedative effect wears off, and the person returns to prior abilities and spirit, staff will see the benefits of reducing antipsychotics.*

**Low Burden:** Staff will not have the challenges of a resident with agitated behavior.

**High Benefit:** Staff are relieved to see someone they care about get better. *And* the surveyor guidance says residents admitted with an antipsychotic medication must have their prescription evaluated for dose reduction within 2 weeks of admission.

There is a tendency among the staff to focus on the **worst case scenario** first because that is what they have the most concern about. However, putting the harder situations to the last allows staff to build up experience with easier situations and not to take on more than they can handle. Having early experiences be difficult can discourage people and make them hesitant about continuing.

Early easy successes build the capacity for staff to problem solve. As their experience grows in the critical thinking to understand and resolve situations causing distress, staff become more able to take on more complex situations successfully. A situation that might have stumped them if taken on too early in the process, can often be resolved once staff are seasoned in figuring out approaches to prevent distress.



- **For each resident with an X, determine and discuss when and why the antipsychotic medication was started.**
  
- **Did the medication start before the person came into the nursing home?**  
Was it a sleep aid or to control behavior while the person was being cared for at home? Often, family caregivers are their wits ends' when their loved one with dementia doesn't sleep at night, because then they don't either. Dementia-related behaviors add to caregivers' distress. When antipsychotics for sleep or sedation are prescribed by a family doctor, the family may not know about the dangers or the alternatives, but they do feel the relief, as both loved one and caregiver are finally able to sleep at night and calmer during the day. Families may be reluctant to allow you to change medications they've come to rely on while giving care at home. You can explain that they have brought their loved one to you because you have a 24-7 capability that allows you to find ways to help a resident sleep and be less distressed. You have more resources and professional skills than they had at home, so you can provide non-pharmacologic approaches.
  
- **Was it during the hospital visit** prior to admission or return to the nursing home, or during a previous hospital visit while the person lived at home?  
Antipsychotic use is a common practice in hospitals in response to the distressed behaviors of people with dementia, who are naturally agitated by an unfamiliar hospital environment that interrupts sleep, and does not provide individualized assistance in activities of daily living. Residents with dementia, unable to express their needs and unable to take care of their needs themselves, can easily become more confused and disoriented from dehydration, constipation, pain and lack of uninterrupted sleep. Hospital staff do not have the time to get to know patients so that they can recognize that the distress may be caused by pain, hunger, thirst, a need to go to the bathroom, fear, unfamiliar noises, etc. Residents' dementia behaviors signaling distress can increase and be compounded by hospital-related psychosis. The antipsychotics add sedation to the mix without reversing the causes of distress. Many people with dementia leave a hospital debilitated and deconditioned. Surveyor guidelines indicate that nursing homes must *re-evaluate the use of the anti-psychotic medication at the time of admission and/or within two weeks of admission (at the time of the initial MDS assessment) and consider whether or not the medication can be reduced (tapered) or discontinued.*
  
- **Was it a sleep aid?** Could melatonin be easily substituted? Is the person having sleep interrupted by care at night, and can this be changed? Lack of REM sleep (which begins during the 3<sup>rd</sup> hour of uninterrupted sleep) contributes to confusion, decreased motor function, and irritability. It also quickens the progression of dementia, while regular REM sleep slows the progression of dementia. Look to condense and limit night-time interruptions and create an environment conducive to deep REM sleep.

- **Was it started at the nursing home in response to a single or series of incidents?** What happened when? How often? Under what circumstances? Talk it through and look at the documentation.

**Was it used in relation to a specific incident or during certain types of care or times of day?** The pilot homes saw that a number of residents' behaviors were associated with bathing, meal-time, morning care. In talking the circumstances through, they saw what that factors the staff could adjust to alleviate residents' distressed behaviors. *One home saw, from review of the documentation, that a resident was frequently agitated when she had to wait a long time for her meal to be served. An easy fix to try was to shorten the wait time. She went on the list of easy people to start with.*

In some cases, the cause of behaviors will be obvious but in other cases, you will need to find out more by talking with the family and with the staff closest to the resident. Look at nurse and CNA documentation to determine what is happening.

Look under MDS Section E on Behaviors at **E6. Rejection of Care** to see if the agitation or aggression is associated with certain types of daily care.

E0800. Rejection of Care - Presence & Frequency	
Enter Code <input type="checkbox"/>	<p>Did the resident reject evaluation or care (e.g., bloodwork, taking medications, ADL assistance) that is necessary to achieve the resident's goals for health and well-being? Do not include behaviors that have already been addressed (e.g., by discussion or care planning with the resident or family), and determined to be consistent with resident values, preferences, or goals.</p> <p>0. Behavior not exhibited</p> <p>1. Behavior of this type occurred 1 to 3 days</p> <p>2. Behavior of this type occurred 4 to 6 days, but less than daily</p> <p>3. Behavior of this type occurred daily</p>

**Note:** Identify any **PRN** use of antipsychotics. This is a red flag that certain care related circumstances are the cause.

- **Look into the person's history, jobs, likes, routines**  
The pilot homes were able to understand more about a resident's behaviors as they understood more of the background. *One resident who had been labeled as hallucinating because she was frequently up and active at night and thought she was at parties, turned out to be someone who had been big in the Mardi Gras community and was in fact a partier by nature. Rather than redirect her back to bed at night, staff tried engaging her in her partying, and making music that she would respond to available to her. Another man was not distressed except when others tried to stop him from his repetitive walking rounds. This pattern matched his history and it became clear that the concern was the perception of others that he was a danger, because of his size, when in fact, as long as he was not interfered with, he was calm in demeanor while he walked.*
- **Was it started after a psych consult or a geri-psych hospitalizations,** and if so, what led to the psychiatric intervention? Get as much information as you can

about the circumstances. Often, when residents with dementia whose behaviors are exacerbated are sent to a geri-psych unit, they come back with additional antipsychotic medications, prescribed by practitioners who are not observing residents in their day-to-day setting where they could identify potential causes of residents' distress.

- **Was it during an off-hours shift** when fewer management supports were in place? Was it while part-time or per diem staff were working or the staff had unscheduled absences? Was the staff person someone the resident was unfamiliar with? The situation is more challenging for staff working during nights and weekends who don't have as many internal resources to turn to when residents' exhibit distress. Some are PRN staff with less in depth familiarity with residents. When night or weekend nurses call physicians in response to residents' distress, they often reach on-call physicians who also do not know residents. As long as these physicians are unfamiliar with the dangers of antipsychotics, when they are asked for assistance, they are inclined to prescribe their use. Survey guidelines indicate that for any new antipsychotic initiated in an "acute treatment period," the interdisciplinary team must evaluate the situation within 7 days *to identify and address any contributing and underlying causes, and attempt non-pharmacological interventions*. Is that being done now? Effectively or for paper compliance?
- **Are there other related problems?**  
Is the person also triggering for falls or reduction in independence with ADL care? Look for links between the use of the antipsychotics and declines or other areas of risk due to the side effects of lowered dopamine and increased sedation. Often there is an unrecognized cascading affect as side effects of antipsychotics are treated with medications. Once antipsychotics are no longer present to generate these side effects, many residents experience restoration of mobility, cognition, and engagement.
- **Look at other medications**  
Take out the **MARs** and look to reduce multiple medications addressing the same medical issue and medications prescribed to address the side effects of other medications. Look at the other medications the person is receiving. Do the medications have side effects that contribute to the resident's behaviors? For example, **Anticholinergics** cause confusion and other discomforts such as dry mouth and constipation that can cause agitation, and are not **recommended for use by older adults**. Overall medication reduction might contribute to reducing a resident's distress and improving function and mood.
- **Review your consultant pharmacist's drug regiment review irregularities**  
Has the pharmacist identified the antipsychotic as lacking a diagnosis? If not, remind the pharmacist that you need to have such irregularities noted in future reviews.

If they are noted what were the physicians' responses? A physician who is not the prescriber may be hesitant to change someone else's prescription. Your medical director can let the attending physicians know you are counting on their oversight and that the medication can only be used if a person has a diagnosis warranting the antipsychotic. (See **Step 7** on Working with Physicians)

**Make an Action Plan:** Conclude each meeting with action steps and assignments so that the team has a clear plan for follow-through.

After you have discussed every resident with an **X**, group residents according to the type of action to take:

**Correct coding errors for people with mental illness**

- Track down diagnosis
- Update all documentation

**Easier issues to resolve for people you need to discontinue**

- Residents with newly started antipsychotics
- Residents receiving PRN antipsychotics for care specific situations
- Residents receiving antipsychotics as a sleep aid

**Residents you need more time and information for**

- Find out more from families about their history and patterns
- Find out more from the staff who work with them about the circumstances

- **Give the team 2 – 4 weeks to correct coding and resolve “easy” issues.**
- **Reconvene the team within a month. Review the most recent CASPER report and discuss the status of each resident still triggering.** Residents will continue to have an **X** until they are no longer receiving antipsychotics without a diagnosis or until the coding correction is made. Discuss progress on coding corrections and talk about each resident whose antipsychotic discontinuation was hoped to be easy to do. Share new information learned and easy fixes that worked. As your leadership team begins to see small adaptations that can be made to alleviate distress, the process will help everyone think critically. The answers will begin to jump out more easily as the team looks at the circumstances. As one pilot Director of Nursing said, *changing minds about use of antipsychotics is truly the first step*. This occurs as the team starts to look more carefully at the origins and causes, and have more experience with alternative approaches working.
- **Pipeline:** As you are reducing antipsychotics, make sure you are not still adding to the list of residents triggering because they were admitted with antipsychotics but without a diagnosis, or they had an acute episode.

- During the **admission** process, if any antipsychotics are on the medication list, determine a diagnosis and find out when and why it was started. This upfront work will save time later.
  - To prevent having residents added to the list because of an **acute episode**, establish a process for off-hour staff to have support and direction to initiate alternative approaches rather than call a physician and request antipsychotics.
- ***If we don't use antipsychotics, what do we do?*** After you discuss the residents with obvious care related stresses that can easily be alleviated by adjustments to the care routine, talk about the more difficult situations, involving residents whose behaviors are a challenge to staff. Even as you understand the dangers of the antipsychotics, you are still faced with the distressed behaviors that need to be addressed.

**Slow down and discuss on one resident at a time.** The action now is to analyze potential causes of distress and ways of alleviating it, one person at a time. Removing antipsychotics is a multi-step process because once residents are no longer sedated, they may return to their distressed behaviors. It is essential that as antipsychotics are eliminated, staff identify causes of the distress and have interventions at the ready to alleviate these causes. A resident who fought in the shower until antipsychotics sedated him so much he had no fight left, will regain his fight as antipsychotics are reduced. He will need to have a different kind of bathing experience. Take your time to think it through.

**Start by looking into the person's background, personality, preferences, and patterns.** Seeing the world through the person with dementia's perspective can shed light on responses that otherwise seemed random. This is a good time to reach out to families. Initially, ask the staff to share what they have observed. Share the social history with staff along with any insights from families. *At one of the pilot homes, one younger larger man with dementia tended to walk all over the nursing home approaching the older women who were frightened of him. When the staff looked in his history, they saw that he had been cared for by his mother who, as a very sociable older woman, had many older woman friends visit and he had been accustomed to joining in these visits. As the staff realized his approach was friendly, they changed their approach from protective to friendly and the other residents did as well.*

**Use quick stand-up huddles to discuss each person with the staff caring for them** to see what the staff were observing and trying. Often staff who work with the same residents regularly recognize early warning signs that a resident is in distress and about to escalate. Many staff also have ways that they have learned to approach residents to alleviate their distress. Have staff share these indicators and approaches with each other and your team. In bringing these

discussions to the staff, let them know about the process and what you're doing at your team meetings, how the information they share is helping. Let them know that you'll be coming around regularly to talk with them about each person whose medications are being reduced.

**By tracking and trending you'll all learn what to do.**

Once the leadership team has had some success with this process in the conference room, it's time to ***shift the locus of the process from the conference room*** to the staff closest to the resident.

- **Choose residents for in-depth work.** As you clear out the coding issues and easy fixes, your target population for discontinuation has gotten smaller, but the situations are now more complex. Review the list of residents that need more time and information. Choose who to focus on - no more than one person per unit. Choose someone who will be easier rather than the hardest situation.
- **Form a communication loop with staff closest to the residents** so that they know what is happening and can take part in the process.

As you prepare to address these more challenging situations, you will need to activate and engage your staff, physicians, and families. Everyone needs to be on board and in sync, and you need to establish open communication links so that as you are embarking on new practices, you are able to hear quickly how they are working and can make timely adjustments.

**Key steps to launch your action include:**

- **Engage the staff closest to the residents**, through staff **education (Step 5)** about why and how, and then through **QI** among the staff closest to the resident **(Step 6)** involving **tracking, trending**, and collaborative problem-solving. Remember to capture any changes on the **care plan!**
- **Engage physicians/other prescribers** and your consultant pharmacist, **(Step 7)** through education about why and how you are changing to non-pharmacologic approaches and have on-going communication as you work with each resident
- **Engage families (Step 8)**, at admission, at care plan conferences and in other meetings, explaining why and how you are tracking, trending, and problem-solving. Seeking information about the residents and encourage their participation to aid in problem-solving.

**Step 5 – Training: Why and How to Reduce Antipsychotics**

The purpose of education is to explain why and how you are eliminating the off-label use of antipsychotics as a launch to staff engagement in the process. You may

decide to pilot the elimination process in one unit first. Time your education to prepare staff to take part. Have a plan to reach all shifts and departments.

***Remember that in the absence of your direct communication, misinformation may abound. At one pilot home, staff on the night shift thought that a resident's untreated pain was because she'd been targeted for antipsychotic reduction, when in fact it was a problem with her morphine patch. They'd had a negative impression of the elimination effort until they had accurate information.***

Keep the training brief (approx. 30 minutes) and interactive. Keep the content practical and put it in the context of staff's day-to-day situations.

Share what you have learned already by your initial efforts to reduce antipsychotics, and share your plan for working one resident at a time with their help.

Here is an overview of key content provided to the pilot homes (see Appendix B for training material for this content):

### **Part 1 – Why: Off-label Antipsychotics do more harm than good**

The research is in – antipsychotics do harm without benefit to people with dementia.

- Antipsychotics have a black box warning against use for people with dementia because they increase mortality through over-sedation, which makes people sluggish, deconditions them, and increases their risk of pneumonia.
- Antipsychotics were designed to lower dopamine levels for people with serious mental illness, but for people with dementia, it gives them a dopamine deficit that makes them more confused, distressed and in danger of falling.

This is a ***change in the standard of practice*** that isn't going away. Across the country nursing home staff are figuring out new ways of caring for people with dementia and we can too!

### **Part 2 – How: Seeing From the Perspective of a Person With Dementia**

For a person with dementia who can no longer communicate through words, behavior is not something to be stopped; it is something to be understood.

- **See through their eyes.** Imagine how you would react if a stranger tried to get you out of bed, or prevented you from leaving to pick up your child at the

bus. When we see the world as a person with dementia is seeing it, we can make sense out of their behavior.

- **Understand what they are communicating.** Not all behaviors are the same. If we look more closely, we see that there are different types of behaviors communicating very different messages.
  - **Agitation:** Behaviors that make us turn and look are asking us to pay attention to a need. A person may be hungry, cold, need the bathroom, need to move. So they may make a noise – call out, clap, bang – to get our attention. This is a self-referred, agitated behavior saying “Help Me!” and expressing an *unmet need*. They need us to figure out what that need is. *One pilot home came to recognize that every time the man started pacing agitatedly, he had to go to the bathroom.*
  - **Aggression:** Behaviors that make us pull back are asking us to stop what we are doing and leave a person alone. We are taking them away from where they are headed and they don’t want to be deterred, or we are approaching in a way that feels scary or invasive and they want us to stop. This fear-based behavior is other-referred, saying “Stop!” and that is what we need to do. *One home described how they had used four staff to shower a resident who fought in the shower until they targeted him for antipsychotic drug reduction and realized that with one person he knew and trusted helping him to wash himself, he showered without a battle.*
- **Apply it to everyday work.** The video clip from Bathing Without a Battle of a resident fighting in the shower illustrates aggression as communication to Stop! Use discussion with staff about their own experiences to launch a process of learning, one resident at a time, what residents’ distressed behavior is communicating.
- **It’s easier to change what we do than ask someone with dementia to change what they do.** When a resident with dementia becomes agitated in a way that demands the immediate attention of a staff person who is currently involved in helping someone else, it does not work to ask the agitated person to wait. Residents with dementia have lost the ability to reason and to wait, and will only escalate until they are attended to. Counterintuitive as it is, it’s even better for the resident who the staff are currently caring for, to pause with that person to go to the person who cannot wait, so that that person doesn’t escalate to a point of great distress both for themselves and for everyone else.

Dementia takes away not just peoples’ memory, but also their ability to coordinate movements in activities of daily living, speak or understand direction or conversation,



and recognize familiar objects and places. When we put ourselves in their place, we can figure out what is causing their distress.

### **Part 3 – How: Track and Trend, Problem-solve and Adjust**

Share your team’s progress so far and your plan going forward to identify one resident at a time for antipsychotic elimination with staff’s involvement.

- **Track and Trend:** In order to understand what a resident is communicating, we need to pay close attention to what is going on, look for early warning signs of distress and identify ways to relieve or prevent distress. With a simple tracking tool, we will note times of day, what was going on and what resolved the situation. Then we can look for trends that help us understand how to prevent distressed behaviors. *The pilot home only understood that the agitated man needed to go to the bathroom because they tracked and trended and saw the pattern. Before that, his outbursts had seemed random.*
- **Huddles:** On each shift and across shifts, staff will check in about the resident who is being tracked and trended, to share information and problem-solve. The team leading the process will round and join a quick huddle to check in as well. This is a whole-team effort. Housekeepers, dietary service staff, activities – everyone who works with the person being tracked – can contribute what they observe and their ideas.

***Let staff know the timetable for action and what they can expect. Leave plenty of time for questions and discussion.***

### **Step 6 – QI Closest to the Resident**

QI closest to the resident brings the process for antipsychotic elimination to the point of care. It uses information gathering and information sharing among the staff at the point of service, for problem solving at the earliest signs of distress. Going right to the source builds the abilities of staff closest to the resident to prevent the distresses that cause the behaviors that prompted the use of medications in the first place.

- As you identify sources of distress and changes to approach, incorporate them into the **care plan**. Don’t wait for the quarterly care plan meeting. Make changes on the spot, to the care plan and the CNA assignment sheet so everyone knows what to do to prevent distress.
- QI Closest to the resident depends on stable staffing at the point of care. Tracking and Trending works best when the same staff work with the resident every day so that they are tuned in to the person’s reactions and can establish trust through an individualized approach to care. ***Use a consistent assignment for residents with dementia so they feel familiar and safe***

***with the people providing intimate personal care.*** (See Appendix E for a tip sheet on consistent assignment).

**QI closest to the resident has two components:**

- **Track and Trend**
- **Huddles**

### **Track and Trend**

As you begin taking on these more challenging situations, where behaviors seem random, the first step is to activate a charting process to look for patterns and triggers, so that the behaviors can be better understood and addressed.

All the pilot homes shared that, as they paid closer attention, they came to understand what was happening and how best to respond.

*At one pilot home, before the tracking and trending, their impression of the man was that he was hallucinating, standing in front of mirrors talking to himself or to someone who wasn't there. As they paid closer attention, they realized he thought the person in the mirror was his brother and he was having very pleasant conversations with him.*

*His behaviors had been aggressive when staff had tried to steer him away from the mirror because others feared him. He fought against being taken away from his conversations with his brother. Once staff understood, they approached him differently. They would say, "so sorry to interrupt. Would you be able to help me? I need help over here" and then they would steer him to another mirror away from residents how were disturbed. Soon, as they were calmer themselves, other residents were no longer afraid.*

**Keep it simple.** Do NOT create a burdensome tracking form or process. Add it to something the staff already use, such as the 24 hour report or the shift report form. Consider using a scale of 1-5 for intensity like the pain scale. Capture time and place, what was going on, and what resolved the distress. Look for patterns and solutions. Also note periods without distress and what made them so.

This requires focus, and works better with only one resident as the focus at a time. The skills of observing and thinking critically will become second nature to the staff over time and will be used even when residents aren't being targeted in a track and trending process. However the ***structure of tracking and trending helps staff put all their observations together and crystallizes what is happening so they can discover it sooner and respond more quickly.***

### **Huddles**

Now that staff are engaged in a coordinated effort to observe and gather information, it is crucial to use what they share. Use quick stand-up huddles. Let staff know that you'll only take 5 minutes of their time but that you need them all to come right away. (See Appendix C for a Tip Sheet on QI Closest to the Resident from the Pioneer Network's Toolkit – also available at [www.PioneerNetwork.net](http://www.PioneerNetwork.net)).

**Every shift.** In huddles on each shift and in shift-to-shift report, share about the resident being tracked. Check in with everyone about what they've observed. Compare notes and share ideas.

**Every event.** If the resident does become distressed, after the situation is resolved, have a quick check-in huddle with all staff who were present to compare notes on what happened and what worked.

**Every week.** As the team leading the effort to eliminate off-label use of antipsychotics, check in regularly with staff about the resident who is the target for reduction, and about any other residents they or you are concerned about.

**Every department.** Serve as a bridge to the rest of the organization to make adjustments, for example if a resident needs a meal at a different time.

Use a **learn-by-doing** approach to develop skills in analyzing causes and developing and deploying interventions. Help staff learn what and how to share information by giving continual feedback and connecting the dots. Role model good quick huddles and teach the nurses how to lead them productively.

### **Step 7 – Engage physicians, prescribers and your consultant pharmacist**

As you progress, engage your medical director, consultant pharmacist, attending physicians and other prescribers, and geri-psych consultants.

**Medical Director:** Share the American Medical Directors Association letter (Appendix D) and the CMS May 13, 2013 memo (Appendix A). Describe your plan and keep open communication as you progress. Ask the medical director to share the material, and off-label use by prescriber, with the attending physicians. Review physicians' responses to consultant pharmacist irregularities (see below).

**Consultant Pharmacist:** Let your consultant pharmacist know about your plan and that you will be reviewing the monthly Drug Regimen Review reviewing irregularities for off-label use. Ask to discuss any potential situations for reducing other medications that could be contributing to a resident's confusion or discomfort.

**Geri-psych:** The pilot homes found they were better able to address distressed behaviors through tracking and trending, than by seeking a psych-consult. One home's geri-psych partner agreed to put stop dates on any medications initiated during an in-house stay.

**Attending Physicians and Other Prescribers:** As your team is discussing any resident, include the physician/other prescribers in your deliberations. Let them know what you are finding as you look into the situation one resident at a time. Keep them informed.

**What about when you call me at 3 a.m.?** Describe how you will be tracking and trending, and making the adjustments needed to prevent the need for a 3 a.m. call. As physicians trust your ability, they will be more comfortable reducing medications.

- **Host a meeting, with food, for physicians and other prescribers, your consultant pharmacist and your geri-psych partners.** Explain your approach. Share the written materials. Give some examples of success stories. Provide details of how the changes are affecting residents and how staff are working with challenging situations. Answer questions and invite discussion. Let them know you are working one resident at a time and will be in touch as their residents are targeted. Invite their engagement.
- **This is not a one and done.** Keep the lines of communication continually open. When they round or review residents, make the tracking and trending, and documentation available to them.

## Step 8 – Engage families

Ask families about residents' backgrounds and routines as you try to understand their behaviors. Share this information with staff working regularly with the residents.

Make gathering this information a focus on the first 24 hours so that staff know right away how to help a new resident be comfortable. The first 24 – 48 hours can be a very disorienting time, especially for someone with dementia. Maintaining familiar routines will ease the distress of so much else that is unfamiliar.

When families have relied on an antipsychotic during their time of caring for their loved one at home, they are hesitant to have the medication eliminated. Let them know why and how you are approaching this process and keep them informed along the way. Seek their partnership in the process.

## Step 9 – Update your policies, procedures and forms

Update your policies, procedures, MARs and other forms to align with the CMS May 13, 2013 memo (Appendix A) and AMDA clinical best practices Appendix B).

- a. Educate all staff on new policies
- b. Develop a policy for 24 hour support to the staff closest to the resident to assist in instances of resident distress
- c. Ban PRN use of antipsychotic medications

## Step 10 – Sustain and Spread

Eliminating off-label use of antipsychotics is a change in practice that isn't going away. It's one that requires a change in mindset, just as with physical restraints.

Going slowly, one resident at a time, starting with the easiest, builds your team's ability to take on increasingly more complex situations. Each success also strengthens their confidence in the benefits of this new approach.

### Keys to Sustaining the Gains:

- **Capture and share key information during the first 24 hours.** Learn as much as you can about a resident and open the lines of communication with family so that you can support a smooth transition that maintains comfortable routines.
- **Huddle** to discuss any emerging concerns or residents being focused on, to catch early warning signs and prevent distress.
- **Adjust to the resident's routine.** For any issues related to care, build trust and adjust the approach to one that feels safe and comfortable for the resident.
- **Review CASPER monthly.** Monitor any residents triggering for off-label use.
- **Manage the pipeline.** Aggressively gather information for residents with serious mental illness, and pro-actively share information with hospital partners about your change in practice related to antipsychotics.
- **Don't call to geri psych.** Think of this as a fork in the road. Geri psych, and antipsychotics, is the road to take for people with serious mental illness who need their dopamine suppressed. For those without mental illness, the road to take is to have the staff that work with the resident every day carefully observing what is going on, tracking and trending to figure out what the person's behaviors are communicating and how to respond.
- **Integrate changes in approach into the care plan.** This is the document that guides your care and that is used by surveyors to understand your approach. Make sure it accurately reflects what you are doing.
- **QAPI.** Include your elimination of off-label use of antipsychotics in your QAPI plan and consider your team a PIP (Performance Improvement Project) team.
- **Spread.** Once you have eliminated off-label use for people with dementia, look at your use of the medication for others who do not have the serious mental illness, such as people with a diagnosis of psychosis. Use the same process of having staff closest to the residents track and trend to learn what is being communicated so they can make individualized adjustments in their approach to care.

### **Leadership Practices to Sustain and Spread:**

On-going leadership communication and support is the key to success. Maintain a ***watch list*** and use daily rounding and quick huddles to check in on these residents.

When staff need to make adjustments to accommodate a resident's routine, follow through to help work it out with other departments. Consistent support from the whole care team will give staff the ability to adapt to residents' needs and reduce their distress.