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Dementia and Drugs: It's Up to Us to Change the Conversation

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Now more than ever, there is an intense focus on dementia and Alzheimer's disease. Since there are more older adults, there are more older adults living with dementia. Age is one of the contributing factors that increases an individual's propensity for dementia. Most agree that 13 percent of Americans over sixty-five and at least half of individuals over eighty-five years old have some form of dementia (Alzheimer's World Report, 2018).

The conversation regarding dementia and drugs is tucked into a larger picture of aging services in America. Consumers assume that those who work with people who have dementia know and understand it, but the truth is most do not. This group includes physicians and other healthcare providers. There is a lack of understanding about what dementia is, the different types of dementia and their symptoms, and the appropriate responses and approaches that are required. As a result, misdiagnosis and inappropriate use of medications occur routinely.

Where we are today is nobody's fault; it is how our society and systems have evolved over many years. The field of aging services (some say eldercare), has been shaped and developed from a medical, institutional perspective. Evolving from this medical perspective, nursing homes, for example, were developed based on the hospital model for efficiency. This explains why traditional nursing home settings often look, function, and feel like hospitals. Residents living in nursing homes are even referred to as "patients," when in fact, individuals are only patients when they are in the hospital or at the doctor's office.

About Antipsychotic Drugs

The inappropriate antipsychotic drugging of nursing home residents, particularly those with dementia, is a widespread, national problem. "Close to 20 percent of nursing home residents (over a quarter of a million people) are given powerful and dangerous antipsychotics despite a 'Black-Box' warning that they are associated with increased risk of death in older adults" (Long Term Care, n.d.).

Antipsychotic drugs are used as a quick fix to address and quell unwanted "behaviors" in people with dementia. In our society, we have developed the expectation of quick fixes. This is true in medical care as well. Physicians are expected to prescribe a drug to quickly address any problem. As people with dementia experience changes in their condition, often these commonly called "negative behaviors" become more evident and happen more frequently. This is especially true when the ability to verbally communicate changes. It can be frustrating for all care partners. Family members ask for drugs that will "control" their loved

one's "negative behaviors." Staff in nursing homes and other congregate settings often do the same thing, especially when they have not been educated and empowered to try other approaches first.

Antipsychotic medications are highly potent drugs that work in the brain to block certain chemicals that can cause symptoms of psychosis, such as hallucinations and delusions. These drugs are most often used with illnesses like schizophrenia, bipolar disorder, Huntington's disease, or Tourette syndrome. They include drugs such as Risperdal, Haldol, Abilify, and Seroquel. These drugs are frequently used to treat so-called behavioral and psychological symptoms of dementia and are often used as a chemical restraint. The drugs sedate residents so that not only their behavior, but also the underlying causes for that behavior, do not have to be addressed by staff. Suppressing behavior makes it impossible to uncover the root cause of what is actually producing the symptoms of distress. These drugs do not address memory problems. They also do not help people with dementia to:

- stop yelling,
- stop repeating the same questions over and over,
- do more for themselves,
- interact better with others,
- stop saying inappropriate things, or
- become less restless.

In 2005, the Food and Drug Administration (FDA) issued the "Black-Box" warning requiring drug companies to label antipsychotics with their side effects and potential dangers. In addition to "destroying social and emotional wellbeing including the loss of independence, these drugs greatly increase risks of stroke, heart attack, diabetes, Parkinsonism, and falls. They are NOT clinically indicated for dementia-related psychosis. They ARE associated with a significant increase in death when given to older people with dementia" according to an alert issued by the Long Term Care Community Coalition (n.d.) — see graphic below.

"BLACK-BOX" WARNING ISSUED BY FDA

Warning: Increased Mortality in Elderly Patients with Dementia-Related Psychosis. Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk of death. [Name of Antipsychotic] is not approved for the treatment of patients with dementia-related psychosis

Antipsychotic Use in Nursing Homes

In 2012, the Centers for Medicare and Medicaid Services (CMS) launched the "National Partnership to Improve Dementia Care in Nursing Homes," which sought to reduce the misuse of antipsychotics among nursing home residents by 15 percent by the end of that year. Even though there was positive movement, the Partnership failed to meet its reduction goal until early 2014, according to the National Consumer Voice for Quality Long Term Care (n.d.).

"Between the end of 2011 and the end of quarter one of 2017, the national prevalence of antipsychotic drug use in nursing home residents was reduced by 34.1 percent, decreasing from 23.9 percent to 15.7 percent nationwide" (Long Term Care, n.d.). All fifty states and every CMS region showed improvement. Rates of antipsychotic drug use can vary greatly in nursing homes. Nursing homes with higher usage rates are encouraged to decrease antipsychotic medication use by 15 percent by the end of 2019 (Long Term Care, n.d.). The CMS Nursing Home Compare website (under Quality of Resident Care) provides antipsychotic usage information on individual licensed nursing homes across the country at www.medicare.gov/nursinghomecompare.

Currently, the National Nursing Home Quality Improvement Campaign's (previously called Advancing Excellence in America's Nursing Homes Campaign) antipsychotic medication goal is being updated, expanded, and renamed the Dementia Care & Psychotropic Medication Goal. The new Dementia Care & Psychotropic Medication Tracking Tool for nursing homes will be available soon, "and will support and prompt individualized care, documentation of key processes, and provide information to identify opportunities to drive improvement" (Long Term Care, 2018).

Clearly, the issue of antipsychotic misuse as it relates to improving dementia care in nursing homes is of extreme importance and focus for CMS, federal and state regulators and surveyors, and providers. However, there is a critical need to bridge the gap between nursing homes and all the other silos of care: the providers of services and supports for older adults as well as consumers, including the people who are living with dementia and changing cognitive abilities.

> "In the U.S., there are millions of people living with dementia and changing cognitive abilities, many more than the numbers we see quoted for people who have Alzheimer's disease. Most of these people will never step foot into a nursing home. The conversation about the misuse of antipsychotics and psychotropics cannot just be a nursing home conversation. Every level of care and every type of care provider must be included in the conversation, including hospitals where many of these drugs are initially first administered. It is vital that everyone who knows someone living with dementia, and the health and care professionals who work with those with dementia, becomes aware of the tremendous danger that antipsychotics and psychotropics can cause. As a society, we have to learn that we absolutely misunderstand what these drugs do, why we are asking for them, and why they are being prescribed. It is time that we acknowledge that giving these drugs to people with dementia for the wrong reasons can cause tremendous harm. In terms of dementia care in this country, it is time that we all wake up and strive to "Do No Harm!"
>
> *—Kim McRae, F.C.T.A. (Family Caregiver Turned Advocate), co-founder, Culture Change Network of Georgia, and president, Have a Good Life.*

Expanding the conversation to EVERYONE is the only thing that is going to make a real difference. In order to address the dangers and challenges around drug misuse, we must continue moving away from all the silos that exist in care, information, services, and supports. Dementia is going to touch everyone's life. All Americans need to become more informed and expect a better response from the care and support systems that are available in this country.

About Dementia

When more people are educated about dementia, positive change occurs. There is less fear, stigma around the disease dissipates, and the community at large becomes more inclusive of individuals living with it. People with dementia should not have to take medications they do not need. The negative side effects can be avoided and people with dementia can have a great life without being drugged.

Because of a lack of education about dementia in this society, dementia and the people living with it continue to be feared. This lack of knowledge is tied to ageism and the stigma associated with dementia in our society. It has caused us to exclude people with dementia from the conversation when actually, they are the experts. This is why it is up to every citizen to change the conversation. Every American must move away from the fear, let go of the negative, and become educated.

Dementia and Alzheimer's

Most people think dementia is only about Alzheimer's disease and memory issues, however, dementia is not

just Alzheimer's disease and it is not just about memory loss. Often the terms "dementia" and "Alzheimer's disease" are used interchangeably, but they are quite different. "Dementia is not a specific disease" according to Alzheimer's Disease International (2018). Dementia is a collective name for progressive brain syndromes which affect memory, thinking, behavior, and emotion. There are over two hundred subtypes of dementia (Alzheimer's Disease International, 2018). In addition, different parts of the brain are affected in different ways which cause different responses.

"Dementia is a general term used to describe symptoms characterized by the loss of cognitive function" according to the Alzheimer's Association (n.d.). Cognitive functioning is characterized by a loss of thinking, remembering, reasoning, and behavioral abilities to such an extent that it interferes with a person's daily life and activities. These functions include memory, language skills, visual perception, problem-solving, self-management, and the ability to focus and pay attention (Alzheimer's Association, n.d.). Alzheimer's disease is the most well-known and common form of dementia, but not everyone with dementia has Alzheimer's disease (Alzheimer's Disease International, 2018).

"Alzheimer's disease is a chronic condition that progressively damages and eventually destroys brain cells" (Alzheimer's Association, n.d.). "It is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks. Symptoms usually develop slowly and get worse over time, becoming severe enough to interfere with daily tasks" (Alzheimer's Association, n.d.).

"Alzheimer's" should not be used as the general term for dementia. This causes a lot of confusion and can actually keep people from getting an accurate diagnosis of the type of dementia they really have. People with other forms of dementia and their families feel very marginalized and ignored when we say "Alzheimer's" instead of "dementia," and it is scientifically incorrect. It is best practice to use the term "dementia, including Alzheimer's."

> "On a regular basis, I speak to people with dementia (especially Lewy body dementia) and their loved ones throughout the U.S. who have been misdiagnosed and prescribed inappropriate medications. Even as a retired pharmacist, this happened to me and I almost died. We have to learn how dangerous, especially antipsychotic drugs, are to people with dementia. We must all learn that different medications are appropriate for different types of dementia. If we do not understand this, especially physicians, we put people with dementia at great risk, not only increasing their confusion, but even causing death."
> —*Robert Bowles, retired pharmacist, dementia advocate, and person living with Lewy body dementia*

Know the Person

To prevent using drugs as the first solution, it is critical for all care partners to really know the person with dementia. Knowing the individual person helps care partners in any setting understand how to properly respond to that person's unique needs or behavioral expressions. When a person with dementia is deeply known, it is easier to focus on his/her strengths, interests, likes, and dislikes. Interactions can be structured around what he/she can do. This moves away from focusing on limitations. The common statement, "If you have seen one person with dementia, you have seen one person with dementia," sets the tone for addressing many of the challenges connected to dementia and drugs. Responding to the belief that each individual is unique is a major step in how person-centered services and supports are developed, and even implemented, successfully.

Even though the focus of the conversation about antipsychotic drugs has mostly been centered on residents in nursing home settings, most data confirm that 70 to 80 percent of people with dementia live in the community at large (Baker, 2017). Obviously, this is NOT just a nursing home problem. People with dementia are everywhere. Because most people with dementia are living in the community, especially in the earlier stages of their condition, they are becoming more visible and vocal. They are fighting the stigma of dementia by advocating for themselves, sharing their stories as well as what they want and expect. At the Dementia Action Alliance conference (2017), individuals with different dementia diagnoses served on a panel to tell their stories. Out of the five panelists, three had been misdiagnosed, and two had almost died due to the drugs prescribed for them.

Listen to the Experts

People with dementia must be acknowledged as the real experts and drive conversations around their conditions and unique journeys. They are the only ones who know what they are feeling, thinking, and experiencing in all aspects of their journeys with dementia. The rest of us must know what they want and expect from us as their condition changes. People with dementia want to be heard and understood. Adopting the mantra from the disability movement, "Nothing

about us without us," people with dementia expect to be a part of every conversation.

Include People Living with Dementia

Individuals living with dementia regularly say they want to live a great life, optimize their strengths, learn and develop new skills, and have educated care partners (including physicians and providers) who have learned to support and empower them. Opportunities must be created to hear from people with dementia. This may include inviting them to speak at various events, so they can share their stories and how their daily lives unfold. Care partners must understand what people with dementia are feeling and thinking, know their preferences, and be prepared to meet their expectations. Highlights of many recent professional development events have been when people with dementia are there to share what many of them call "the lived experience."

Use the Right Language

To better support people with dementia, it is critical to use the right language. Describing people with dementia as "victims," "suffering," and "demented" is totally unacceptable. There may be times during the dementia journey when there is suffering. However, simply having a dementia diagnosis does not mean a person is regularly suffering. Changing the language associated with dementia is a critical step that does not cost any money. For more information, see the Dementia Action Alliance website's article on the subject at www.daanow.org/WordsMatter.

Nurses are Key

Staff working with older adults in any setting, especially nurses in long-term care (nursing homes, assisted living, life plan communities and board and care homes), must be educated and empowered to try other interventions besides drugs first. Nurses are key to person-centered dementia care in many ways. They can change the way they interact with physicians, and help the physicians learn as well. Instead of automatically contacting the physician for a dosage increase or for a new drug to be prescribed, nurses can ensure they and their colleagues have obtained the professional development needed to best interact with and support people with dementia. When contacting physicians, nurses can let the doctors know what they are trying first before asking for a drug intervention. This creates new conversations, enhances relationships, and empowers nurses to better serve older adults. Using alternative solutions helps move away from the drugs-first, medical-focused mentality.

QUESTIONS TO ASK ABOUT PRESCRIPTION DRUGS

Antipsychotic drugs such as Risperdal, Haldol, Abilify, and Seroquel are often inappropriately prescribed for older people with dementia. Family members and other care partners can take an active role with the health care team to monitor the use of drugs to control behavior by asking the following probing questions about their use.

If your loved one is already taking drugs to control behavior, ask the following questions:

- **What type of drug is my loved one on?**
- **What caused the drug to be prescribed?**
- **How has the care team tried to help solve the problem without drugs?**
- **What is the plan to decrease or stop the drugs?**

If your loved one is not currently on an antipsychotic, BEFORE any are prescribed ask:

- **What is causing the drug to be prescribed?**
- **What has the care team done to respond to my loved one's challenging behaviors?**
- **How will they track the behaviors once the drug is started?**
- **What is the plan to decrease or stop the drug?**

Source: ACHA/NCAL Quality Initiative. "What you Need to Know about Antipsychotic Drugs for Persons Living with Dementia."

This is especially important if a reaction or behavioral expression is caused by one of the staff care partners. It is now known that many times the negative reactions of people with dementia are caused by their care partners, no matter the setting.

Care partners must learn how to get the best results when interacting with a person with dementia. The way a person with dementia is approached is critical to successful communication. Care partners

must create a calm environment and not approach someone from behind or grab them unexpectedly. A gentle touch from the front at eye level is often the best approach. Awareness of body language and facial expressions is required, and a smiling face sets the stage for success. The tone of voice is also critical. Even when people are not recognizing specific words, they see their care partners and hear the tone of voice, and respond accordingly.

Change is Underway

As a result of government mandates, increasing awareness of best practices, better resources, and a more humanizing perspective of individuals living with dementia, changes in practices are becoming evident. Even though many agree that changes in dementia care are moving slowly, early adopters, by sharing their successes, are lending encouragement to consumers, providers, and the entities that are in charge of government oversight.

Several key innovative organizations have been leading the way to create awareness and support consumers and providers. Pioneer Network, LeadingAge, The Eden Alternative, and the Dementia Action Alliance are providing education, professional development, and certifications while sharing best practices. The Culture Change Network of Georgia offers social media clips on its website that can be used in many settings to explain the culture change movement, as well as person-centered care and services (www.CultureChangeGA.org).

Many resources are available for nursing homes that want to make changes. For example, nursing homes can apply for Civil Monetary Penalty (CMP) funds through state Medicaid agencies. The funds must be used to improve the quality of life for nursing home residents, including those living with dementia. CMP funds have been used to provide education and resources to effectively reduce the misuse of antipsychotic drugs. The funds have also provided the means to incorporate innovative approaches to dementia care, such as Virtual Dementia Tours, the Music & Memory program, and It's Never 2 Late technologies. Additionally, the funds have been used for nursing home staff to become Certified Eden Associates through The Eden Alternative. For more information, visit www.medicaid.ms.gov/wp-content/uploads/2014/03/CMPGrantProposalRequirements.pdf.

For society to begin to change the norms surrounding dementia, including how and why antipsychotic drugs are being used, it is up to every person to become educated. So many times, we expect the person with dementia to make changes in their behavior. The reality is, we are the ones who have to make the changes. We must be proactive and intentional about creating the conversations that are needed to change the way we think and feel about people who are living with dementia. Dr. Al Power said it best: "We have to change our minds about people whose minds have changed" (Power, 2017). •CSA

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