Why Comfort Matters: Reducing Reliance on Antipsychotic Medication for People Living with Dementia
Mildred’s Story
What’s this Session About...

• Examine the progression of dementia and what we can expect from persons living with the disease.

• Describe how people with dementia communicate when verbal abilities decline.

• Discuss a different way to thinking about dementia-related behavior.
Understanding Dementia
# Progression of Dementia

## Disability Focus

<table>
<thead>
<tr>
<th>Mild</th>
<th>Moderate or Mid-Stage</th>
<th>Severe or Late Stage</th>
<th>Terminal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Impaired memory; Personality changes; Spatial disorientation</td>
<td>Confusion; Agitation; Insomnia; Aphasia; Apraxia</td>
<td>Resistiveness; Incontinence; Eating difficulties; Motor impairment</td>
<td>Bedfast; Mute; Intercurrent infections; Dysphagia</td>
</tr>
</tbody>
</table>

(Hurley & Volicer, 1998)

**ADVANCED DEMENTIA**
## Progression of Dementia

### Ability-Focused

<table>
<thead>
<tr>
<th>INDEPENDENCE</th>
<th>Mild</th>
<th>Moderate or Mid-Stage</th>
<th>Severe or Late Stage</th>
<th>Terminal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Verbal/non verbal communication and emotions are intact</td>
<td>Non verbal communication and emotions are intact</td>
<td>Non verbal communication and emotions are intact</td>
<td>Non verbal communication and emotions are intact</td>
<td></td>
</tr>
<tr>
<td>Expert on personal comfort</td>
<td>Expert on personal comfort</td>
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<td></td>
</tr>
</tbody>
</table>

(Alonzo 2019)
Defining Comfort for People Living with Dementia

Merriam-Webster’s definition
1.  To give strength and hope to
2.  To ease the grief or trouble of

Synonyms:
Assure, cheer, console, reassure, soothe

Antonyms:
Distress, torment, torture, trouble
People with Dementia are Comfortable if...

• They are free from pain
• They sleep when they’re tired and wake when refreshed
• They eat what they enjoy when they’re hungry
• They receive care on their own terms
• They are engaged in things that make sense to them
• They experience an environment which meets their needs at every level
The Resilient Brain

Information from our senses can create a positive or negative response with our emotions.

When people feel comfortable they don’t display challenging behavior.
The Dilemma with Dementia-Related Behavior
Dementia-Related Behavior or Indicator of Distress
Why are Antipsychotic Medications Prescribed?

It isn’t uncommon to believe

• there is a medication to “fix” any problem

• antipsychotic medications have manageable side effects and the benefits generally outweigh the risks.

• Antipsychotic medications are the only way to treat dementia-related behavior.
What are Antipsychotic Medications?

A class of medication primarily used to manage psychosis (including delusions, hallucinations, paranoia or disordered thought), principally in schizophrenia and bipolar disorder.
## Common Antipsychotic Medications

<table>
<thead>
<tr>
<th>Generic Name</th>
<th>Brand Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aripiprazole</td>
<td>Abilify</td>
</tr>
<tr>
<td>Clozapine</td>
<td>Clozaril</td>
</tr>
<tr>
<td>Olanzapine</td>
<td>Zyprexa</td>
</tr>
<tr>
<td>Quetiapine</td>
<td>Seroquel</td>
</tr>
<tr>
<td>Risperidone</td>
<td>Risperdal</td>
</tr>
<tr>
<td>Ziprasidone</td>
<td>Geodon or Zeldox</td>
</tr>
</tbody>
</table>
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. Analyses of seventeen placebo-controlled trials (model duration of 10 weeks) largely in patients taking atypical antipsychotic drugs, revealed a risk of death in drug-treated patients of between 1.6 to 1.7 times the risk of death in placebo-treated patients. Over the course of a typical 10-week controlled trial, the rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group. Although the causes of death were varied, most of the deaths appeared to be either cardiovascular (e.g., heart failure, sudden death) or infectious (e.g., pneumonia) in nature. Observational studies suggest that, similar to atypical antipsychotic drugs, treatment with conventional antipsychotic drugs may increase mortality. The extent to which the findings of increased mortality in observational studies may be attributed to the antipsychotic drug as opposed to come characteristic(s) of the patients is not clear.
More Evidence Against Taking Antipsychotic Medications
## Indicators of Distress - What is the Person Trying to Tell Us?

<table>
<thead>
<tr>
<th>What is the person doing</th>
<th>What is the person telling us</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person with dementia hits his/her care partner during dressing, grooming or bathing.</td>
<td>The ADL care causes me physical pain or I’m afraid.</td>
</tr>
<tr>
<td>Person with dementia calls out for help.</td>
<td>I’m have an unmet need and can’t tell you what it is.</td>
</tr>
<tr>
<td>Person with dementia attempts to leave where s/he lives.</td>
<td>I’m tired and I need to rest but I can’t find my bed or comfortable chair. I’m bored and I need something to do.</td>
</tr>
</tbody>
</table>
Medications Don’t Work, Now What?

What is the person doing?

What does the person’s actions mean?

What can I do to make it better?
Mildred’s Story
Session Wrap Up

People with dementia:

• Know when they are comfortable and when they are not
• Communicate through their actions
• Benefit from feeling comfortable
Thank you!
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