Creating Dementia Capable Environments

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The following training was produced by Georgetown University’s Center for Child & Human Development as part of the the DDA Health Initiative project. This project supports the mission of the District of Columbia’s Developmental Disabilities Administration, and focuses on improving the physical, behavioral and mental health supports that affect the quality of living for people with intellectual and other disabilities.

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At the completion of this training, participants will be able to:

1. **Define** dementia and it’s general impact.
2. **Identify** challenges in identifying dementia among people with disabilities.
3. **Describe** strategies to diagnose dementia.
4. **Describe** strategies for creating “dementia capable” environments.
Dementia is not actually a diagnosis, but rather a catch-all phrase that refers to a variety of symptoms.

- Alzheimer’s Disease is the most common and most commonly recognized dementia-like diagnosis.

- Other less known types – but quite commonly occurring – include Vascular Dementia, Dementia with Lewy Body, and Frontotemporal Dementia.
Domains Affected

- Depression
- Personality
- Seizures
- Familiar Tasks
- Memory
- Walking
- Sleep
- Language
- Planning
- Daily Living
- Aggression
- Impulse Control
- Sensory Deficits
The global prevalence of dementia is estimated to be between 5% and 7% of adults age 60+

An estimated 5.7 million Americans of all ages are living with Alzheimer's dementia in 2018.

One in 10 people age 65 and older has Alzheimer's.

Almost two-thirds of Americans dementia are women.

African-Americans are about 2 times more likely to be diagnosed with a dementia.

Hispanics are about 1.5 times more likely to be diagnosed with a dementia.
People with Disabilities

• Prevalence rate among people with disabilities is about the same compared to non-disabled peers except ...
• People diagnosed with Down Syndrome are at higher risk for early onset and at faster progression.
• About 22% of people aged about 40 diagnosed with Down Syndrome are also diagnosed with dementia.
• This number leaps to 65% at about age of 60+
• People with disabilities are living longer ... so the rate of a diagnosis of dementia is rising.
Cost of Care

• Average cost of care is about $287,000 per person. Compare this to the cost of heart disease or cancer (about $175,000 per person).

• For seniors with dementia, the cost of care is about 23 times higher than seniors without dementia.

• Annual cost exceeds $215 billion.
Dementia is caused by damage to brain cells.

• This interferes with the ability of brain cells to communicate with each other. Cognition, behavior and feelings can be affected.

• The brain has many distinct regions, each responsible for different functions. When cells in a particular region are damaged, that region cannot function normally.

• Damage to brain tissue can vary tremendously in location, progression and severity.
For Example
Neural Cell Changes

We know some forms of cell changes in the brain are associated with dementia:

- There might be **fewer** cells
- **Plaques**, abnormal clusters of protein fragments, can build up between nerve cells
- Protein pieces called **beta-amyloids** can clump together and builds up into plaques.
- Dead or dying nerve cells contain **tangles**, which are made up of twisted strands of other proteins
Neural Cell Changes

• We don’t understand why these cell changes occur.
• We don’t understand how these cell changes cause specific symptoms.
• We cannot directly observe these changes among living people.
There isn’t a single test to determine whether dementia is present.

We use **differential diagnosis** to identify dementia, including the medical history, physical exams, laboratory tests, and observing changes in thinking, day-to-day function and behaviors.

It is hard to determine the exact type of dementia because the symptoms and brain changes of different dementias can overlap.

Development of dementia is not a normal process of aging.
May Look Like Dementia ...

- Depression
- Medication side effects
- Excess use of alcohol or drugs
- Thyroid problems
- Vitamin deficiencies
- Hearing loss or other sensory changes
- Dehydration
- Stroke
- Malnutrition
- Sleep apnea
Cultural & Linguistic Issues

• Cultural bias play a limiting role in identifying symptoms and impact of dementia.
• Why are people of color and women more likely to be diagnosed, but less likely to be identified early?
• People with a disability are at an even greater disadvantage due to how they may be valued in their communities ... tendency to discount the relative impact, less likely to detect due to language ability, less likely to believe accounts.
• Presence of pre-existing behavioral, cognitive and ability limitations among people with disabilities.
1. **Requires** a stronger focus on screening.

2. **Broader** use of preventative strategies.

3. **Emphasis** on advance planning form in-home supports and community programs that addresses loss of independence.

4. **Multi-element** cross-disciplinary basis of community treatment including family support, counseling, medical, behavioral, cognitive care.
Words of Caution

There is no cure for dementia. Our focus must be on prevention if possible, and then on quality of life.

The greatest difficulty is accepting that their reality is changing, that we can have a limited impact on that reality, and that we must join with their reality in order to find ways to support them.
<table>
<thead>
<tr>
<th>(18) Activities of Daily Living</th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>New symptom in past year</th>
<th>Does not apply</th>
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<tbody>
<tr>
<td>Needs help with washing and/or bathing</td>
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<tr>
<td>Needs help with dressing</td>
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<td>Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)</td>
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<td>Undresses inappropriately (e.g., in public)</td>
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<tr>
<td>Needs help eating (cutting food, mouthful amounts, choking)</td>
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<td>Needs help using the bathroom (finding, toileting)</td>
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<tr>
<td>Incontinent (including occasional accidents)</td>
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<tr>
<th>(20) Language &amp; Communication</th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>New symptom in past year</th>
<th>Does not apply</th>
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<tbody>
<tr>
<td>Does not initiate conversation</td>
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<td>Does not find words</td>
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<tr>
<td>Does not follow simple instructions</td>
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<tr>
<td>Appears to get lost in middle of conversation</td>
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<tr>
<td>Does not read</td>
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<td>Does not write (including printing own name)</td>
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<table>
<thead>
<tr>
<th>(21) Sleep-Wake Change Patterns</th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>New symptom in past year</th>
<th>Does not apply</th>
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</thead>
<tbody>
<tr>
<td>Excessive sleep (sleeping more)</td>
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<tr>
<td>Inadequate sleep (sleeping less)</td>
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<tr>
<td>Wakes frequently at night</td>
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<td></td>
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<tr>
<td>Confused at night</td>
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<tr>
<td>Sleeps during the day more than usual</td>
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<tr>
<td>Wanders at night</td>
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<tr>
<td>Wakes earlier than usual</td>
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<tr>
<td>Sleeps later than usual</td>
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<table>
<thead>
<tr>
<th>(22) Ambulation</th>
<th>Always been the case</th>
<th>Always but worse</th>
<th>New symptom in past year</th>
<th>Does not apply</th>
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<tbody>
<tr>
<td>Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces</td>
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<tr>
<td>Unsteady walk, loses balance</td>
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<tr>
<td>Falls</td>
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<tr>
<td>Requires aids to walk</td>
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## Differential Diagnosis

### Dementia Differential Diagnosis Checklist

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<thead>
<tr>
<th>Person</th>
<th>DOB</th>
<th>Agency</th>
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</thead>
</table>

Check All That Apply. Key informants should include people who have a thorough knowledge (at least 6 months) of the person.

### Section I

<table>
<thead>
<tr>
<th>Date</th>
<th>Completed by Key Informants</th>
<th>Notes</th>
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<tbody>
<tr>
<td></td>
<td>NTG Early Detection Screen for Dementia (EDSD)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>EDSD results reviewed by clinical staff</td>
<td></td>
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<tr>
<td></td>
<td>EDSD results included in annual wellness report</td>
<td></td>
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<tr>
<td></td>
<td>EDSD scheduled for follow-up screening</td>
<td></td>
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<tr>
<td></td>
<td>Referred to primary care physician for assessment</td>
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<tr>
<td></td>
<td>Referred to specialist(s) for assessment</td>
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</table>
Possible Protective Strategies

1. **Diet**: Foods with higher levels of anti-oxidants, polyunsaturated fats, and lower calories beneficial.

2. **Exercise**: The universal cure. Obesity is a correlate to increased risk, along with diabetes.

3. **Cardiovascular**: Hypertension and high blood pressure are added risks, as are high cholesterol.

4. **Cognitive**: Active learning, reading and playing games associated with cognitive “longevity.”

5. **Social**: Although unclear, social networks appear to have a protective effect against onset of dementia.
Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment.

Prescribed for early to moderate Alzheimer’s Disease.

May delay worsening of symptoms for 6 to 12 months.

Examples include Aricept, Namenda, Exelon, Razadyne, Namzaric.

Antidepressants may also be useful as a preventative technique.
Family & Social Supports

• People with limited social/family networks and low social engagement may be more likely to develop dementia.

• Social engagement combined with activities such as movies, clubs, centers, and volunteering may protect against cognitive impairment.

• However, low social engagement may also be an early symptom of cognitive impairment.
• The interaction between social activity, cognitive activity, and physical activity may also be important.

• Leisure activities that include cognitive, social, and physical components might be the best strategy to reduce the risk of cognitive impairment or reduce the rate of decline.

• For people with Intellectual Disability, understanding their baseline cognitive and adaptive skills is especially important. “Diagnostic overshadowing” is a constant concern.
Key Support Strategies

- Maintenance
- Redirection
- Orientation
- Life Story
- Validation

Adapted from *Habilitation Therapy in Dementia Care*. Paul Raia, PhD. 2011.
• Considered **best practice** in dementia care.
• **Proactive** approach can eliminate hours of reaction.
• Focus is on **support of remaining abilities**.
  – Respect the changing needs of the person
  – Provide meaningful, failure-free activity.
  – Allow the person to do as much as they can for themselves but...be aware that as the disease progresses the need for assistance will increase.
• Can **reduce or eliminate difficult behaviors** at all stages by reducing frustration, boredom, anxiety, fear, etc.
• Can be done in **all settings by all staff**.
Redirection

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
- Redirected with gentle distraction or by suggesting a desired activity.
- Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone. Body language is important.
Orientation

• Do not correct or try to **reorient** the person.
• The person with dementia may no longer be able to make sense of the present. Lost memories of years past will become their new reality and they even may re-live past events.
• To avoid frustration and agitation, you must enter their reality. **Don’t argue.** This is not lying, it is respecting their reality.
Everyone has a life story that needs to be honored and respected...

• The story is the *essence* of each person and should be documented over the lifespan.
• When a person can no longer tell their own story, activities related to storytelling can still be used to inform caregiving and plan activities.
Validation

Focuses on empathy and understanding.

• Based on the general principle the acceptance of the reality and personal truth of a person's experience... no matter how confused.

• Can reduce stress, agitation, and need for medication to manage behavioral challenges.

• Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.

• Emotions have more validity then the logic that leads to them.
Challenges

• Behavioral and emotional outbursts tend to increase over time, and may not respond to standard behavioral treatments.

• Language skills tend to decrease over time. Staff must be creative in using non-verbal skills.

• Sensory and perceptual skills will decline. Environmental modifications will be needed.

• Memory loss leads to confusion and repetition, with an underlying emotional base of fear, anxiety.
And More Challenges ...

- Wandering
- Sundowning
- Hoarding
- Delusions
- Paranoia
- Hallucinations
- Sleep disruption
- Sexual disinhibition
- Resistance to care
- Sensory sensitivity
- Inability to communicate pain
- Tactile defensiveness
The rate of decline and types of changes are highly variable ... we must be responsive to nuanced changes of each person we support.

Our behavior and environment must be the focus of change and adaptation ... rather than focusing on changing the person.

It can be a sad experience for staff. Celebrating the person and the staff must become a focal point or risk losing valued caregivers.
References