ALZHEIMER'S DISEASE

Information and Intervention Suggestions With an Emphasis on Cognition

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This is an adaptation of the handout Caring Sheet #11 from the Michigan Dementia Care Series. More information is at the end of this Handout.

The Michigan Dementia Care Series can be found on the Michigan website called Improving MI Practices at **https://www.improvingmipractices.org**

This handout is a **brief summary** of information about **Alzheimer's Disease (AD)**, with an emphasis on cognitive abilities. It suggests some **intervention** strategies.

See the resources in the next section below for more intervention suggestions with details and examples.

The information in this handout is intended to **highlight differences** between **Alzheimer's Disease** (**AD**) and two other types of dementia: **Dementia with Lewy Bodies** (**DLB**) and **Frontotemporal Dementia** (**FTD**).

FOR MORE DETAIL AND INTERVENTION STRATEGIES

More information and detail (especially about the brain and cognitive abilities in dementia) and suggestions of interventions (including support strategies) are in:

1. Other **CAIS Handouts** (for example, in **CAIS Handouts #7** and **#8** about **dementia** and **Alzheimer's Disease**, **#29** about **visual-spatial** interventions, **#35** about interventions for the **frontal lobe**, and **#32** about **making decisions**). CAIS Handouts **#6**, **#7**, and **#8** also identify specific cognitive abilities associated with specific parts of the brain.
2. The *Cognitive Abilities and Intervention Strategies (CAIS) Questions to Ask* and the ***CAIS Intervention Strategies*** by S Weaverdyck. These provide **detailed intervention** strategies that address specific cognitive abilities, the environment, tasks and daily routines, and your communication with this person. These interventions can be **individualized** to a particular person and situation.
3. The **CAIS Educational Series** (for example, **Session #1**)
4. **Background resources** regarding the CAIS Educational Series and the CAIS online course

All of these are available on the above Michigan website at **https://www.improvingmipractices.org**

For a summary of information and possible intervention strategies for other specific disorders, see **CAIS Handout #20** (summary) and **#37** (interventions) about **Dementia with Lewy Bodies**, **#21** (summary) and **#38** (interventions) about **Frontotemporal Dementia**, **#35** (interventions) about the **frontal lobe**, and **#36** (interventions) about the **right hemisphere** of the brain. All of these are also available on the above website at https://www.improvingmipractices.org

Additional information about Alzheimer's Disease can be found on the following two websites: The Alzheimer's Association at **https://www.alz.org** and the National Institute on Aging at **https://www.nia.nih.gov/health/alzheimers**

INTRODUCTION

CAIS Handouts #20 and #21 summarize information and intervention suggestions regarding **Dementia with Lewy Bodies** (**#20**) and **Frontotemporal Dementia** (#**21**). With this handout **#19** about **Alzheimer's Disease**, these three CAIS Handouts briefly outline the brain changes in each type of dementia, the impact these changes have on cognitive abilities and behavior, and implications for effective intervention. They **highlight** the **differences** among these three types of dementia.

The three CAIS Handouts (#19, #20, and #21) are **companion pieces** in outline form with essentially each line or section of one handout corresponding with each line or section of the other two. The three can be laid out side by side and compared section by section.

DEMENTIA

Dementia is a **gradual decline** in a person's cognitive abilities. This decline occurs because of changes in the **brain**.

Cognitive abilities include a person's ability to **think**, **understand** what they see or hear, figure out how to do things, **remember**, imagine, and many **other cognitive functions**. Cognitive abilities allow a person to **communicate**, understand and **respond** to their surroundings, create, and **perform tasks**.

If the decline in cognitive abilities is caused by a treatable disorder, for example, a urinary tract infection, vitamin deficiency, reactions to medications, dehydration, pain, or depression, it is likely **temporary** and **treatable**. (This is sometimes called delirium.)

In other cases the brain changes and resulting cognitive decline are **irreversible** and **progressive** (that is, increasingly severe). They are caused by disorders such as Alzheimer's Disease, vascular disorders, Creutzfeldt-Jakob Disease, Dementia with Lewy Bodies, or Frontotemporal Dementia. There are over 100 different disorders that can cause this progressive dementia.

Alzheimer's Disease is by far the **most common** cause of dementia in persons over the age of 65 years.

While there is no cure for Alzheimer's Disease, there is much we can do to help a person feel comfortable, competent, and engaged by addressing the changes in their cognitive abilities. This is addressed in more detail in the other CAIS Handouts and resources noted above.

The information below applies generally to Alzheimer's Disease. Each person experiences Alzheimer's Disease differently, so **careful observation** and **response** to each person as an **individual** is important.

CHARACTERISTICS

1. Brain disorder
2. Most obvious **symptoms**: memory loss and changes in cognitive abilities
3. **Progression**: increasing severity of symptoms over time (a progressive dementia)
4. **Onset**: insidious; generally age 40-90 or older; most over age 65
5. **Duration**: average 4-8 years after diagnosis and ending in death (could be 20 years; may vary with time of diagnosis)
6. **Cause**: unknown
7. **Cure**: no cure at this time, but there is treatment to address symptoms
8. **Diagnosis**: no single definitive test available at this time; clinical diagnosis based on pattern of symptoms, imaging, and lab and other test results (for example, cerebrospinal fluid or blood test); good level of accuracy if thorough evaluation conducted; verified at autopsy for clinical purposes

9. Most common cause of dementia: 60% - 80% of all dementia cases in the United States (US)
10. Of the US population, AD affects: 3% age 65-74; 17% age 75-84; 32% age 85 or older
11. Women are 2/3 of AD cases in US
12. Risk factors: age, genetics (APOE-e4 gene, Down syndrome), family history (parent or sibling had AD), cardiovascular factors, diabetes
13. Hereditary: 40-65% of diagnosed cases in US have APOE-e4 gene that affects risk of getting AD; 1% or less of diagnosed cases in world have genes that **cause** AD (and those genes cause only a rare AD with onset of symptoms at age early 40s to mid 50s)
14. **Course**: gradual, steady decline; decline may be 2-4 points per year on Folstein Mini-Mental State Exam (MMSE); no spontaneous improvement; stages have been identified
15. Alois Alzheimer first described neuropathology in a 51-year-old woman in 1906 (published in 1907)

NEUROPATHOLOGY

1. Atrophy (that is, loss) of brain tissue; nerve cell death
2. **Beta-amyloid plaques** outside of nerve cells in brain
3. **Tao tangles** inside nerve cells in brain
4. Inflammation from the inability of microglia (immune system cells in brain) to remove from the brain the toxic proteins (including plaques and tangles) and debris quickly enough
5. Neurotransmitter reduction (for example, less Acetylcholine)

LOCATION OF CORTICAL BRAIN CHANGES

1. Cortical refers to the cortex (that is, the outer layer) of the brain
2. Changes (neuropathology) occur in the cortex and in internal (subcortical) structures of the brain
3. Changes (neuropathology) occur on both sides of the brain
4. Changes (neuropathology) continue to increase within each structure as they spread to additional structures of the brain (so symptoms continue to increase in severity, even as new symptoms appear)
5. Only some of the brain structures affected in AD are included here
6. Order (in general) of cortical brain structures affected, creating stages:
    a. Hippocampus (subcortical)
    b. Parietal lobes with some frontal lobe
    c. Temporal lobes
    d. Frontal lobe

COGNITIVE CHANGES (decline due to AD)

Among **many** changes in cognitive abilities, this person may experience **difficulty with**:

1. Processing information in general, including for example:
    a. **Comprehension** and **Perception**, for example, understanding words and recognizing the location of objects and people
    b. **Executive** functions, that is, using the information they receive to, for example, make decisions
    c. **Expressive** functions, that is, their brain's ability to tell their body how to move and to coordinate movements, as well as what words to say and how to speak
2. Memory (is usually first easily noticed cognitive change)
3. Visuospatial perception and skill including difficulty with, for example:
    a. Recognizing distance between objects and from self
    b. Noticing objects and people in all parts of this person's visual field
    c. Arranging objects in space
4. Language including difficulty with, for example:
    a. Nuance and adaptation to an individual conversation (for example, a reliance on cliches)

    b. Having a pool of words available to use
    c. Understanding and using speech
    d. Reading and writing
    e. Understanding what is being read (when this person reads)
5. Insight into their own situation and that of others
6. Judgment
7. Problem solving
8. Being oriented (for example, to time or place)
9. Concentration or ability to sustain focus
10. Abstract processing (for example, being able to conceptualize what they can't feel, see, hear, smell, or taste)
11. Attention (for example knowing what to focus on, and focusing on it; moments of a blank look during a conversation beginning early in the course)
12. Sense of time (for example, knowing how much time has passed)
13. Ability to analyze, plan, organize

However, this person may experience:

14. Minimal sensory loss (though may occur with normal aging)
15. Minimal disturbance of consciousness
16. Increasing dependence on their environment and other people throughout the AD course

EMOTIONAL CHANGES

This person may experience:

1. Depression at any time throughout course, especially in the early stages of AD
2. Sometimes a mismatch in expression of emotion and the intensity with which they feel the emotion (for example, they may express their emotions more intensely than they actually feel them)
3. Emotional lability (they may switch quickly from one emotion to another)
4. Less expression of emotional intensity and switching in the later stages of AD

BEHAVIORAL CHANGES

This person may, for example:

1. Get lost in familiar places occasionally in early stages, and increasingly often throughout course
2. Lose objects occasionally in early stages, and increasingly often throughout course
3. Have difficulty adjusting to a change in plans
4. Repeat a question or concern, forgetting what they or someone else just said or did
5. Remember something unimportant rather than the important piece of information
6. Feel distress by behavior of others that doesn't support their cognitive changes (for example, someone talking too fast or too much)
7. Engage in behavior distressing to themselves or to others, triggered (especially in **middle stages**) by **anxiety**, **confusion**, and **misinterpretation** of their environment or other people.
8. Engage in behavior distressing to themselves or to others, triggered (especially in **later stages**) by **physical pain** and discomfort.

However, this person may experience:

9. Minimal difficulty with gait or physical movements until later stages
10. Minimal difficulty with social graces until later stages
11. Minimal incontinence until later stages
12. Minimal hallucinations (if and when they do occur, they would tend to occur in later stages)

EXAMPLES

Examples from persons living with Alzheimer's Disease (AD):

1. **Using a visual cue to compensate for sensory changes**: A woman was sitting in the living room

in the morning in her nightgown when an assistant came and said "Let's go get dressed". The woman said "Drecked?" The assistant replied "Let's go put your clothes on". The woman looked toward the window and said "closed?" The assistant finally went to this woman's bedroom, gathered her clothes, and walked toward the living room. The assistant was halfway down the hall when the woman saw her and immediately walked toward the bedroom to get dressed. The woman's brain (her frontal lobe) had difficulty compensating for her hearing loss by figuring out what the assistant was saying (by noting, for example, it's morning, I am in my nightgown, this assistant usually helps me get dressed, she must be saying it's time to get dressed). The clothing as a visual cue compensated for her inability to hear and understand what the assistant said.

2. **Mixed cues**: A daughter was clearing the table of breakfast dishes when she told her mother she would help her with a shower next. When the daughter came to take her mother to the shower, her mother said "I need to eat. I can't go now." Her mother remembered the visual cue of clearing breakfast rather than the auditory cue of taking a shower. Talking about one task when you are doing another task can be confusing to a person with AD.
3. **Fatigue from visuospatial processing**: Because so many tasks rely on visuospatial processing (for example, sitting up in bed, aiming an arm to the armhole in the shirt sleeve, aiming the spoon for the cereal) a person with AD can become stressed, fatigued, and irritable. When an assistant leaned down to help this person with her shoes, this person kicked the assistant. Seeing the assistant come close and unexpectedly move quickly through her visual field was the "straw that broke the camel's back".

INTERVENTIONS: COGNITIVE AND NONMEDICAL

1. See **detailed intervention** and support strategies in the **resources** identified at the beginning of this handout, including interventions that address **specific cognitive abilities** associated with **specific brain structures**. The resources also include a method of identifying an individual's particular cognitive strengths and needs, so that interventions can be **individualized** to this person and situation.
2. **Address cognitive changes** associated with each part of the brain that is affected in AD (for example, **memory** for the hippocampus, **executive functions** for the frontal lobe, **visuospatial** functions for the parietal lobe, and **language** for the left temporal lobe).
    a. Due to the parietal lobe changes, for example, it is usually helpful to **structure** this person's **environment** and keep it **consistent**. Avoid making changes in it unless necessary when this person's specific needs and preferences change, and then change it as little as possible. (For example, see **CAIS Handout #29** Visual-Spatial Interventions.)
    b. Due to the frontal lobe changes, for example, it is usually helpful to **structure** this person's **time** with events and routines, and keep the order, time, and duration of these **consistent**. That is, avoid changing the events and routines unless necessary as this person's specific needs and preferences change, and then change them as little as possible. (For example, see **CAIS Handout #35** about frontal lobe interventions.)
3. Identify this person's cognitive abilities (including their **cognitive strengths** and their cognitive **needs**)
4. Assess this person regularly **over time** as their dementia progresses
5. Use intervention and support strategies that build on this person's cognitive strengths and support or **compensate** for this person's cognitive needs
6. Examine and modify their **environment**, your **interactions** with this person, and their **tasks** and daily routines to accommodate this person's cognitive strengths and needs throughout the course of AD (For example, see the ***CAIS Intervention Strategies***)
7. Modify expectations and interventions as change occurs
8. Maintain appropriate **stimulation** that **engages** this person
9. Avoid meaningless or confusing stimulation
10. Communicate both **verbally** and **nonverbally** with gestures, body language, and how you position your body so this person can more easily see and interpret what you are saying and doing

11. Use **touch** as appropriate when communicating, if this person is comfortable with touch
12. **Simplify** daily routines and tasks
13. Provide information through **cues** in their environment and when communicating
14. Ensure cues are **understandable** to this person
15. **Explain** to this person the situation, what you are doing, and what you would like to do next
16. **Slow** down; speak naturally, but slowly and with pauses as needed for this person to process what you are saying; give this person time to respond
17. Use **concrete** requests and concrete cues
18. Help this person **remember** and **know what** to remember, for example:
    a. Identify the most **important** information by highlighting it or making it the **most powerful stimulus** (for example, contrast the object with its surroundings, when you speak to this person remove distracting movement and backgrounds by standing in front of a plain wall rather than an open doorway, emphasize the important word when you say it, draw this person's attention to it)
    b. Avoid **unintended** or mixed **cues** (for example, don't talk about one task when they are focused on another task)
    c. Use both **visual** and **auditory** cues (for example, show an object as a reminder in addition to saying what they will be doing with the object)
    d. **Adapt** the information to this person's abilities (for example, show a photo as a reminder rather than a written note if this person has difficulty reading)
    e. **Repeat** information and cues as often as this person needs it
    f. Be patient and respond as though this were the **first time** you heard this person's repeated stories, requests, questions, or concerns
19. **Watch** and **listen** to this person closely to notice how they respond to what you say and do; much of their expression of confusion or anxiety may be nonverbal
20. Be **consistent** with this person regarding who interacts with them, how tasks are done, and the timing of the daily schedule and routines
21. **Prevent confusion**, fatigue, stress, and embarrassment
22. Help this person feel **comfortable**, competent, and safe
23. Express warmth and compassionate support for this person, **verbally** and **nonverbally**
24. Respect this person as an **adult**; avoid treating this person as a child (if they are an adult)
25. Stay **calm** and help this person feel **relaxed** (so their brain can more easily think and process information)
26. **Avoid arguing** with this person
27. **Discern why** this person is distressed or why this distressing situation is occurring
28. Address this person's **feelings** and **then distract** this person in a distressing situation, or when this person is engaging in behavior that is distressing to themselves or to others
29. **Avoid engaging in behavior**, yourself, that might cause **distress** for this person (for example, moving or talking too fast)
30. Compensate for **sensory changes** that occur with normal aging (seeing, hearing, feeling, tasting, smelling). The frontal lobe and rest of the brain will likely have more difficulty figuring out what this person might be seeing or hearing, that is, they will be less able to compensate for sensory changes.
31. Discuss with this person and their family:
    a. The possible course of this person's AD
    b. Medical, financial, and legal issues regarding this person and AD

MEDICAL TREATMENTS

1. Cure unknown
2. Treat symptoms
3. Medication to reduce loss of certain neurotransmitters, for example, acetylcholine (inhibits acetylcholinesterase)

a. Aricept (donepezil), Exelon (rivastigmine), Razadyne (galantamine)
b. May be most effective in mild-moderate stages

4. Medication to regulate activity of glutamate (a neurotransmitter)
    a. Namenda (memantine)
    b. May be effective in moderate-severe stages (for persons with MMSE score of 3-14)
5. Medication to reduce depression (antidepressants) and anxiety (anxiolytics), if necessary to augment non-medication interventions
6. Medication for hallucinations and extreme agitation (antipsychotics) only if necessary to augment non-medication interventions - use with extreme caution
7. Control diabetes
8. Address cardiovascular risk factors: Exercise, Diet, No smoking, Reduce obesity, Cholesterol-lowering medications (statins)

COMMENTS

1. In 1984 criteria for clinical diagnosis were created and have since been updated
2. Red flags that suggest a disorder may not be AD:
    a. Onset before age 60 years
    b. Sudden onset
    c. Rapid progression
    d. Symptoms that do not occur in the order of typical AD stages
    e. Behavior changes or hallucinations occur much earlier than changes in memory
    f. Incontinence occurs before later stages
    g. Seizures occur before later stages (exception: may occur earlier if this person is also living with Down syndrome)
    h. Abnormal neurological symptoms (impaired gait, falls, weakness) occur before later stages

MORE ABOUT CHANGES IN THE BRAIN AND COGNITIVE ABILTIES

More details about changes in the brain and resulting changes in cognitive abilities in Alzheimer's Disease are in **CAIS Handouts #7** and **#8**.

Though these changes in behavior and cognitive abilities result from brain changes, changes in a person's behavior or cognition are often mistakenly viewed as intentional or manipulative. For example, this person may mistakenly be seen as stubborn, "mean", ornery, or lazy.

There are many **changes** in the **brain** with Alzheimer's Disease. Five of these **neuropathological** changes are: atrophy**,** beta-amyloid plaques, tao tangles, inflammation, and neurochemical changes.

1. **Atrophy** is the **reduction** in **size** of a structure. Atrophy due to death of nerve cells in Alzheimer's Disease causes much of the confusion and change in cognitive abilities. Atrophy occurs with normal aging, but is especially pronounced and is pathological in Alzheimer's Disease. The atrophy is visible on a computed tomography (CT) scan, a magnetic resonance imaging (MRI) scan, or at autopsy. Terms such as "widened sulci", "narrowed gyri", and "enlarged ventricles" refer to evidence of atrophy, that is, loss of brain tissue (nerve cells) in identified locations.
2. **Beta-amyloid plaques** are little patches or collections of debris located **outside of nerve cells** in the brain. A protein called beta-amyloid is a primary component of the plaques. The number of beta-amyloid plaques generally correlates with a person's performance on cognitive tests (such as neuropsychological tests).
3. **Tao tangles** are **inside nerve cells** in the brain. They are collections of a protein called tau that begins to act abnormally to disrupt the transport of cell nutrients within the nerve cell,

contributing to the cell's death. The number of tao tangles generally correlates with a person's performance on various cognitive tests (such as neuropsychological tests).

4. **Inflammation** occurs when the microglia (the immune system cells in the brain) **cannot keep up** with the **removal** of the **toxic proteins** (including the beta-amyloid and tao) and debris (from dead and dying nerve cells) from the brain.
5. **Neurochemicals** (or neurotransmitters) facilitate the process of communication between nerve cells (that is, neurons), so essential to the brain's maintenance and functioning. A neurotransmitter is released from a nerve cell into the gap between it and another nerve cell. There are many types of neurotransmitters. There is a **reduction** in the **amount** of some of these neurotransmitters, including a neurotransmitter called acetylcholine. Some of the medications that treat the symptoms of AD inhibit acetylcholinesterase (which breaks down the acetylcholine). This allows more acetylcholine to remain in the brain.

These changes (neuropathological changes) continue to **increase within each structure** as they spread to **additional structures** of the brain. Because each of the structures in the brain mentioned in this handout is associated with specific cognitive abilities, the **cognitive abilities** associated with each structure **continue to decline**, even **as new cognitive abilities** become affected. For example, as the hippocampus becomes affected, this person's memory begins to decline. Their memory continues to decline throughout the course of the AD, even as the neuropathology spreads to other structures, such as the parietal, temporal, and frontal lobes causing other cognitive abilities to begin to decline.

For more information

1. The Michigan website called Improving MI Practices at **https://www.improvingmipractices.org** has updates and many additional handouts and resources, including all of these **CAIS** H**andouts** (43 total), the Cognitive Abilities and Intervention Strategies (**CAIS**) **Questions to Ask** and the **CAIS Intervention Strategies**, **CAIS** information and background **resources**, and the **Caring Sheets**:Thoughts and Suggestions for Caring that are a part of the Michigan Dementia Care Series.
2. Mace, N., Coons, D., Weaverdyck, SE. (2005) Teaching Dementia Care: Skill and Understanding. Baltimore, Md.: Johns Hopkins University Press.

Original Sources

3. Weaverdyck, S.E. (1991) "Assessment as a Basis for Intervention" and "Intervention to Address Dementia as a Cognitive Disorder". Chapters 12 & 13 in D. Coons (Ed.) Specialized Dementia Care Units. Baltimore, Md.: Johns Hopkins University Press.
4. Weaverdyck, S.E. (1990) "Neuropsychological Assessment as a Basis for Intervention in Dementia". Chapter 3 in N. Mace (Ed.) Dementia Care: Patient, Family, and Community. Baltimore, Md.: Johns Hopkins University Press.

Dementia Care Series

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