A Disease Process Module:
UNDERSTANDING DEMENTIA

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A Disease Process Module: Understanding Dementia

IS IT OR ISN’T IT DEMENTIA?

Meet John. John is a 71-year-old widower with Alzheimer’s disease (AD, for short). He lives alone but his two grown sons live close by and visit often. Until recently, John’s AD symptoms have been mild, mostly just minor forgetfulness.

Over the past three months, John’s sons have noticed a decline in their father’s abilities. He seems agitated and can’t follow simple instructions. They suggest hiring an Aide to help with bathing and feeding, but John refuses.

One day, John’s son receives a call from a neighbor who reports seeing John walking around the yard in just his underwear. When asked about the incident, John slurs and struggles to find the words, “I wanted to go for a walk but I couldn’t find the gate to get out of the yard.”

And this is Lottie. Lottie is an independent 83-year-old woman who lives at home with her adult granddaughter, Maria. Lottie is mentally sharp and physically strong.

One day, while fixing breakfast, Maria notices her grandmother seems quieter than usual. In fact, she doesn’t even answer when Maria asks if she would like tea or coffee. She just glances at Maria, then looks away.

Later, Lottie declines to go on her usual morning walk, even though it is her favorite part of the day. And that afternoon Maria finds her grandmother sitting on the sofa, struggling to get up. She approaches her to help but Lottie shoves Maria out of the way and yells, “You’re trying to kill me!”

"I'm not. It's me, Gram. I love you." Maria says. "Leave me alone!" Lottie shouts.

Maria is unsure what to do, so she phones the doctor’s office and describes the situation to the nurse.

Do you think John and Lottie are showing signs of dementia? Keep reading to learn what dementia is . . . and what it is not! In addition, you will find lots of practical information on how to best care for clients like John and Lottie when they show symptoms of dementia.
WHAT HAPPENS TO THE BRAIN?

Dementia isn’t a specific disease—it’s a group of symptoms. Depending on the type and the underlying cause, dementia can affect the way a person thinks, functions and the way he or she interacts with others.

What’s happening in the brain of someone with dementia?

There are two areas of the brain that, when affected, can cause dementia—the cortical region and the subcortical region.

Cortical Dementias come from a disorder that affects the cerebral cortex, (the outer layers of the brain). This area of the brain plays a critical role in memory and language.

People with cortical dementia typically have:
- Severe memory loss, and
- Aphasia (the inability to recall words and understand language).

Subcortical Dementias result from damage deeper in the brain. People with subcortical dementias tend to show:
- Changes in their speed of thinking, and
- Difficulty starting activities.

Vascular Dementias include damage to both parts of the brain. This type of dementia is common following a series of small strokes.

The most common causes of dementia are Alzheimer’s disease and having multiple strokes.

The Facts

- At least 25 percent of people over the age of 75, and 40 percent of people older than 80 years of age have some form of dementia.
- Although dementia mainly affects older people, it is not a normal part of aging.
- Worldwide, nearly 8 million new cases of dementia are diagnosed each year. That’s one new diagnosis every four seconds!
- The number of people with dementia is expected to nearly double every 20 years, to 65.7 million in 2030 and 115.4 million in 2050.
- Most people with dementia are cared for by loved ones in the home—and the responsibilities can be overwhelming. Caring for a loved one with dementia can be physically, emotionally and financially challenging.

Grab your favorite highlighter! As you read this inservice, highlight five things you learn that you didn’t know before. Share this new information with your co-workers!
A CLOSER LOOK AT CORTICAL DEMENTIAS

Alzheimer’s, Pick’s disease, and Creutzfeldt-Jakob disease all affect the cortical region (outer layer) of the brain and cause the characteristic problems with memory and aphasia.

ALZHEIMER’S DISEASE: By far, the most common cause of dementia is Alzheimer’s disease—or AD, for short. Alzheimer’s disease is an irreversible disorder of the brain.
- Dementia caused by AD usually begins gradually. The first sign is often a decline in short term memory.
- Eventually, people with Alzheimer’s disease lose the ability to take care of their personal needs—and even become unable to walk.

PICK’S DISEASE: Pick’s disease, also called Frontal dementia, is a rare brain illness that causes dementia. The symptoms of Pick’s disease are similar to Alzheimer’s disease: memory loss, inability to concentrate, changes in behavior, deterioration of language skills and problems performing personal care. However, there are some major differences between Alzheimer’s and Pick’s disease, including:
- People usually develop Pick’s disease before age 70.
- In Pick’s disease, behavioral changes—including being socially and sexually inappropriate—are often an early symptom. These behavior problems occur even though the person’s memory has not deteriorated.
- Another early symptom of Pick’s disease is the inability to speak so that others can understand—even though the memory is intact.

CREUTZFELDT-JAKOB DISEASE (CJD): CJD is a rare condition, affecting about 200 Americans each year. Unfortunately, there is no treatment, and nearly all patients with CJD die within one year.
- In the early stages of CJD, people experience personality changes, impaired memory and lack of coordination. As the disease progresses, the dementia worsens rapidly. People suffering from CJD may also lose the ability to move, speak and even see.
- There is no test for diagnosing CJD, and the only way to confirm a diagnosis of CJD is by doing an autopsy after death. The disease causes the brain to develop holes where nerve tissue used to be, giving the brain a “sponge-like” appearance.

WHAT EXCITES YOU?

WALK AWAY FROM DEMENTIA

A new study from the University of Pittsburgh found that walking about a mile a day, at least six days a week seems to protect against brain shrinkage, which in turn may slow and even prevent dementia.

It shrinks? Yes, indeed!

Brain size tends to shrink in late adulthood and can lead to the onset of dementia.

Why does walking work?

Researchers think that when people walk, their hearts pump more blood to their brains. The increased blood flow to the brain helps keep it healthy by providing nutrients and removing toxic waste products.

So lace up those shoes and get yourself and your clients moving!
A LOOK AT SUB-CORTICAL DEMENTIAS

Dementias that arise from the sub-cortical region (deeper in the brain) include Parkinson’s, Huntington’s Disease and AIDS dementia complex. These dementias cause changes in personality and a slowing down of thought processes. Language and memory remains largely unaffected.

PARKINSON’S DISEASE: People diagnosed with Parkinson’s disease have a shortage of dopamine. This brain chemical controls muscle activities, emotions and thought processes.

- Without dopamine, people with dementia related to Parkinson’s disease may have slow or even slurred speech. In addition, people with PD often experience “freezing” or difficulty starting an activity.

HUNTINGTON’S DISEASE (HD): Huntington’s Disease is a progressive brain disorder caused by a defective gene.

- This disease causes changes in the central area of the brain which affect movement, mood and thinking skills.

AIDS DEMENTIA COMPLEX (ADC): ADC is a type of dementia that occurs in advanced stages of AIDS. HIV experts believe that dementia in the late stages of AIDS occurs when the virus itself inflames or kills nerve cells in the brain.

- Progression of ADC is different for everyone affected. Symptoms can develop quickly or slowly, but generally affect four different areas of brain function, including: 1) thinking abilities, 2) behavior, 3) coordination and movement and 4) mood.

COMBINED CORTICAL AND SUB-CORTICAL DEMENTIA

VASCULAR DEMENTIA, AKA MULTI-INFARCT DEMENTIA (MID): MID is mental deterioration caused by a series of strokes in the brain. These strokes are more common among men and usually begin after age 70.

- Depending on the part of the brain affected, people may lose specific functions, such as the ability to count numbers or read. People with MID may also have more general symptoms, such as disorientation, confusion and behavioral changes.
- In general, people with MID decline in “steps”. Each stroke causes more damage, but, in between strokes, they may experience periods of stability or slight improvement.
- MID is not reversible or curable, but controlling problems like high blood pressure or diabetes may prevent more strokes from happening.
IS IT DEMENTIA, DELIRIUM OR DEPRESSION?

Dementia can often be mistaken for delirium or depression since the symptoms can be similar or overlapping. Unfortunately, a delayed or missed diagnosis of dementia can delay treatment. Here are some guidelines to help you distinguish between dementia, delirium and depression:

<table>
<thead>
<tr>
<th></th>
<th>DEMENTIA</th>
<th>DELIRIUM</th>
<th>DEPRESSION</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>How does it start?</strong></td>
<td>Slowly, then get’s worse over time.</td>
<td>Suddenly.</td>
<td>Suddenly, usually related to a specific event.</td>
</tr>
<tr>
<td><strong>How long does it last?</strong></td>
<td>Usually permanent.</td>
<td>A few hours to a few days.</td>
<td>Can come and go, or can be persistent or chronic.</td>
</tr>
<tr>
<td><strong>What time of day are symptoms worse?</strong></td>
<td>No change throughout the day.</td>
<td>Worse at night, sleep-wake cycle may be reversed.</td>
<td>May have insomnia.</td>
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<tr>
<td><strong>How is the person’s thinking, memory and attention?</strong></td>
<td>Has trouble with judgment and memory. May have trouble understanding simple instructions.</td>
<td>Has trouble with memory and difficulty paying attention.</td>
<td>May complain of memory loss, forgetfulness and inability to concentrate.</td>
</tr>
<tr>
<td><strong>What is the person’s activity level?</strong></td>
<td>Unchanged from usual behavior.</td>
<td>Activity levels may increase or decrease and may fluctuate throughout the day.</td>
<td>Lack of motivation, tired, restless or agitated.</td>
</tr>
<tr>
<td><strong>What does the person’s speech sound like?</strong></td>
<td>May struggle to find words.</td>
<td>It may sound like paranoid rambling or may be confused and jumbled.</td>
<td>May be slow to understand and respond during conversations.</td>
</tr>
<tr>
<td><strong>How is the person’s mood?</strong></td>
<td>Depressed, uninterested in usual activities.</td>
<td>Rapid mood swings, fearful, suspicious.</td>
<td>Extreme sadness, anxiety and irritability.</td>
</tr>
<tr>
<td><strong>Are there any delusions or hallucinations?</strong></td>
<td>There may be delusions, but no hallucinations.</td>
<td>The person may see, hear or feel things that are not really there.</td>
<td>The person may have delusions about worthlessness.</td>
</tr>
<tr>
<td><strong>Can it be treated?</strong></td>
<td>Rarely. Most dementias get worse over time. (However, treatment may slow down the disease.)</td>
<td>Yes, if the underlying cause is found and treated.</td>
<td>Yes, medication and therapy can help.</td>
</tr>
</tbody>
</table>

WHAT DO YOU THINK? Look back at John and Lottie from the beginning of this inservice module. Try to determine if they are suffering from dementia, delirium or depression. Pay attention to whether the symptoms are gradual or sudden. What does their speech sound like? How is their thinking or memory? Discuss your ideas with your supervisor and co-workers. Find out what they think.
THE THREE STAGES OF DEMENTIA

EARLY STAGE: People in the early stage of dementia may show signs of a gradual decline, such as:

- Becoming more forgetful of details or recent events.
- Misplacing objects frequently.
- Losing interest in hobbies or activities.
- Being unwilling to try new things.
- Showing poor judgment and making poor decisions.
- Taking longer to do routine tasks.
- Repeating themselves during conversations.
- Having trouble handling money.
- Blaming other people for “stealing” from them.
- Becoming less concerned with other people’s feelings.

MODERATE STAGE: During the moderate stage of dementia, the problems become more obvious, such as:

- Being very forgetful of recent events.
- Becoming confused about time and place.
- Getting lost in familiar surroundings.
- Forgetting names of friends or family members.
- Seeing or hearing things that are not there.
- Neglecting personal hygiene.
- Forgetting to eat.
- Behaving inappropriately, such as going outside without clothes.
- Wandering.

SEVERE STAGE: People who have severe dementia are in the third stage and need total care. Their symptoms may include:

- Being unable to remember things, even for a few minutes.
- Losing their ability to understand or use speech.
- Being incontinent.
- Showing no recognition of family or friends.
- Needing help with all their personal care.
- Being restless, especially at night.
- Becoming aggressive or combative.
- Having difficulty walking.

If you notice these signs developing in your clients, report the situation to your supervisor. Your observation may help them receive an early diagnosis—and treatment—for dementia.
HOW IS DEMENTIA DIAGNOSED?

Currently, there is no one test that spots dementia. However, the ability to diagnose dementia has improved a lot in the past few years. Now, many physicians have enough firsthand experience to allow them to distinguish Alzheimer’s disease from other similar conditions in 8 out of 10 patients.

To help them make a diagnosis of dementia, physicians will:

- Perform a thorough physical examination.
- Ask the person to complete a variety of mental status tests, such as the Mini Mental Status Exam (see side bar).
- Look for the signs and symptoms of dementia.
- Try to rule out all the conditions that mimic dementia. This may involve ordering blood work and/or other tests such as CT, PET or MRI scans.

HOW IS DEMENTIA TREATED?

The treatment for dementia depends on what is happening in the brain to cause the symptoms of dementia. If the doctor can pinpoint the cause, the dementia can sometimes be reversed. For example, the doctor may prescribe:

- Vitamins for a B12 deficiency.
- Thyroid hormones for hypothyroidism.
- A change in medicines that are causing memory loss or confusion.
- Medicine to treat depression.

If the dementia cannot be reversed, treatment involves helping the person remain as comfortable and independent as long as possible. The treatment plan may include:

- Counseling or therapy that can teach the person new ways to remain independent.
- Medications like Aricept, Exelon or Namenda. These medicines are generally used to treat Alzheimer’s disease, but can also ease some of the symptoms of dementia.

  - **Side effects** of these drugs may include dizziness, headache, confusion, nausea, vomiting and diarrhea.

  - Antipsychotics or antidepressants to help control mood or behavior problems.

    - **Side effects** of these medications may include drowsiness, dizziness when changing positions, blurred vision, rapid heartbeat, sensitivity to the sun and skin rashes.
CAN DEMENTIA BE PREVENTED? YOU BET IT CAN!

Remember, the most common causes of dementia are Alzheimer's disease and having multiple strokes. The good news is that there are things that can be done to prevent AD and strokes! Here's what researchers know:

PREVENTING ALZHEIMER’S DISEASE

There are certain factors that put people at risk for developing AD that cannot be changed. For example, you cannot change your age or your genetics.

But, there are other factors that can be controlled!

A growing mountain of evidence now suggests that the same lifestyle changes doctors recommend to prevent or control diabetes, heart disease and obesity can also delay the onset of Alzheimer’s Disease!

HEALTHY DIET: Eating plenty of fruits, vegetables, and whole grains, plus foods that are low in fat and sugar can reduce the risk of many chronic diseases. Now, studies are beginning to suggest this can also reduce the risk of developing AD!

EXERCISE: Researchers know that physical activity is good for the brain as well as the heart and the waistline! One study found that the risk of developing AD was 40 percent lower in people who exercised at least 15 minutes a day, 3 or more times a week!

PREVENTING STROKES (CVAs)

Just like Alzheimer’s disease, there are some factors that put people at risk for strokes that cannot be changed, including age, gender, genetics and having had a previous stroke.

But, risk factors that people can control include:

High Blood Pressure—High blood pressure is the most important risk factor for a stroke. Many people believe that because more and more people are being treated for high blood pressure, fewer people are dying from CVAs.

Cigarette Smoking—In recent years, studies have shown that cigarette smoking DOUBLES a person’s risk for stroke. Also, the use of birth control pills combined with cigarette smoking greatly increases the risk of stroke.

Diabetes—Diabetes is a risk factor for stroke and is strongly related to high blood pressure. While diabetes is treatable, having it increases a person’s risk of stroke. In addition, people with diabetes are often overweight and have high cholesterol, increasing their risk even more.

Carotid artery disease—There are arteries in the neck that supply blood to the brain called carotid arteries. A carotid artery that becomes blocked by a blood clot or by cholesterol can result in a stroke.

Heart disease—A diseased heart increases the risk of stroke. In fact people with heart problems have more than twice the risk of stroke as those with hearts that work normally. Atrial fibrillation (rapid beating of the heart’s upper chambers) raises the risk for stroke. Heart attack is also the major cause of death among survivors of stroke.
CHALLENGES FOR PEOPLE WITH DEMENTIA: DEALING WITH CATASTROPHIC REACTIONS

Catastrophic reactions are emotional (and sometimes physical) outbursts that seem inappropriate, irrational and/or “completely out of the blue.”

These outbursts can be triggered by a:

- Certain person.
- Task that is overwhelming.
- Memory.
- Difficulty expressing a feeling or communicating a need to the caregiver.
- Sudden change in activity or environment.

WHY DOES IT HAPPEN?

People with dementia can easily become overwhelmed by routine activities. And making matters worse, the damage in the brain that is typical of people with dementia often leaves the person with a limited set of emotions to call upon when things get tough.

Panic and anger are the easiest “go-to” emotions when frustration, information overload, or trouble communicating arises.

How you can help . . .

- Pay attention to the “who, what and where” details when catastrophic reactions occur for your client, then try to avoid those triggers.
- Keep distractors that aggravate your client to a minimum—such as televisions or radios on in other rooms, loud telephones and certain people.
- Never argue or try to reason with a person during a catastrophic reaction. This could make the situation worse.
- If your client does not present a danger to himself or to others, observe from a safe distance and allow him to settle on his own.
- Observe body language and help your clients identify their emotions. For example, you might say “You seem angry, can I help?”
- Provide frequent reassurance: “I’m here to help,” and “Everything is going to be OK.”
- Always speak in short uncomplicated sentences to avoid confusing or overwhelming people with dementia.

TALK ABOUT IT!

You provide care for Jess, an 83-year-old woman with severe dementia.

When Jess’s symptoms first started, her daughter tried to take care of her at home. But the job was too much and the family decided to place Jess in your facility.

For the first few years, Jess’s daughter visited several times a week. But now that Jess doesn’t recognize her daughter anymore, she only visits once a month because it is just too sad and stressful.

What would/could you say to Jess’s daughter to help her remain positive and supportive of her mother in this situation?

Talk to your supervisor, your co-workers, a social worker and even a chaplain to find out what they would say in a situation like this.
PERSONAL HYGIENE ACTIVITIES

*While most of us take getting bathed and dressed for granted, people with dementia can become confused by this rather complex process.*

If you think about it, there are probably one hundred small steps involved in washing, brushing your teeth, combing your hair and putting on clothes. Eventually, most people with dementia lose interest in personal hygiene. This may be because they:

- Have forgotten how to dress themselves.
- Don't like feeling out of control.
- Get anxious about being naked.
- Are afraid of getting wet.

How you can help . . .

- Make sure the client's room is warm enough for getting dressed or undressed.
- Provide for your client's privacy.
- Try to use the same location each day for dressing and a different spot for undressing.
- Make sure your client's clothes fit comfortably and are not so long the client might trip.
- Simplify the dressing process by offering only a few clothing choices.
- If possible—and if your client seems to enjoy it—play calming music during bath time.
- Make sure the bathroom is warm and well-lit.
- Avoid mirrors if your client no longer recognizes him or herself.
- Try to schedule a bath during the time of day that your client is most relaxed.
- Let your client feel the water before getting into the bathtub or shower. Say something like, “This water feels nice.”
- For additional tips, see the In the Know inservice entitled “Bathing Tips”.

PROBLEMS WITH SLEEP

*It is not unusual for people with dementia to have sleeping problems. These may come from:*

- Confusion about whether it's day or night.
- Frequent need to urinate during the night.
- Depression.
- Pain.
- Leg cramps or “restless legs”.
- A disruption in their daily routine.
- Certain medications.
- “Sundowning,” or restlessness, agitation and disorientation, usually at the end of the day.

How you can help . . .

- Try increasing your client's level of activity during the day.
- Limit sugar and caffeine, especially late in the day.
- Keep afternoon and evening hours calm, filled with quiet activities only.
- Close the drapes and turn on the lights well before sunset. This cuts down on shadows which can add to confusion.
- Place a night light near the bed.
- Keep daytime clothing hidden at night. Your client may see the clothes and think that it's time to get up and get dressed.
- Some dementia clients enjoy soft music playing near their bed at night.
CHALLENGES FOR PEOPLE WITH DEMENTIA:
DIFFICULTY AT MEALTIMES

A common problem for people with moderate to severe dementia is to have some difficulty at meal time. Why? There are a number of possible reasons, including:

- Changes in appetite—either increased or decreased.
- Feeling rushed at meal time.
- Forgetting to eat.
- Distracted by the table setting and/or environment.
- Being frightened by a noisy dining room.
- Forgetting how to chew and/or swallow.
- Confusion about how to use silverware.
- Confusion over too many food choices.
- Too agitated to sit for an entire meal.
- Feeling rushed at meal time.

How you can help . . .

- Offer five to six small meals per day, rather than three larger ones.
- Remind your dementia clients that it is meal time.
- Demonstrate how to use silverware or offer foods that can be eaten easily with the fingers.
- Simplify the meal by using just one plate, one piece of silverware and just a few food choices.
- Avoid tablecloths and dishes that are patterned as they may be too distracting.
- Reduce the amount of noise in the dining area to avoid frightening your dementia clients.
- If possible, serve foods that are familiar to your client.
- Check the temperature of foods before you serve them.
- Avoid using foam cups—dementia clients may try to eat them.
- Use bowls rather than plates to make it easier to get food onto a spoon.
- Demonstrate how to chew and say “chew now” in a friendly tone of voice.
- To encourage clients to swallow, stroke them gently on the throat and say, “swallow now”.
- Encourage your clients to finish one food completely before moving on to another. (Some people get confused by a change in texture.)
- Give your dementia clients plenty of time to finish their meal.
- Be sure to report any sudden changes in appetite or other eating difficulties. There may be a medical or treatable cause for the problem.
**FINAL THOUGHTS ABOUT DEMENTIA CARE**

- **Focus on strengths!** Most types of dementia cause an inevitable decline of a person’s memory, intellect and personality. However, this usually occurs only in the middle to late stages. During the early stage of dementia, it is especially important to focus on the person’s remaining strengths . . . and not on what he or she is losing.

- **Last in, first out!** For most people with dementia, the things they learned most recently are the most easily forgotten. Allow your clients to focus on what they do remember.

- **Stimulate, don’t overwhelm.** There is a fine line between providing stimulation to people with dementia and overwhelming them. Get to know each client as an individual so you know what their limits are.

- **Childlike, not childish.** People with moderate to severe dementia tend to lose the ability to care for themselves. Just like small children, they need help with eating, dressing, walking and toileting. But, remember, just because some of their needs and behaviors may be childlike, they are not children. Be sure to treat them as adults; don’t patronize or “talk down” to them.

- **Personality Plus!** Typically, dementia tends to exaggerate personality traits that already existed. For example, someone who was bossy in his younger years may be completely domineering due to dementia. Or, dementia may make a person who was always tidy become obsessed with neatness.

- **Follow the leader.** People with dementia tend to take on characteristics of their caregivers and/or family members. For example, a visit from an anxious and irritable spouse can lead to an anxious an irritable client.

- **All in the family.** When a loved one has dementia, the whole family is affected—especially if they have primary responsibility for the person’s care. Studies have shown that family members of dementia clients have a higher risk of depression, anxiety and even illness.

- **Change the environment, not the person.** Watch how your client reacts to different situations throughout their day. If you notice that a noisy dining room seems to trigger a catastrophic reaction, then serve your clients meals someplace quiet.

- **Try switching shoes!** As with all clients, try to imagine how you would like to be treated, and talked to, if you were suffering from the confusing symptoms associated with dementia.