A Disease Process Module:

UNDERSTANDING ALZHEIMER’S DISEASE

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A SMALL, MESSY CLOSET IN THE BRAIN

Think about a messy closet...things are tossed in without care. Over time, it becomes unorganized, unstable, a place where things you forgot about long ago are misplaced or hidden!

The rest of the house can function normally with a messy closet . . . until you have to open the closet door to retrieve something. Then, who knows what you will find!

It's kind of like that with Alzheimer's disease (AD for short). In the beginning, it's like there is a small messy closet tucked away in the brain. The rest of the body functions normally. No one would even know about the messy closet unless the person had to open that door to access some memory or feeling or skill.

Over time, the closet gets messier and messier. Then other closets begin to clutter up. Finally, the closets are so full and messy, the doors can no longer be closed. Eventually, the messy closets spill out and take over the whole house.

Keep this picture in mind when you see a client with AD having trouble remembering people and places or how to perform routine tasks.

So, What Is Alzheimer’s Disease?

- Alzheimer’s disease is **progressive**, meaning it gets worse over time.
- It's also **degenerative**, which means it causes cells to waste away and never return.
- And, it is a disease for which there is **no cure**.

Keep reading to learn what exactly is going on in your AD client’s brain. Find out how AD is diagnosed and treated and how to best care for AD clients while maintaining their sense of dignity and pride.

You’ll learn that no one knows what causes AD and that there is no cure. But there are a few things **everyone** can do to prevent it!
WHAT’S HAPPENING IN THE BRAIN?

Inside a normal brain, a complex network of nerve cells, called neurons, send and receive the messages that control everything a person feels, says, remembers and acts upon.

- With Alzheimer’s disease, **plaques and tangles** block the messages and disrupt the network, preventing the person from sending and receiving messages. This leaves people with AD unable to feel, speak or remember things the way they used to.

- **Plaques** form when certain proteins in the neuron cell membrane are released in short fragments. The fragments find each other and clump together. The clumps (or plaques) become toxic (or poisonous) and begin to interfere with the transmission of messages.

- **Tangles** form when a protein that is responsible for keeping the neuron stable and working properly begins to fall apart. Strands of this protein break off and form tangles inside the neuron. This interferes with sending and receiving messages and eventually destroys the cell.

- As more and more plaques and tangles develop in the brain, neurons begin to die. Eventually the brain shrinks and loses all function.

FACTS ON ALZHEIMER’S DISEASE

- More than 5 million Americans have AD. By 2050, the number is expected to increase to 15 million.

- Approximately 350,000 new cases of Alzheimer’s disease are diagnosed each year.

- About 73 thousand people die each year as a result of Alzheimer’s disease.

- Alzheimer’s disease usually begins after age 60 and the risk increases with age. Younger people in their 30s, 40s and 50s may get Alzheimer’s disease, but it is rare.

- Approximately 5 percent of all cases of Alzheimer’s disease are believed to be familial (hereditary).

- Alzheimer’s disease accounts for about 70 percent of all cases of dementia...making it the most common cause of dementia.

- On average, people with AD live for 8 to 10 years after diagnosis, but the disease can last as long as 20 years, or as little as 3 to 4 years if the patient is over 80 years old when diagnosed.

  - Seventy percent of AD sufferers are cared for at home.

  - Nearly half of all nursing home residents have AD or a related disorder.

Grab your favorite highlighter! As you read through this inservice, **highlight five things** you learn that you didn’t know before. Share this new information with your supervisor and co-workers!
WHAT CAUSES ALZHEIMER’S DISEASE?

GENETICS OR LIFESTYLE?

No one really knows what causes Alzheimer’s disease. Scientists have managed to figure out what goes wrong in the brain, but they don’t know why it goes wrong. If they can figure out the cause, then they may be able to find a cure.

Even though, researchers don’t know why AD happens, they have a few theories as to what causes it. Some say AD is caused by a mutated gene that can be inherited and therefore seen in several generations of family members.

Scientists around the world are studying genes and trying to find a genetic origin for Alzheimer’s disease.

Other researchers believe certain lifestyle choices put people at risk for developing AD. For example, scientists now know that a nutritious diet, physical activity, a rich social life and playing games or doing puzzles that exercise the brain may help prevent Alzheimer’s disease.

WHAT DOCTOR’S KNOW FOR SURE:

• Physicians do know that the risk for getting Alzheimer’s disease increases with age.

• Alzheimer’s disease does tend to run in families. This type of Alzheimer’s is known as “familial” Alzheimer’s disease.

• There seems to be an association between AD and other chronic conditions such as heart disease, stroke, high blood pressure, diabetes, and obesity.

While scientists are still far away from finding the exact cause of Alzheimer’s disease, their research has made huge progress over the past 30 years. Every day researchers get one step closer to being able to predict and prevent this devastating disease.
A Disease Process Module: Understanding Alzheimer’s Disease

The only way to diagnose Alzheimer’s disease for sure is by performing an autopsy after the person has died.

However, doctors can be pretty sure of their diagnosis by performing a series of tests and studies. These include:

- **A complete physical exam** where the doctor asks questions about the person’s overall health, past medical problems, ability to carry out daily activities and changes in behavior and personality.

- **Mental ability tests** that measure the client’s memory, problem solving skills, attention span, and ability to count and use language.

- **Routine lab tests**, such as blood, urine, or spinal fluid to rule out other underlying disease or illness that can look like Alzheimer’s Disease.

- **Brain scans**, such as computerized tomography (CT) or magnetic resonance imaging (MRI)

These tests can be started as soon as symptoms are noticed and may be repeated over time to see how the brain function changes as time passes.

**SOME PROMISING RESEARCH:**

The most exciting and most promising area of research is neuro-imaging (neuro=brain, imaging=picture). Scientists now have fine-tuned, high-tech MRI machines that allow doctors to see even the smallest changes in the brain. This helps people get diagnosed with AD in the very early stages and to begin the treatment earlier to slow the progression of the disease.

Other ongoing research includes a study that links the loss of the sense of smell to the development of Alzheimer’s disease.

Researchers discovered they could predict which people with mild memory problems would go on to be diagnosed with Alzheimer’s disease with a simple smell test. Patients who had trouble identifying ten common smells—including lemon, lilac, strawberry, smoke, soap, menthol, clove, pineapple, natural gas and leather—were much more likely to develop AD.
A Disease Process Module: Understanding Alzheimer’s Disease

There is no magic pill that will stop the progress of Alzheimer's disease. However, the FDA has approved a few drugs that may help improve mental function for those who are suffering.

- Your client with **mild or moderate AD**, may be on the medications **Aricept, Exelon** or **Razadyne**.
- A client with **moderate to severe AD** might be on **Aricept** or another medication called **Namenda**.
- Your AD client may also be on **antidepressant medications** to help regulate mood and **sleep medications** to promote more restful sleep.

Alzheimer’s disease medications may help your client maintain thinking, memory and speaking skills for as little as a few months or as much as a few years. They work by regulating the chemicals in the brain that are responsible for sending and receiving messages between neurons.

**You can help your client on AD medication by recognizing and reporting any side effects you see.**

- **Side effects of Aricept, Exelon and Razadyne include:** Diarrhea, dizziness, loss of appetite, muscle cramps, nausea, trouble sleeping, vomiting and weight loss.
- **Side effects of Namenda include:** Constipation, dizziness and headache.
- **Side effects of antidepressants include:** Drowsiness, nervousness, sweating and anxiety.
- **Side effects for sleeping pills include:** Fatigue, confusion, slurred speech and incontinence.

*Any side effects that you observe should be reported to your supervisor.*

Aside from medication, one of the best treatments for Alzheimer’s disease is for the caregivers, family and friends to help the Alzheimer’s client cope with the disease. For example, people with Alzheimer's disease do better if their caregivers help them stick to a familiar daily routine.

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**HOW IS ALZHEIMER’S DISEASE TREATED?**

The word “dementia” comes from a Latin word that means “out of one’s mind.” Dementia is actually a group of symptoms that indicate a person’s ability to think is failing. That is why a person with dementia suffers from loss of memory, problems with all kinds of skills, orientation problems and changes in behavior.

People are often diagnosed with dementia when they lose their mental skills and abilities, including the ability to take care of themselves.

**Alzheimer’s disease is just one kind of dementia.** And, it is the most common kind.

- So, that means, **all people with Alzheimer’s disease have dementia**.
- **But a diagnosis of dementia does not mean that someone has Alzheimer’s.**

There are about 50 different conditions that can cause dementia, some of which are treatable.
THE STAGES OF ALZHEIMER’S DISEASE

THE “EARLY STAGE” OF AD

The symptoms of the early-stage of Alzheimer’s disease come on slowly. A person with early-stage Alzheimer’s disease may look well and may be able to “cover up” the signs of the disease. This stage of the disease is also known as the Onset Period and may last up to five years. The symptoms include:

- Poor concentration and a short attention span.
- Problems making decisions.
- Short-term memory problems. (For example, forgetting a meal that was just eaten).
- Forgetfulness, such as forgetting names, dates, how things work or how to pay bills.
- Depression.
- Some personality changes such as becoming cranky, silly, frustrated or very quiet.
- A very early sign can be changes in the patient’s sense of smell.

THE “MIDDLE STAGE” OF AD

The middle-stage of Alzheimer’s disease is also known as the Progressive Period. It may last up to 12 years. The symptoms of the middle-stage of Alzheimer’s disease include all the signs of the early stage, but now they get much worse. There are also new symptoms, such as:

- Episodes of getting lost, even in familiar places.
- Problems with speech—not being able to remember words or be part of a conversation. May talk “in circles”.
- Tendency to follow people around (also called shadowing).
- Behavior problems such as urinating in strange places, cursing, acting silly or making sexual advances.
- The desire to put everything in the mouth.
- Problems with following directions.
  - Problems sleeping at night.
  - A shuffling walk with a stooped posture.

SYMPTOMS OF THE “LATE STAGE” OF ALZHEIMER’S DISEASE

The late-stage of Alzheimer’s disease can last for three years or more. It is also known as the Terminal Period, since these Alzheimer’s patients are nearing death. People with late-stage Alzheimer’s disease are often bedridden and at risk for a number of infections. The symptoms include:

- Weight loss.
- Loss of balance and ability to walk.
- Loss of short and long-term memory.
- Loss of speech, although Alzheimer’s patients may groan or scream.
- Inability to perform basic skills such as eating or drinking.
- Failure to recognize others or even themselves.
- Respiratory infections (people with Alzheimer’s disease often die from pneumonia).
It’s important to have safety features in the bathroom such as a raised toilet seat and grab bars. (In addition, there are toilet seat “locks” available if your patients tend to throw things in the toilet bowl.)

It is unsafe to leave Alzheimer’s clients alone in the tub or shower. They could burn themselves with the hot water and/or slip and fall.

Encourage your Alzheimer’s clients to use any eyeglasses that have been prescribed for them. Poor vision can increase their confusion and frustration—and also puts them at a higher risk for falls.

Put decals on glass doors to prevent Alzheimer’s clients from walking into the glass.

People with AD often have a reduced sense of smell. Keep in mind that they might not be able to smell something burning and should be monitored when cooking and/or smoking.

Make sure the client’s living area is well lit to reduce confusion and/or accidents.

Remember that people with Alzheimer’s disease have been known to drink household cleansers, thinking they were beverages. Don’t leave any chemicals within reach of your clients.

Pad any sharp corners on furniture in your client’s living area and make sure any sharp objects—such as scissors—are kept in locked cabinets.

Post pictures or signs as clues to help your Alzheimer’s clients find their way around.

The majority of people with Alzheimer’s disease are likely to wander at some point. Make sure the outside doors and windows are securely locked.

For home health aides: encourage your client’s family to look into the Alzheimer’s Association Safe Return Program (www.alz.org/SafeReturn). This is a nationwide program that identifies people with dementia who have wandered away from their homes.

Spouses, adult children or others who care for loved ones with Alzheimer’s disease are at an increased risk of developing caregiver burnout. Be sure to check in with your client’s caregivers.

Here are some easy conversation starters:

- How are you doing?
- Is there anything I can do for you right now?
- Can I help you find a support group, social worker or therapist to help you shoulder this burden?
- I’m here for you when you need me. We take care of the whole family, not just the “patient.”

“Sometimes he is right there, watching and listening. Other times, he floats off, content to drift away from us. There’s a strange beauty to it, a peacefulness. The silence feels silken. ‘It’s like talking to a cloud,’ my mother has said of those moments.”

- Patti Davis writing about her father, Ronald Reagan, and his battle with Alzheimer’s, in The Long Goodbye
PERSONAL CARE NEEDS OF THE AD CLIENT

Keep the environment calm and peaceful: Bathing and getting dressed involves a lot of steps and the use of many different skills. It can be a very confusing time. When people with Alzheimer’s disease get confused or frightened, they may become irritable, uncooperative or upset. Turn off any TV or loud music before beginning personal care.

Avoid sudden changes in temperature: A sudden change in temperature during undressing or bathing can be very stressful to someone with AD. Make sure the room is comfortably warm before proceeding with your care.

Be patient and flexible: Provide assistance with personal care as needed, but allow your clients as much independence as possible. Keep in mind that Alzheimer’s clients may forget to brush their teeth on Wednesday, but remember on Friday.

Help with mouth care: This is especially important for terminal patients whose mouths may become very dry and uncomfortable.

Prevent complications of immobility: People in the later stage of Alzheimer’s disease suffer from lack of mobility and may be bedridden or chair-bound. Skin breakdown, pressure sores and contractions may result from lack of mobility. Remember to turn these clients every two hours—or according to your orders.

Comfort is the key: Use pillows to help support the arms and legs in order to maintain a good body alignment. Make certain that the client is comfortable.

Protect fragile skin: Check each client’s skin every day as it can become very fragile. Use a mild soap and blot the skin to prevent tearing. Apply lotion gently to the knees and elbows because rubbing or massaging may tear the skin.

Limit choices: It’s best to limit clothing choices for people with Alzheimer’s. Asking “What would you like to wear today?” will probably just cause confusion.

Break down dressing into small steps: Instead of saying “Get dressed now.” Say “Put on your shirt.” “Good. Now, put on your pants.” And so on.

Take regular bathroom breaks: Stick to a regular routine of trips to the bathroom. (Every 90 minutes is usually good.) Watch Alzheimer’s clients for signs that they have to urinate such as restlessness, pulling at a zipper or pulling down their pants.

Use signs to lead the way: Sometimes Alzheimer’s clients forget where the bathroom is. You might try taping a brightly colored sign with a picture of a toilet on the bathroom door.

Accidents happen: Be gentle with clients who have “accidents”. They can’t help it! Assist them to get clean and dry as soon as possible.

Encourage regular exercise: Encourage your Alzheimer’s clients to get some regular exercise every day. Even helping to bathe themselves and getting dressed is a little bit of exercise. Assisting them to walk helps them get rid of excess tension and anxiety.

Perform ROM exercises as ordered: In order to prevent contractures, range of motion exercises should be performed according to your agency’s policies. A physical therapist may be needed to instruct you in the proper techniques.

Get your flu shot: Clients who are immobile have a greater risk of infection, therefore many agencies require their caregivers to obtain an annual flu shot.

Keep the routine: If possible, stick to the routine the person had before developing Alzheimer’s disease. For example, if your client was used to showering in the morning, try to continue that routine.
NUTRITIONAL NEEDS OF THE AD CLIENT

Be patient: It may take a good 30 minutes to feed an AD client.

No surprises: When feeding people with Alzheimer’s disease, make sure they see the food before you put it in their mouths. If you “surprise” them with a mouthful of food, they might choke.

Gentle reminder cues: If Alzheimer’s clients clamp their mouths shut during eating, try stroking their cheeks or pretend to yawn. This may get them to open their mouths.

Serve liquids at room temperature: Cold liquids cause choking more often than room temperature ones.

Stay hydrated: Encourage your Alzheimer’s clients to drink plenty of fluids. If they get dehydrated, it could add to their confusion. Bendable straws often make it easier for the patient to drink.

Eliminate choking hazards: Alzheimer’s clients may try to eat small items like buttons, coins, plant leaves or paper clips. Make sure to keep the environment free from these little “temptations.”

Finger foods: People with Alzheimer’s disease usually like to eat with their fingers. (Using silverware can be too confusing.) Make sure food is cut into bite-sized pieces and not too hot to be picked up.

Know what to do if the person chokes: Coughing and choking can lead to an emergency situation. Be sure you are prepared to use the Heimlich maneuver or follow your agency’s emergency protocol.

Make sure your clients are getting enough to eat: Some Alzheimer’s clients hide food. Often, this is because they are afraid they won’t be able to eat when they are hungry again.

Dinner may be a challenge: People with Alzheimer’s disease may be more distracted in the evening since they are tired from trying to concentrate all day.

Change plates: Some Alzheimer’s clients have trouble seeing their food. For example, if your client has mashed potatoes on a white plate, she may not be able to see them. It may help to put the food on a dark or brightly colored plate.

Serve foods one at a time: Sometimes, AD clients get confused about what to eat first so they just don’t eat anything. If the meal has meat, a vegetable and fruit, try serving the items one at a time.

It’s best not to argue: If your client refuses to eat, try to understand why he is upset or try again in a few minutes.
**Encourage but don’t push:** Try to help your client have pleasant moments throughout each day.

**Listen:** Listen to your clients when they talk about their feelings. Let them know you understand they feel bad about the changes in their lives.

**Understand repetitive behaviors:** The repetitive behavior common to people with Alzheimer’s disease can come from their brain being “stuck” on a certain task or idea. It can also come from an emotional upset. For example, if your Alzheimer’s client gets confused or overwhelmed, she may begin to pace or rock or repeat a hand motion over and over. Try to find out if (and why) your client is upset, or try to turn the repetitive motion into something useful like sweeping, dusting or folding towels.

**Feeling crazy?** Remember that Alzheimer’s clients are not trying to drive you crazy! Changes in emotions and behavior are part of the disease.

**Distraction:** Inappropriate sexual behavior is also a common part of Alzheimer’s disease. If your clients perform inappropriate sexual activity such as masturbation, try to distract them by giving them something to hold or assigning some task they are able to perform.

**Keep area clean and clutter-free:** Your Alzheimer’s clients may become upset or overstimulated by a cluttered environment. Keep their living area neat and free from clutter.

**Use night lights:** Total darkness may scare or confuse your client.

**Monitor wanderers:** Some Alzheimer’s clients wander off because they feel the need to find something familiar. They may be looking for their childhood home or the place they used to work. Remember to keep outside doors and windows locked.

**Limit choices:** Alzheimer’s clients become frustrated very easily. Don’t give them a choice if there isn’t one. For example, don’t say “Do you want to take a bath now?” Instead say “It’s time for your bath now.”

**It’s not personal:** Some Alzheimer’s clients become cranky or irritable. They might say things to you that hurt your feelings. Try not to take it personally. Think about what they might be trying to tell you. For example, if a client says “You never feed me!”, he might mean that he is hungry. If your client says “I know you are stealing from me!”, she might be telling you that she feels like she has been robbed of her life. Remember, too, that people with Alzheimer’s disease do not choose to behave badly. It is part of the disease.

**Try to stay calm and positive:** If you are feeling stressed or irritable, your mood can easily rub off on someone with Alzheimer’s disease. Try to stay calm and positive; your client will probably “mirror” your good mood.

**Be respectful:** Treat your Alzheimer’s clients as people. Don’t talk about a client as if he weren’t in the room. Assume that your clients can understand every word you say. And, be sure to talk to them even if they can’t talk back to you.

**Watch for signs of depression:** Depression is very common with Alzheimer’s and can make someone feel restless or exhausted, have no appetite, and/or sleep too much.

**You might be the most familiar person:** Remember that Alzheimer’s clients live in a scary world that becomes less familiar every day. You might be the most familiar person to them each day and they might follow you around. While this can be annoying, try to be patient. Remember how lost the clients feel without you.
COMMUNICATING WITH AD CLIENTS

Approach Alzheimer’s clients from the front: Don’t speak to them suddenly from behind or you might startle them.

Keep your voice low and unhurried: Use simple, everyday words, but don’t use “baby talk.”

Identify yourself: Don’t be offended if your client doesn’t remember you from day to day.

Keep it simple: Ask one “yes” or “no” question at a time. Repeat the question using the same words if the client doesn’t answer you.

Give plenty of time to respond: It can take up to one minute for your AD client’s brain to process each sentence you speak.

Alzheimer’s clients will often copy your actions: If you smile, they will smile. If you frown or get angry, so will they!

Describe everything: Be sure to let Alzheimer’s clients know what you are doing—one step at a time.

Don’t talk in terms of time: For example, say “We’ll take a walk after lunch.” not “We’ll take a walk in one hour.” People with Alzheimer’s disease lose their sense of time.

Use nonverbal communication: Try using nonverbal cues such as touching or pointing to help your clients understand what you are saying.

Never scold or criticize: Alzheimer’s clients are the victims of a serious disease.

Remain respectful: Be sure to call your clients by name, and be respectful, saying things like “thank you”, “please”, “yes, ma’am” or “no, sir”. This helps them feel like the healthy adults they once were.

Praise your Alzheimer’s clients: They need to hear positive words like “Good job!” or “You’re doing great.” or “You look beautiful today.”

Put on a happy face: Look your Alzheimer’s clients in the eye when you speak to them...and don’t forget to SMILE!

Now that you’ve read this inservice on Alzheimer’s disease, take a moment to jot down a couple of things you learned that you didn’t know before.

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