

## **D.C. Office on Aging's**

Behavior Symptom Management (BSM) Training Program

500 K Street N.E., Washington, D.C. 20002

### **DCOA's Mission**

The D.C. Office on Aging's mission is to advocate, plan, implement, and monitor programs in health, education, employment, and social services which promote longevity, independence, dignity, and choice for:

- older District residents (age 60 and over);
- persons living with disabilities (age 18 to 59); and
- their caregivers.

Understanding and Managing Challenging Behaviors in Dementia

## **Objectives**

Upon completion of this module, the learner will be able to:

- Define ADRD-Alzheimer's Disease and Related Dementias
- Be familiar with statistics about the prevalence of Alzheimer's

disease and dementia in D.C.

Understand how ADRD impacts people with Intellectual and

**Developmental Disabilities** 

### **Objectives continued**

Use best communication practices when interacting with a

person who has cognitive challenges

Understand reasons for challenging behaviors and approaches

for managing them, based on the ABC approach

Know strategies for promoting safety and well-being

### **Objectives continued**

Build confidence and skills to address issues that arise during the

progression of the disease

- Understand the factors in sexual behavior in dementia
- Identify programs and services in D.C. that can help

### What is dementia?

Dementia is a general term for a decline in mental ability severe enough to interfere with daily life.

Dementia is not a specific disease.

Dementia is often incorrectly referred to as senility.

It is not a normal part of aging.

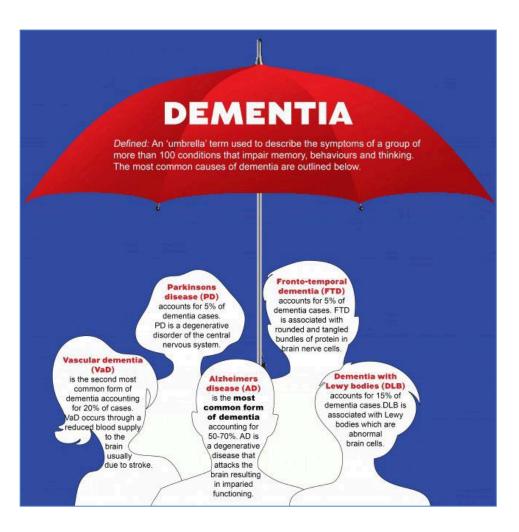
Irreversible dementias are progressive.

Adapted from the Alzheimer's Association / www.alz.org

### **Irreversible Dementias**

The symptoms we call "dementia" can have many different causes.

Alzheimer's disease is the most common.



NTG Education & Training Curriculum on Dementia and ID. Copyright 2014. All rights reserved.

### Terminology

The term "Alzheimer's" has often been used as a catch-all phrase to describe the symptoms known as dementia.

More accurate terms that are often used are ADRD, or Alzheimer's Disease and Related Dementias or "neuro-cognitive disorders."

Other general terms that are sometimes used include "cognitive impairment", "confusion", and "impaired memory."

Finding the best language to use continues to be challenging! Even the word "dementia" means "without a brain" or "empty headed." The term "dementia" may one day become obsolete.

## Wide Range of Symptoms

ADRD describes a wide range of symptoms associated with a decline in memory or other thinking skills severe enough to reduce a person's ability to perform everyday activities. It affects:

- Memory
- Communication and language
- Ability to focus and pay attention
- Reasoning and judgment
- Visual perception

### Alzheimer's Association 10 Warning Signs of Alzheimer's

- 1. Memory loss that disrupts daily life
- 2. Challenges in planning or solving problems
- 3. Difficulty completing familiar tasks at home, at work or at leisure
- 4. Confusion with time or place
- 5. Trouble understanding visual images and spatial relationships

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### Alzheimer's Association 10 Warning Signs of Alzheimer's

- 6. New problems with words in speaking or writing
- Misplacing things and losing the ability to retrace steps
- 8. Decreased or poor judgment
- 9. Withdrawal from work or social activities
- 10. Changes in mood or personality

### Vascular dementia

Caused by stroke

Impaired judgment or ability to make decisions, plan or organize is

more likely to be the initial symptom, as opposed to the memory

loss often associated with the initial symptoms of Alzheimer's.

### **Dementia with Lewy Body**

Often have memory loss and thinking problems common in

Alzheimer's, but are more likely than people with Alzheimer's to

have initial or early symptoms such as sleep disturbances, visual

hallucinations, and muscle rigidity.

### **Mixed Dementia**

In mixed dementia abnormalities linked to more than one type

of dementia occur simultaneously in the brain. Recent studies

suggest that mixed dementia is more common than previously

thought.

### **Frontotemporal Dementia**

Symptoms include changes in personality and behavior and

difficulty with language. Nerve cells in the front and side regions

of the brain are especially affected.

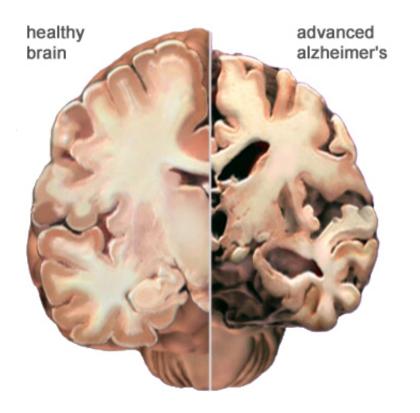
## **Other Types of Dementia**

Many conditions cause damage to the brain or nerve

cells and in some cases cause irreversible dementias, for example:

- Parkinson's disease
- Huntington's Disease
- Creutzfeldt-Jacob disease

Alcoholism (Wernicke-Korsakoff syndrome)



Here is a view of how massive cell loss changes the whole brain in advanced Alzheimer's disease. In the Alzheimer's brain: •The cortex shrivels up, damaging areas involved in thinking, planning and remembering. •Shrinkage is especially severe in the hippocampus, an area of the cortex that plays a key role in formation of new memories. •Ventricles (fluid-filled spaces within the brain) grow larger

### **RISK FACTORS**

- ADRD can affect anyone!
- "Everyone with a Brain is at Risk for Alzheimer's"

(Source: Alzheimer's Association 2015 Alzheimer's Disease Facts and Figures )

### Risk Factors

- Age
- Family History
- Genetics

### **Risk Factors**

Age

### The greatest known risk factor for Alzheimer's is

**advancing age**. Most individuals with the disease are age 65 or older. The likelihood of developing Alzheimer's doubles about every five years after age 65. After age 85, the risk reaches nearly 50 percent.

Family History

# **Another strong risk factor is family history.** Those who have a parent, brother, sister or child with Alzheimer's are more likely to develop the disease. Environment may influence.

#### Genetics

Scientists know genes are involved in Alzheimer's.

Most experts believe that the majority of Alzheimer's disease occurs as a result of complex interactions among genes and other risk factors

### **Medical evaluation**

Behavior changes, especially if symptoms appear suddenly, are a signal for a thorough medical evaluation. An examination may reveal other treatable causes, such

as:

- Medication side effects
- Environmental changes
- Infection
- Worsening of a chronic condition
- Loss of hearing or vision

## **Seeing your doctor**

Begin keeping a journal and note any changes with the following:

- Repeating or asking the same questions over and over
- Remembering appointments, family occasions, holidays
- Writing checks, paying bills, balancing checkbook
- Shopping independently
- Taking medications according to instructions
- Getting lost while walking or driving in familiar places

Make a note about when the symptoms began

## Questions to ask your doctor

- Will I need to have testing?
- Will you refer me to a specialist?
- Could medications I am taking be causing these symptoms?
- What should I expect if I have Alzheimer's?
- What treatments are available, and what are the benefits, risks and possible side effects?
- Is there anything else I should know?

## Finding the right doctor Specialists

Neurologists:

Specialize in diseases of the brain and nervous system

**Psychiatrists:** 

Specialize in disorders that affect mood or the way the mind works <u>Psychologists:</u>

Have special training in testing memory and other mental functions <u>Geriatricians</u>: Doctors who specialize in working with older people

### Information to bring to your doctor's appointment

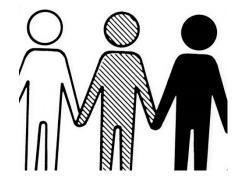
- I. Bring your journal
- Bring a list of your current medications, including over the counter medications and vitamins
- 3. Your medical history, including diagnoses
- 4. List of questions (don't try to remember your questions! Write them down before the visit.)

### **ADRD Statistics in D.C.**

In 2015, 15% of all D.C. residents age 65

and over have Alzheimer's disease.

- Age 65-74: 1,300
- Age 75-84: 3,000
- Age 85+: 4,000





Number of D.C. Alzheimer's Family Caregivers

### 2014

# of Caregivers:

Total Hours of Unpaid Care:

27,000

Value of Unpaid Care:

\$378 Million

**31** Million



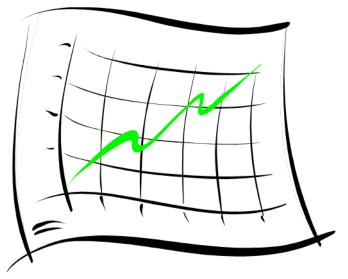
### TREATING ALZHEIMER'S DISEASE

- > There is currently no cure for Alzheimer's disease.
- There are medications that may be prescribed by the doctor that may slow the progression of the disease or address specific behaviors.
- It is always a good idea to keep the body and mind as healthy and active as possible. There is research being done in this area.

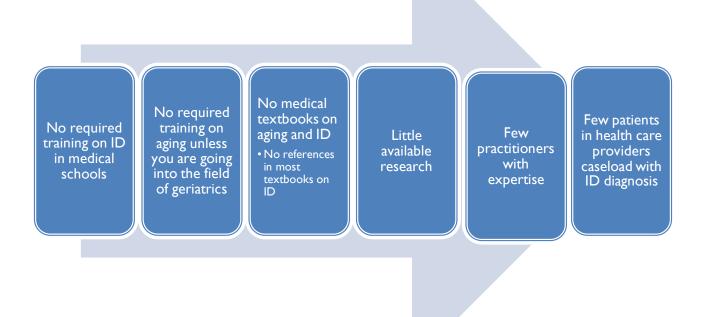
### What about people with Intellectual Disability (ID)?

- Intellectual disabilities are characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills.
- A term that was previously used for Intellectual Disability was "Mental Retardation".
- Most adults with ID are typically at no more risk for developing ADRD than the general population.
- Exception:

Those with Downs Syndrome are at increased risk (younger diagnosis, 40s and 50s and more rapid progression).



### Finding the Right Care for those with ID is complex



### In Down's Syndrome: Increased lifespan = Increase in dementia

### What this means:

- Raise "index of suspicion" among staff and families,
- Programs and services need to become "dementia capable,"
- Improve Diagnostic and technical resources,
- Improve Care management supports (to prolong the "aging in place" of adults affected by dementia).

# Atypical Presentation of Alzheimer's in people with Down's Syndrome

- Earlier onset than general population (> 40).
- Management similar to general population.
- No strong evidence that Alzheimer's drugs benefit.



# Atypical Presentation of Alzheimer's in people with Down's Syndrome

- Depression and thyroid disease common in DS and can mimic dementia.
- Normal age-associated deficits are common.
- Often present with behavioral symptoms instead of memory loss.
- Seizures, myoclonus (sudden, involuntary muscle contractions or relaxation)

### **Questions to Consider**

- How can we better understand the changes that are taking place in the brain?
- How will this understanding help me to be a better caregiver and communicator?
- Will this knowledge help to reduce challenging behaviors?

### Changes in Communication: A Hallmark of Dementia

- Difficulty expressing thoughts and emotions
- Difficulty finding the right words
- Difficulty understanding what is being said



## Changes in Communication continued

- Using familiar words repeatedly
- Describing familiar objects rather than calling them by name
- Easily losing a train of thought



## Changes in Communication continued

- Difficulty organizing words logically
- Reverting to speaking a native language
- Speaking less often (isolation)
- Relying on gestures more than speaking



## **Reframing our Thinking**

Are they Challenging Behaviors?



Or are they Behavior as Communication?

# There is a reason behind the behavior

- Is the person uncomfortable and unable to communicate it?
- Are they feeling irritable because they don't want to do what we are asking them to do?
- Are they confused or anxious later in the day as the sun is casting longer shadows?
- Is the person bored?

## Whose Problem is it?

Behaviors can range from the merely frustrating to those that have the potential for serious harm.

- Is this behavior just a problem for me?
  - For example, mismatched clothes
  - If yes, let it go
- Does this behavior have the potential for harm to either the individual or to another?

## **General Tips**

- Do not try to reason or argue
- Stay calm
- Make sure you have their attention
- Short sentences with yes/no answers



## **General Tips continued**



- Loud voice can be interpreted as angry
- Allow time
- Respond to emotion
- Distract and redirect
- Step away and try again in a few minutes

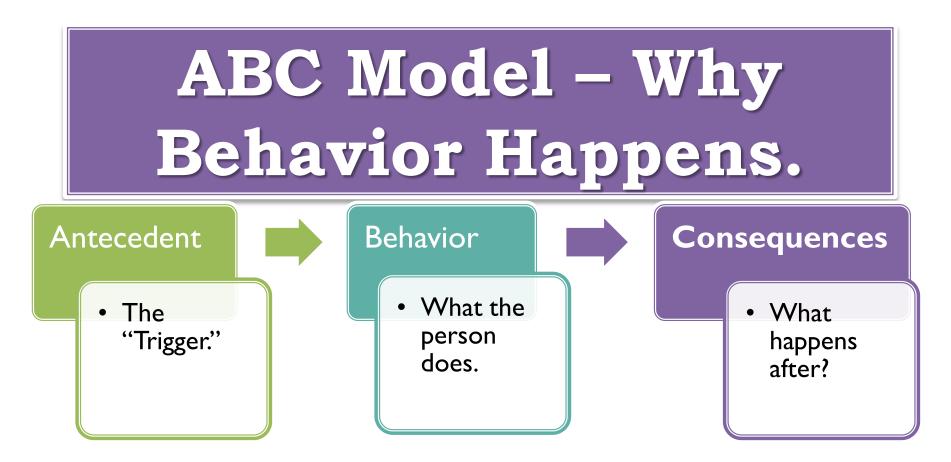
## **Take a Step Back**

Answer some questions to more fully understand what is happening:

- What exactly are they doing?
- What time of day does it happen?
- Who is present?

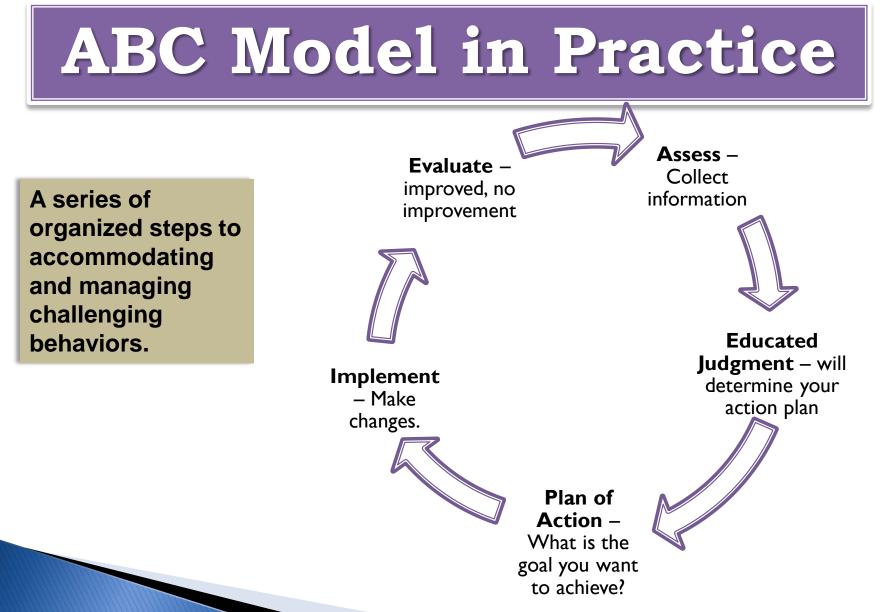
## Take a Step Back continued

- Does it only happen with certain staff, family?
- What happened immediately before? After?
- What has been tried in the past?
- What do you know about this person's life history?



If we know that the person becomes agitated at social events we might be tempted to discontinue taking them.

Is there a way that person could continue to enjoy social activities but in a way to not cause them distress and disrupt the event?



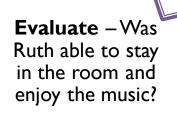
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## **Case Study**

Mary's sister Ruth is 63 and has been diagnosed with young-onset Alzheimer's. Mary knows how much Ruth loves music and makes arrangements to take Ruth to hear a resident guitarist at a local café.

Not long after arriving at the small café, Ruth begins to act irritated and another 15 minutes later becomes agitated and wants to leave. Use the ABC model to help decide the course of action Mary should take.

## Example



Implement -

Musician plays

guitar

unplugged

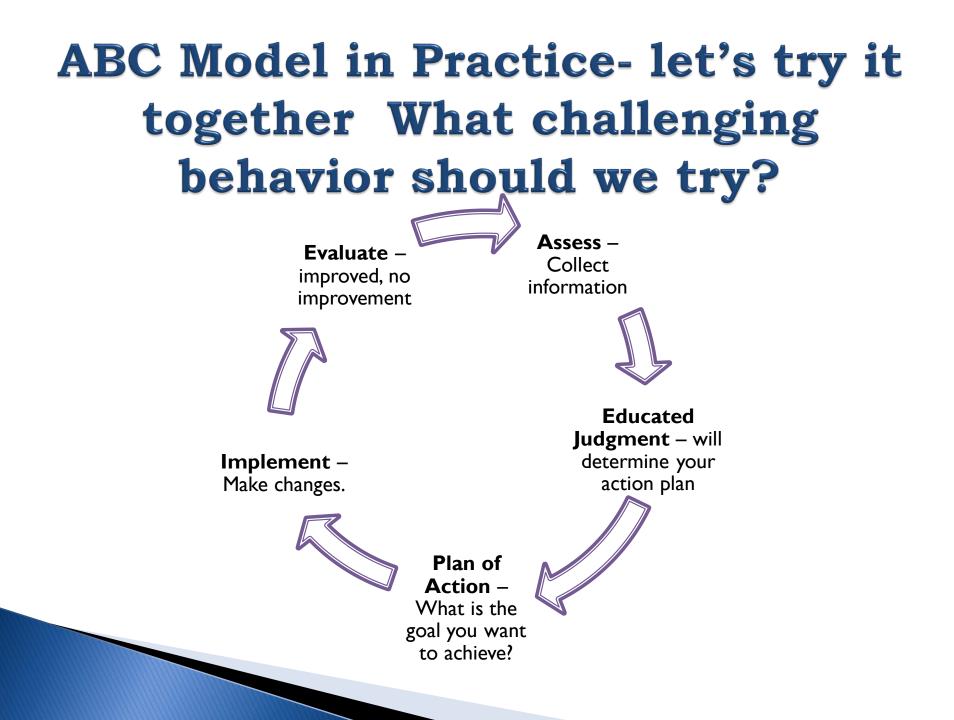
Assess – Ruth is agitated by the musician and wants to leave the room

#### **Educated Judgment**

We know she loves music. Is it the volume? The guitar? Too many people? His hair?

#### Plan of Action

 We want Ruth to enjoy the music, so will ask the musician to unplug the amp



## More Tools for your Toolbelt



## Validation Approach

- Focuses on empathy and understanding.
- Based on the general principle of validation...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.

## Validation Approach

- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
  - "I want my mother"
  - "I need to get to work"
- Emotions have more validity then the logic that leads to them.

## **Case Study**

John is an 87 year old man with dementia. He often insists that someone has stolen one of his possessions. Today he is quite agitated. When his son Mark asked what was wrong, he told him that the neighbor has stolen his book.

What might Mark say to his father?



- John (agitated):
  Someone stole my book.
- You: "I'd be upset too, if that happened to me. I'll help you look for it."



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Best practice in dementia care:

Do not correct or try to "reorient" the person. This plan requires the care partner to shift her care philosophy.

## Which is Better?

#### Example:

"What time is my mother coming?" (You know Ken's mother died 20 years ago.)

#### Which response is better:

- a. "Your mother is dead, Ken. Your sister will pick you up at 4:00."
- b. "She'll be here in a little while. Let's get a dish of ice cream while we wait."

## REDIRECTION

## **Distract AND Divert**

- 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.

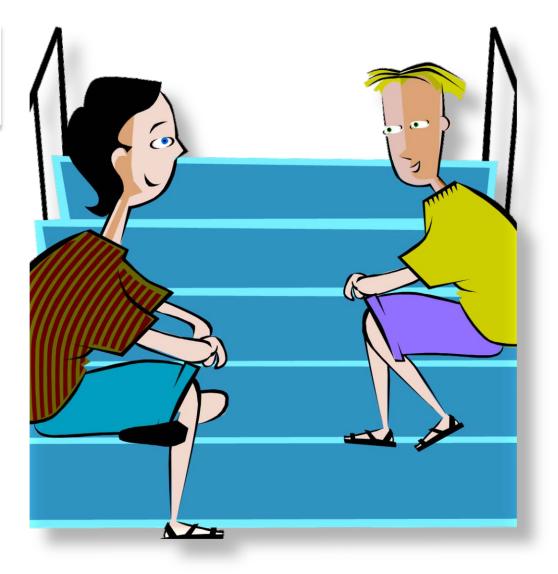
## **Case Study**

Joe wakes up in the morning and begins to rifle through the closet. He is clearly agitated and goes from closet to bathroom and then back. Mary, his care partner, asks what he is looking for. Joe looks exasperated and says, "I've got to get ready, I've got to catch the bus or I will be late for work."

What can Mary do?

## Example

- JOE [agitated]: I need to get to work. I'm going to miss my bus!
- MARY: Okay, Joe, but I just made breakfast. How about you eat with me first ?



### **Helpful Hints for Redirecting**

- Body Language: People with dementia are very adept at picking up on your body language.
   Smile, try to relax, and be warm and open when redirecting someone with ADRD.
- Ask questions. A good all-purpose phrase is: "tell me about it."

Example:

Betty: "I want to go home!"

You: "Tell me about your home. Is it a big house?" Then gently redirect the conversation away from what is bothering Betty..."I'm hungry. Betty, would you help me get a snack?"



## **Specific Behavioral Challenges**

Some of the most common behaviors that may impact a person's health, safety or ability of a caregiver to provide adequate and compassionate care are:

- Resistance to Bathing
- Wandering
- Rummaging and Hiding Things
- Agitation and Aggression
- Hallucinations, Delusions and Paranoia
- Sundowning

## **RESISTANCE TO BATHING**

The person with dementia may refuse to bathe or resist help bathing.

### Possible Causes

- Fear of the bathroom, tub or shower
- Anger about needing help
- Reluctance to get undressed in front of someone else
- Lack of awareness about the need for personal hygiene

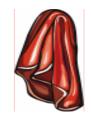


## **Tips for Resistance to Bathing**

- Plan ahead of time: Have all items such as soap, washcloth, towels, etc. in easy reach
- Be gentle and respectful but matter of fact: "It's time for your bath". Don't argue about the need for a bath.
- Play soft music and make sure the bathroom is warm.
- Consider using a bath chair and/or hand held shower as this may be safer and feel more secure.

## Tips for Resistance to Bathing continued

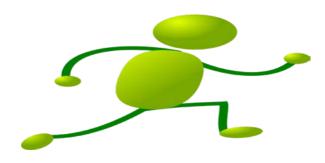
- Put a towel over the person's shoulders or lap to help them feel less exposed.
- If a full bath or shower is not possible, try starting with a foot and hand soak. Try gradually working your way toward the middle of the body.
- A sponge bath may be more readily accepted.



### WANDERING

Reasons a person with ADRD may wander out of the house or away from their caregiver:

- May be trying to go to a place that feels more familiar, "go home", "go to work", take the children to the bus stop", etc.
- Restlessness (See Agitation)
- Shadows, time of day (See Sundowning)



## **Tips for Managing Wandering**

- Make sure the person carries ID or wears a medical alert bracelet. One option is Alzheimer's Association Safe Return Program: <u>www.alz.org</u> or 1 888 572-8566
- Keep doors locked; consider a keyed deadbolt, placing an extra lock at the top or bottom of the door, a silent alarm
- Keep shoes, keys, suitcases, coats, etc. out of sight

Adapted from the ADEAR Center, National Institute on Aging

> www.nia.nih.gov/alzhei mers/topics/caregiving

## Tips for Managing Wandering continued

- Place a STOP sign or DO NOT ENTER sign on the door
- Camouflage the door with a large poster.
- If the person does get out, try to calmly follow them and walk with them until you can distract them or turn them around toward home.

### **RUMMAGING, HIDING THINGS**

Reasons a person with ADRD may rummage through

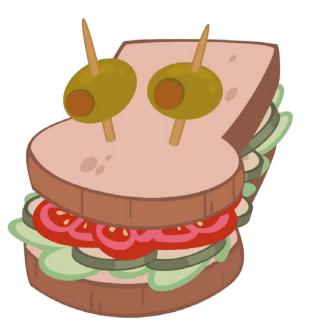
drawers, closets, cabinets or the refrigerator:

- They may be looking for something but not know what it is
- They may hide things but not remember where they put them



### Rummaging, Hiding Things continued

- Hunger
- Boredom
- Restlessness (See Agitation)
- Time of Day (See Sundowning)



## Tips for Managing Rummaging and Hiding

- Move dangerous products from reach, including spoiled food from the refrigerator.
- Move valuable or important items such as jewelry, keys, important papers out of sight and reach
- Consider creating a special drawer or container for the person to rummage.
- Close doors to rooms that are not in use.
- Check trash containers before emptying in case something valuable has been thrown away.

Adapted from the ADEAR Center, National Institute on Aging www.nia.nih.gov/alzheimers/topics/caregiving

## Possible Causes of Agitation and Aggression

- Agitation occurs when someone is restless or worried or can't settle down. It may result in pacing or sleeplessness.
- Aggression is another symptom of agitation. Aggression is when a person lashes out verbally or physically.
  - Pain (consider tooth pain?)
  - Lack of sleep
  - Constipation
  - Soiled underwear or incontinence pad
  - Changes in routine
  - Noisy or confusing environment
  - Being pushed to do something, such as bathe



# Tips for Managing Agitation and Aggression

- Try to find the cause of the agitation or aggression so the cause can be addressed, if possible.
- Use calm, reassuring, tone
- Try to maintain a routine
- Try to keep the environment quiet, calm, and uncluttered
- Try gentle touch, soft music, reading or walks
- Distract if possible
- Discuss the problem with the physician; medication may be considered.

### Understanding Hallucinations, Delusions and Paranoia

- A hallucination is when the person sees, hears, smells, tastes or feels something that isn't there.
- A delusion is a false belief that the person thinks is real.
- Paranoia is a type of delusion in which the person may become suspicious or fearful and feels others are stealing, lying or targeting them.
- Violent or Upsetting television can create problems
- Shadows, Glare or other visual perception difficulties
- Medications may sometimes cause hallucinations or delusions



### Tips for Managing Hallucinations, Delusions and Paranoia

- Try not to argue or over-react.
- Comfort the person if they are afraid
- Try distraction: moving to another room or going for a walk.
- Turn off the TV if it seems to be upsetting.
- Use gentle touching.
- Discuss the behavior with the physician; medication may be considered.

## Sundowning Definition and Causes

- Sundowning is restlessness, agitation, irritability or confusion that worsens as daylight begins to fade and may continue into the night.
- Confused sleep/wake cycles
- Overly tired
- Hunger or thirst
- Depression
- Pain
- Boredom



# Tips for Managing Sundowning

- Try to be calm and reassuring
- Try distraction with a favorite snack or simple activity.
- Reduce noise and confusion.
- Play soothing music.
- Try gentle touch.



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# Tips for Managing Sundowning continued

- Turn on the lights and close the curtains to minimize shadows.
- Avoid caffeinated drinks late in the day.
- Try to strike a balance between getting physical activity each day without overtiring.
- Discuss the behavior with the physician; medications may be considered to help the person relax.

# Sexuality

Why are we discussing this?

- KEY POINTS
- Physical touch is a human need and it remains even after a person develops ADRD.
- There is no single 'normal' way of dealing with this very personal issue.
- For couples: It is important for the spouse to find someone with whom they can talk about these issues if needed
- Both partners must be able to express consent in some way it doesn't need to be verbal but if one person is clearly upset by the interaction, that may be their way of saying "NO"
- Behavior that appears sexual may actually be a way of expressing something else.

## Adapting to Changes in the Person with Dementia

- Brain is the 'control center' for behavior and emotion, thus affecting sexual expression
- The following changes depend on the part of the brain affected by the dementia:
  - more interest in sex, less interest, or no interest
  - more or less ability to perform sexually
  - changes in sexual 'manners' for example, appearing less sensitive to the other person's needs or appearing sexually aggressive
  - changes in levels of inhibitions (the person may do or say things that they would not have done previously).

# Capacity to consent (agree) to sexual relations

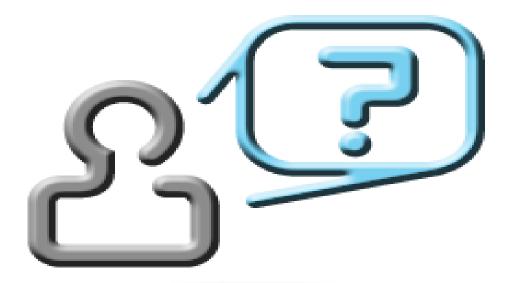
- Both parties must always consent to sexual relations
- Capacity requires the person to be able to:
  - Understand his or her situation
  - Understand the risks
  - Communicate that decision based on that understanding
- Capacity may differ depending on the issue to be decided
- Capacity can be expressed in different ways; it doesn't have to be verbal.



- Dementia is a general term for a decline in mental ability severe enough to interfere with daily life.
- Alzheimer's Disease is the most common type of dementia. It is progressive and irreversible.
- Memory, communication, executive functioning and behaviors may be affected.
- A skilled medical evaluation is very important!
- Behaviors are a form of communication.
- Be flexible.....There are many ways to approach challenging behaviors. Every person and situation is different!
- Some approaches to challenging behaviors include:
  - determining and addressing the trigger of the behavior
  - validating the person's feelings rather than trying to correct
  - distracting and diverting

- Sexuality both partners must be able to consent.; behaviors that appear to be sexual in nature may not be.
- Seek help and support. The D.C. Office on Aging, Department on Disability Services and the Alzheimer's Association are good places to start!





# **D.C. Office on Aging**

#### **DCOA's Mission**

The mission of the District of Columbia Office on Aging (DCOA) is to advocate, plan, implement, and monitor programs in health, education, employment, and social services which promote longevity, independence, dignity, and choice for older District residents (age 60 plus), persons living with disabilities (age 18 to 59), and their caregivers.

#### **DCOA's Aging and Disability Resource Center**

The Aging and Disability Resource Center provides a single, coordinated system of information and access for individuals seeking long-term care services and supports. This is accomplished through the provision of unbiased, reliable information, counseling, and service access to older adults, individuals with disabilities, and caregivers. The Aging and Disability Resource Center works closely with a network of community-based non-profit organizations and private sector businesses in each Ward of the city to ensure that appropriate, consistent and quality referrals are made to residents in their own neighborhoods.

To speak with a professional that will assist you in identifying and connecting to services that meet your specific needs, contact DCOA: 202-724-5626 or email: IRA.ADRC@dc.gov

#### ADRC SUMMARY OF SERVICES

The following is a list of core services provided by DCOA's Aging and Disability Resource Center staff, or referred to DCOA-Funded providers within the Senior Service Network. Several of the listed services have eligibility requirements and are provided at varying costs based on income:

Adult Day Health Case Management Caregiver Support **Commodity Supplemental Congregate Meals** Deaf and Hard of Hearing Services **Employment Assistance** Food Program; Senior Farmers' Market Home Delivered Meals In-Home Support Hospital Discharge Planning Medicaid Waiver Enrollment Assistance

Memory Care (Alzheimer's & Dementia) Nutrition Counseling & Education Nutrition Programs: Options Counseling (Community Supports & Long Term Planning) Public Benefits Assistance Senior Wellness Centers Transportation Veterans Resources

### The Alzheimer's Association National Capital Area Chapter 24/7 Helpline: 1.800.272.3900

The Alzheimer's Association works on a global, national and local level to enhance care and support for all those affected by Alzheimer's and other dementias.

- The professionally staffed <u>24/7 Helpline</u> (1.800.272.3900) offers information and advice to more than 250,000 callers each year and provides translation services in more than 200 languages.
- More than 4,500 <u>support groups</u> are offered throughout the country and connect people across the globe through <u>online message boards</u>.

### www.alz.org

### **The Alzheimer's Association**

- Alzheimer's and Dementia Caregiver Center, provides comprehensive online resources and information
- <u>Alzheimer's Association TrialMatch</u> helps people find clinical studies
- Educational programs offered in 15 languages

- <u>Alzheimer's Navigator</u>, a free on line toolprovides individuals with Alzheimer's and their caregivers with step-bystep guidance and customized action plans
- <u>Community Resource Finder</u> provides instant access to community resources and services.
- > <u>Alzheimer's Association Green-Field Library</u>, the nation's largest ADRD library and resource center
- Comfort Zone<sup>®</sup> and MedicAlert<sup>®</sup> and Alzheimer's Association Safe Return<sup>®</sup>, provide location management for people with Alzheimer's who wander.
- Walk to End Alzheimer's, an annual event to raise awareness and funds.

### DDS

### **Department on Disability Services**

#### 1125 15<sup>th</sup> St NW Washington, DC 20005

The DC Developmental Disabilities Administration provides an array of community-based services and supports. If your family member has an intellectual disability, they are eligible for services.

### dds@dc.gov

- **Contact Phone:** (202) 730-1700
- **Contact TTY:** (202) 730-1516



### **Thank you for attending!**

This program was made possible through a grant from the U.S. Department of Health and Human Services Administration on Community Living and the D.C. Office on Aging





### Thank you to our Partner Agencies!

