Nursing Best Practices in the Community: Recognizing Dementia in People with Intellectual and Developmental Disabilities and Planning Appropriate Health Services

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Marisa C. Brown MSN, RN

Objectives: Upon completion of this course, the nurse will:

1. Use a dementia screen for adults with intellectual disabilities.
2. Recognize the differential diagnosis process as applied to the dementia diagnosis.
3. Describe elements of environmental changes that support people with the diagnosis of dementia.

4 Most Important Facts About Dementia

1. “A loss of cognitive (thought) function severe enough to interfere with daily functioning.”
2. The term “dementia” describes a group of symptoms.
   a. It is not a specific disease!
   b. “The doctor said my son has dementia…thank goodness he doesn’t have Alzheimer’s!”
3. The condition we refer to as dementia may be caused by many things.
   a. Some may be treatable (Ex. Dehydration, B12 deficiency)
   b. Others are irreversible (Ex. Alzheimer’s, Vascular, Lewy body).
4. Dementia is NOT part of normal aging.

Risk of Dementia in ID

Most adults with ID are typically at no more risk than the general population.

Exception: Adults with Down syndrome are at increased risk:
   • Younger (40’s and 50’s)
   • More rapid progression.

Dementia Prevalence: ID vs. DS

<table>
<thead>
<tr>
<th>Age</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intellectual Disability</td>
</tr>
<tr>
<td>40+</td>
<td>3%</td>
</tr>
<tr>
<td>60+</td>
<td>4%</td>
</tr>
<tr>
<td>80+</td>
<td>12%</td>
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</tbody>
</table>

Prevalence of Dementia and Impact on Intellectual Disability Services


Increased lifespan = Increase in dementia.

What this means for programs:
• Need to raise the “index of suspicion” among staff and families,
• Programs and services need to become “dementia capable,”
• Need to improve:
  • Diagnostic and technical resources,
  • Care management supports (to prolong the “aging in place” of adults affected by dementia).

Warning Signs
These problems must be serious and usually occur in a cluster

Dementia is a group of behavioral and cognitive changes commonly caused by different conditions or diseases.

Warning Signs
These problems must be notable and usually occur in a cluster

Dementia is a group of behavioral and function change symptoms caused by different conditions or diseases.

Community Care Needs of Adults with ID and Dementia

• Dementia is a condition that impairs an individual’s ability to self-direct and be left alone.
• Thus…independent living will not be an option as the disease progresses.
• What will be needed?
  • In home supports (to family caregivers and the person)
  • Advanced planning for alternative care
  • Diagnostic, medical and behavioral health care
  • Support groups for caregivers (family or staff)
  • Dementia capable community housing
  • Day care programs and respite for family caregivers

Conditions Common to Aging That Can Mimic Dementia

Dehydration, Malnutrition
Metabolic Disorders
Vitamin & Mineral Deficiencies
Sensory Impairments

Aging & DD Services...Build a Bridge

• Community support provider agencies
  • Private/parent based [e.g., Arc chapters]
  • Public – state/local government entities
• Area Agencies on Aging (AAAs)
• Aging and Disability Resource Centers (ADRCs)
• Alzheimer’s Association chapters
• Other local dementia care groups
• State and local Protection and Advocacy Networks
• Faith-based organizations
• Statewide or Community-based Respite/Caregiver Coalitions

Normal Age-Related Memory Changes vs. Dementia

<table>
<thead>
<tr>
<th>Normal Age-Related Memory Changes</th>
<th>Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Confusion about minor details</td>
<td>Confusion about major events</td>
</tr>
<tr>
<td>Keeps things in order</td>
<td>Can’t follow an organized plan</td>
</tr>
<tr>
<td>Requires planning</td>
<td>Plans spontaneously</td>
</tr>
<tr>
<td>Requires help to prepare meals</td>
<td>Prepares meals without help</td>
</tr>
<tr>
<td>Falls frequently</td>
<td>Falls rarely</td>
</tr>
<tr>
<td>Seeks help in familiar places</td>
<td>Doesn’t ask for help</td>
</tr>
<tr>
<td>Takes excessive time to return home</td>
<td>Returns home immediately</td>
</tr>
<tr>
<td>Slower decision making in unfamiliar places</td>
<td>Faster decision making in unfamiliar places</td>
</tr>
<tr>
<td>Less frequent social skills</td>
<td>More frequent social skills</td>
</tr>
<tr>
<td>Less frequent social activities</td>
<td>More frequent social activities</td>
</tr>
</tbody>
</table>

Adapted from: The American Medical Association

Typical Aging
Symptoms of Dementia

2/28/2018
**Differential Diagnosis**

**Definition:** The distinguishing of a disease or condition from others presenting with similar signs and symptoms.

**Two Stage Process:**
- Establish dementia is present.
- Determine the cause.

*Not all dementia is irreversible!*

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**Clinical Features of Various Dementias**

<table>
<thead>
<tr>
<th>Dementia Type</th>
<th>Memory</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s</td>
<td>Visual spatial and memory impairment</td>
</tr>
<tr>
<td>Lewy Body</td>
<td>Depression</td>
</tr>
<tr>
<td>Vascular</td>
<td>Vision impairment</td>
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</table>

Although the brain neuropathy will differ, caregivers need to note the nature of the behaviors exhibited.

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**Why is it Important or Useful to Know Type of Dementia?**

Different types of dementia have different characteristics. It’s far more helpful to know that particular behaviors are part of the disease process and not bad behavior

- Lewy body – visual hallucinations
- Fronto-temporal – profound personality change, disinhibition

The type of dementia may impact what medications are used.

- Lewy body – sensitivity to certain antipsychotics.
- Fronto-temporal – does not respond to common Alzheimer’s medications such as Aricept.

Ensure that treatable causes of the symptoms have been ruled out.

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**Common Conditions to Rule Out through Differential Diagnosis.**

- Stroke
- Side effects of medications
- Nutritional deficits and imbalances
- Alcohol and drug abuse
- Hypothyroidism
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus
- Sleep apnea

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**Progression of Alzheimer’s Through the Brain**

Source: Alzheimer’s Association

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**Dementia Affects All Aspects of Functional Ability**

- Memory
- Language skills
- Ability to focus and pay attention
- Reasoning & judgment
- Sensory perception
- Ability to sequence tasks

Source: Alzheimer’s Association
### Stage Related Changes in Alzheimer’s

<table>
<thead>
<tr>
<th>Stage</th>
<th>Early Stage</th>
<th>Middle Stage</th>
<th>Late Stage</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Confusion and memory loss</td>
<td>Difficulties with ADLs</td>
<td>Loss of speech</td>
</tr>
<tr>
<td></td>
<td>Disorientation in space</td>
<td>Apathetic, paranoid, agitation and other compromising behaviors</td>
<td>Loss of appetite, weight loss</td>
</tr>
<tr>
<td></td>
<td>Problems with routine tasks</td>
<td>Sleep difficulties</td>
<td>Loss of bladder and bowel control</td>
</tr>
<tr>
<td></td>
<td>Changes in personality and judgment</td>
<td>Difficulty recognizing familiar people</td>
<td>Loss of mobility</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Total dependence on others</td>
<td>Death</td>
</tr>
</tbody>
</table>

### Health Care Advocacy

**Health care advocate** - a person who is not a health care professional, but can assist a patient in obtaining high-quality health care. An advocate may be a counselor at a service organization, a relative, or a friend of the patient.

[www.communityhealthadvocates.org/advocates-guide/appendix/glossary](www.communityhealthadvocates.org/advocates-guide/appendix/glossary)

### Dementia and Health Advocacy

- Dementia-related health advocacy is:
  - Speaking for the adult affected by dementia
  - Looking after their interests during health interviews and visits
  - Ensuring that concurrent conditions are diagnosed and treated
  - Tracking the rate and course of dementia and helping the health practitioner better understand the changes occurring
  - Coordinating care when various providers are involved
  - Arranging for appropriate care and supports

### You May be in a Position to be a Health Advocate If:

- You are given the responsibility to look after the welfare of the adults that are in your program, residence, or organizational activity
- You are a care manager
- You work along with health personnel
- You are a relative or family member
- You are a friend or mate
- You are involved in way that the health of adults you work with can be your concern
- You are engaged in some other capacity that gives you access to health practitioners

### Importance of Health Care Advocacy

1. Staff and family are the experts about individuals with ID.
2. A safe and healthy environment for the individual is critical.
3. Health care is an art, not a science!
Why is Dementia Health Care Advocacy Needed?

- Unable to “self-advocate.”
- ‘Ageism’ (prejudice or discrimination on the basis of a person’s age) by health care providers.
- Providers may assume that there will be automatic losses and declines in functioning as part of aging.
- “Diagnostic overshadowing.”
- Providers may assume that the diagnosis is dementia, when another issue may be the cause of behavioral changes.

### Four Steps of Health Advocacy

#### #1. Observe

- Functional and behavioral changes observed on a form of communication.
- Use a screening tool for observation (NTG-EDSD).

#### Look for changes in the person such as:

- Behavioral
- Personality
- Activity level
- Unintended weight loss or gain (10%)
- Changes in sleeping patterns
- Diet changes/medication

#### #2. Report

- Document observations
- Be accurate and specific
- Report to the right person
- Use correct forms and processes

**Important components of reporting:**

- Time of the day, who is present, where did it happen?
- How often do you observe this symptom?
- What was happening before? After?
- Making sure there is a system/process for reporting to the right person!

#### #3. Prepare for the health care appointment

- Hold a team meeting (residential/family/program/individual advocates) to bring together symptoms observed.
- Prioritize symptoms and concerns to be addressed.
- Prepare a checklist or form for the attending caregiver to bring to the appointment.
- Make sure the person who goes to the appointment with the individual is:
  - Included in the team meeting
  - Able to communicate symptoms
  - Has some health care advocacy skills

#### #4. Follow-up after the appointment

A bit more on diagnosis. Proper diagnosis is important to...

- Rule out treatable conditions.
- Receive appropriate treatment and support services.
- Maintain the highest possible quality of life and functioning.
Remember: Rule out possible treatable conditions first.

- Stroke
- Side effects of medications
- Nutritional deficits and imbalances
- Hypothyroidism
- Alcohol and drug abuse
- Dehydration, malnutrition
- Cardiovascular disease
- Environmental challenges
- Sensory impairments
- Depression
- Lyme disease
- Normal pressure hydrocephalus

Factors That Increase the Risk of Side Effects from Medications

- Advancing age
- Decreased kidney and liver function.
- Increased potential for side effects.
- Dosage guidelines developed for younger persons.
- Lifetime use of medications, especially psychotropic.
- Polypharmacy.
- Decreased fluid intake (due to incontinence).

4 Steps of Health Care Advocacy

#4. Follow-up after the appointment

- Follow-up recommendations with all caregivers
- Make sure recommendations are understood.
- Are there any follow-up questions?
- Continue observing and reporting.
- Don’t give up!
- You may have to search out a new provider
- Be as prepared for the follow-up as for the first appointment

Final Tips for Health Care Advocacy

- Be aware of myths and stereotypes about aging in persons with ID.
- Know the possible side effects and interactions for medications used by the individual.
- Physician’s Desk Reference: www.pdr.net/browse-by-drug-name
- Never assume the changes you see are the result of aging or the disease of Alzheimer’s dementia!

What to Do When Dementia is Suspected?

- Benefits of a screening instrument - can help to identify early signs of dementia.
- If screening instrument results are positive, refer for assessment.
  - Refer to Agency MD, local MD, psychologist, nurse, other person who may do formal assessment to validate suspicions
- If assessment confirms screening results, refer for diagnostic work-up.
  - Ideally: neurologist, geriatrician, geriatric psychologist

A Screening Tool is not a Diagnostic Instrument.

- Screen - an instrument that permits the recording of select data that is associated with a condition or disease.
  - EDSS
- Diagnostic instrument - is one that is based on valid measures that are associated with agreement on the presence of a condition.
  - For example, a MRI will show an image of the brain that may show shrinkage and validate suspicions of the presence of Alzheimer’s disease
What Does a Diagnosis Mean?

- The person has a name for the problems being experienced.
- Has it changed the person?
  - No. It does, however, give caregivers some comfort in knowing ‘why and what’
  - Why are the changes occurring?
  - What can we expect for the future?
- Allows for important service planning to take places.
- Provides access to helpful resources and organizations.

Caring for a person with dementia means we must understand that...

- S/he does not see the world the same way we do.
- What we see as normal can be very confusing and threatening.
- We must enter their reality as they cannot conform to ours.
- Need us to be patient, supportive and understanding.
- WE HAVE TO CHANGE BECAUSE THEY CANNOT.

Key Concepts in Dementia Care

- Maintenance Support
  - Generally accepted as the best practice in dementia care.
  - Proactive approach
  - A few minutes of pro-action can eliminate hours of reaction.
  - Focus is on support of remaining abilities.
  - Respect changing needs of the person.
  - Provide meaningful, failure-free activity.
  - Allow the person to do as much as they can for themselves but... be aware that as the disease progresses the need for assistance will increase.
  - Can reduce or eliminate difficult behaviors at all stages by reducing frustration, boredom, anxiety, fear, etc.
  - Can be done in all settings by all staff.

Key Concept in Dementia Care #1

Maintenance Support

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Orientation Tips

- Whose reality is it?
  - A person with dementia can no longer make sense of the present and lost memories of years past will become their new reality and they even may re-live past events.
  - To avoid frustration and increasing agitation you must enter their reality. Don’t argue. This is not lying, it is respecting their reality.
  - Wouldn’t you be upset if someone told you your parent was dead if you were sure they were alive?

Key Concept in Dementia Care #5

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.
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 AD.
- **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?”

Be flexible...

What works today may not tomorrow.

- Solutions that are effective today may need to be modified tomorrow—or may no longer work at all.
- The key to managing difficult behaviors is being creative and flexible in your strategies to address a given issue.

Key Concept in Dementia Care #2: Life Stories

Everyone has a life story that needs to be honored and respected.

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

Communication Strategies

4 Communication Strategies

- **Technique:** Change your:
  - approach to the person
  - reaction to the behavior
  - the environment

1. **Difficult behaviors cannot be changed with words.**

   Example: Donna tells you she is a movie star. Agree with her. It hurts no one to let them live in a reality that may be more reflective of their dreams than the life they actually lived.

   - You cannot reason with a person who has lost the intellectual ability to process thoughts in a logical and rational manner.
   - Arguing will encourage frustration, fear, and anger.
   - The goal is not to be correct!
   - Remember—the person is experiencing a decline in their reasoning skills at the same time they are experiencing an increase in their emotional reactions.
   - Feelings are more important than facts.

2. **Don't say “No” and NEVER ARGUE!**
**Communication Strategies Continued**

3. It’s their reality and you must enter it.

- **Technique:** Validation
  - Builds empathy and creates a sense of trust and security that reduces anxiety.
  - Enter their reality and reminisce with them.
  - Match their emotions.

  **Example:** Tom tells you that his mother was here today (but you know his mother died last year). You say, “That’s wonderful. You must love your mother very much.”

4. Reduce fear by acknowledging underlying emotions.

- As the disease progresses the person loses the ability to express and cope with their fears.
- A person with dementia cannot "self soothe" if their fears become overwhelming.
- Reassure the person and respond to their emotion.

**Common Behaviors**

- Wandering
- Repetitive questions
- Rummaging, hoarding
- Verbal outbursts – yelling, excessive vocalizations, cursing
- Physical – hitting, spitting, kicking
- Paranoia
- Hallucinations
- Sleep-wake disorders
- Sundowning
- Resistance to personal care
- Inappropriate sexual expression

**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?
- Ignore it
- Ex. Mismatched clothes

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.
- 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**

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

A series of organized steps to accommodating and managing challenging behaviors.

1. **Assess**
   - Educated Judgment
   - Will determine your action plan
2. **Plan of Action**
   - What is the goal you want to achieve?
3. **Implement**
   - Make changes.
4. **Evaluate**
   - Improved, no improvement

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**Wandering**

Serious safety issue!

70% of people with dementia will wander.

**Possible Cause(s):**
- May be related to searching for something, escaping from something, reliving the past, confusion in space and time.

**Strategy:**
- Orienting cues, reduce falls hazards, provide a safe place to wander, camouflage doors, “Dutch” doors, GPS tracking device, plan distractions.
- Make sure the person carries personal identification.
- Understand your state’s regulations regarding locked doors, etc.

**Repetitive Questions**

Causes:

- Can be stressful for caregiver but are rarely harmful.
  - Inability to retain information (short term memory).
  - May be trying to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

**Strategies:**
- Focus on the emotion behind the behavior.
- Stay calm.
- Provide an answer, even if you have to keep repeating.
- Distract.
- Try memory aids.

**Rummaging and Hoarding**

Causes:

- Unable to remember where they put something.
- Creates a sense of security and safety.
- Fear of losing an item.
- Boredom, under stimulation.

**Strategies:**
- Organize, but do not remove, the items.
- Make rummaging an activity. Create “rummage boxes” of safe items the person can sort through.
- Identify the places the person hides things (under cushions, inside shoes, coat pockets, wastebaskets).
- Redirect to another activity.
- Check wastebaskets before you empty them!

**Verbal Outbursts**

Screaming, yelling, cursing, etc.

Most common in later stage dementia.

**Cause(s):**
- Pain (studies suggest that 90% of verbal outbursts may be due to pain)
- Medication interaction
- Loneliness, boredom, need something.

**Strategies:**
- Physical evaluation.
- A new occurrence of verbally disruptive behavior in a patient with dementia may be the main presenting symptom for many acute conditions such as pneumonia, urinary tract infection, arthritis, pain, angina, constipation, or poorly controlled diabetes melitus. (McGinn, 2005.)
- Is it something in the environment? Caregiver interaction?
- Quiet music, lollipop

**Physical Aggression**

Causes:

- Prior personality?
- Pain, physical discomfort?
- Biological – disinhibition, loss of emotional control
- Misunderstanding caregiver actions (esp. personal care)
- Feeling threatened.

**Strategies:**
- Stay calm. Try not to show fear or anxiety.
- Do not shout or initiate physical contact.
- Reassure.
- Make eye contact.
- Distract.
- Try to identify a trigger.
Paranoia
(suspicion, jealousy, accusations)

Causes:
• Sensory deficits
• Memory loss
• Unfamiliar environment
• Misperception of environment

Strategies:
• Help them look for lost item, then distract to another activity.
• Respond to the feeling behind the behavior and reassure the person.
• Distraction
• Keep a log.
• Medication may be helpful in some instances.

Hallucinations

Causes:
• Vision, hearing impairments.
• Lewy body dementia.
• Change in medications.

Strategies:
• Ignore if harmless.
• Don’t argue.
• Check hearing aid batteries.

Sleep-Wake Disorders

Causes:
• Sundowning
• Pain
• Hunger
• Side effects of medications
• Disruption of circadian cycle due to brain damage.
• Dietary: caffeine, sugar

Strategies:
• Increase daytime activity, esp. physical exercise.
• Quiet, calm evening hours.
• Medication as last resort (can increase confusion the next day).
• Is bedroom comfortable? Not too hot or too cold.
• Treat potential pain.
• Maintain bedtime and waking routine.
• Light snack before bed.
• Avoid upsetting activities late in the day (e.g., bathing).

Sundowning
(late afternoon or evening)

Causes:
• Changes in circadian rhythm.
• Fatigue is a common trigger.

Strategies:
• Stick to a schedule and routine.
• Turn lights on before it gets dark.
• Close curtains.
• Minimize stress, quiet music.
• Large meal at lunch instead of dinner.
• Keep a journal.

Resistance to Personal Care

Causes:
• Short term memory loss.
• Embarrassment, fear.

Strategies:
• Stick to familiar routine.
• Respect modesty.
• Use dry shampoo for hair washing.
• Towel or bed bath as alternative.

Inappropriate Sexual Behavior

Causes:
• Caused by the disease – reduced inhibitions.
• Uncomfortable clothing – too hot, too tight.
• Pain – UTI, vaginitis, constipation.
• Mistake caregiver for partner.

Strategies:
• Comfortable clothing.
• Distract, redirect.
• Keep a journal to determine triggers.
• Evidence to support pharmacologic interventions is limited.
The behaviors you see in dementia are due to a brain disease. Trying to change or control behavior will meet with resistance.

- Accommodate the behavior, not control the behavior. For example, if the person insists on sleeping on the floor, place a mattress on the floor to make him more comfortable.
- We can change our behavior or the physical environment. Changing our own behavior will often result in a change in the person with dementia’s behavior.

WHO HAS TO CHANGE? WE DO!

Task

- Too complicated
- Too many steps
- Unfamiliar
- Not modified for increased impairment

Early Stage

Middle Stage

Late

Environmental Considerations

Dementia alters visual perception as well as intellectual functions.
People with the disease may be unable to shut out extraneous stimuli.
Both under- and over-stimulating environments can increase confusion and trigger problem behaviors.

Maximizing Location & Function

Environmental cues:
- Ex. Pictures on door
- Familiar textures for matching.
- Ex. On the seat for meals.
- Lighting.
- Contrasting colors.
- Reduce unnecessary stimuli.

Example of a Residence for Adults with ID

Lack of color contrasts, significant shadowing, and glare increase likelihood of difficulty functioning for the adult with ID and dementia.
Example of Program or Senior Activity Center

Key Concept in Dementia Care #3
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.
• Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
• Emotions have more validity than the logic that leads to them.

Key Concept in Dementia Care #4
To Reorient or Not Reorient

Resources

• National Task Group on Intellectual Disabilities and Dementia Practices
  • Information: My Thinker’s Not Working https://aadmd.org/ntg/thinker
  • Training Workshops: https://aadmd.org/ntg/schedule

We hope we have given you ideas so you can make a difference!

• Remember the basic essence of each person.
• Find laughter and joy each day, there are gifts within the disease and the essence of each person.

“To the world you may be one person; but to one person you may be the world.” — Dr. Seuss