# Intellectual Disability and Dementia: Identification and Symptom Management

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# Objectives

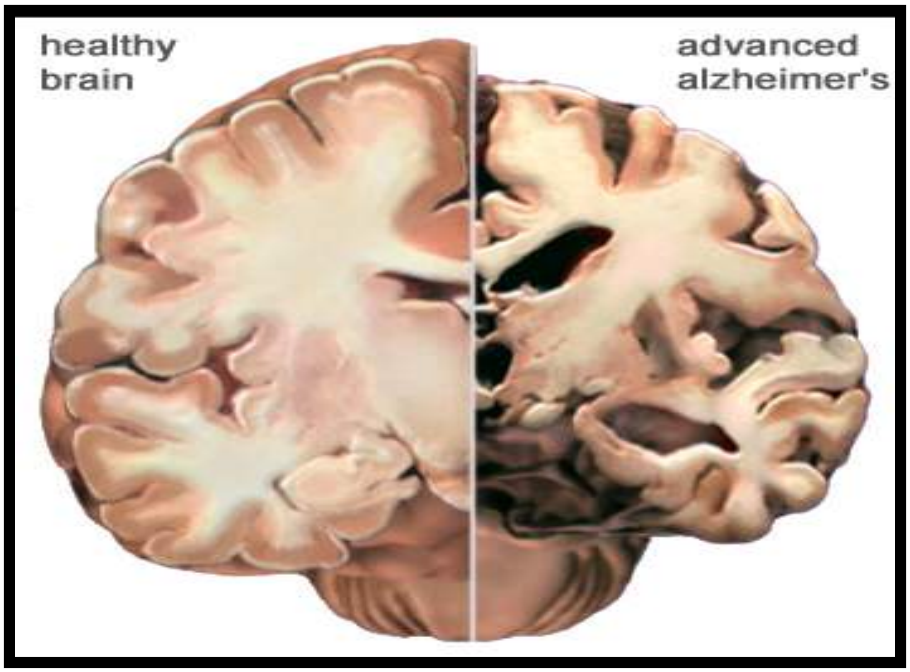
- Name and describe a screening tool designed for individuals with ID/D and dementia.
- Describe person-centered approaches to supporting individuals with intellectual disabilities who are affected by dementia.
- Name additional resources related to I/DD and dementia.

# DSM-5: Neurocognitive Disorders (NCD)

- "NCD" is a broader than the term "dementia"

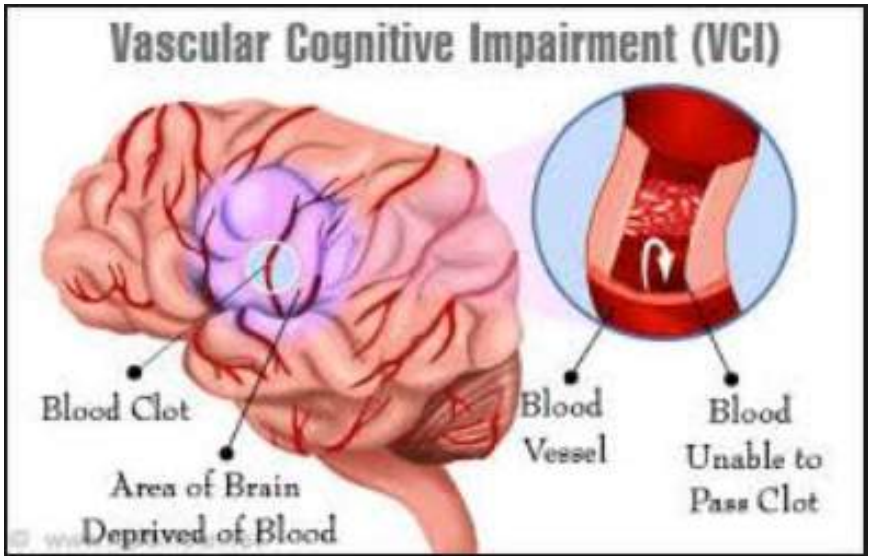
- Subtypes of Major & Minor NCD
  - NCD due to Alzheimers
  - Vascular NCD
  - NCD w/Lewy Bodies
  - NCD due to Parkinson's disease
  - Frontotemporal NCD
  - NCD due to traumatic brain injury
  - NCD due to HIV infection
  - Substance/medication-induced NCD
  - NCD due to Huntington's disease
  - NCD due to Prion disease
  - NCD due to another medical condition
  - NCD due to multiple etiologies
  - Unspecified NCD

# Alzheimer's Type



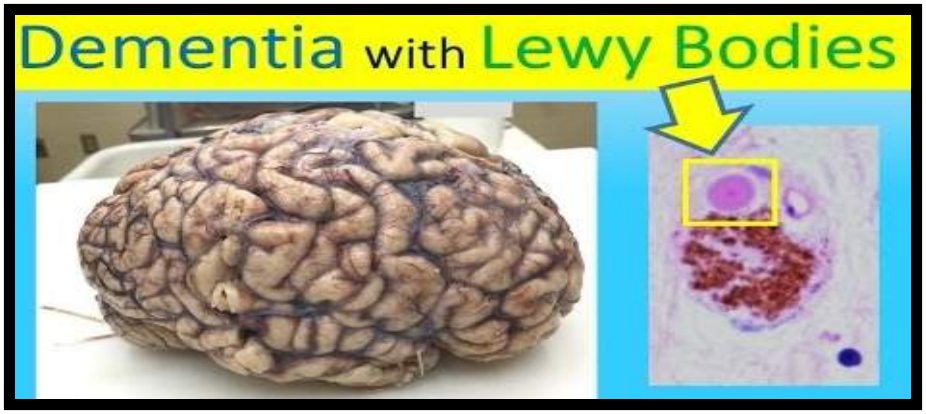

- Most common.
- Cause unknown, although genetics and lifestyle likely contribute.
- Gradual onset.
- "Probable diagnosis vs absolute."

## Vascular




- Sudden onset if caused by an acute, specific event such as a stroke or transient ischemic attack where the blood flow to the brain has been interrupted.

- Gradual onset if caused from very small blockages or slow downs of blood flow.




**Lewy Body**

- Intensity of symptoms may fluctuate from day-to-day.
- LBD is characterized by hallucinations and parkinsonian (movement) symptoms, e.g. shuffling gait, fixed posture, etc.
- 1/3 may have increased sensitivity to drugs
- Rapid eye movement sleep behavior disorder
- **Increased risk for falls**

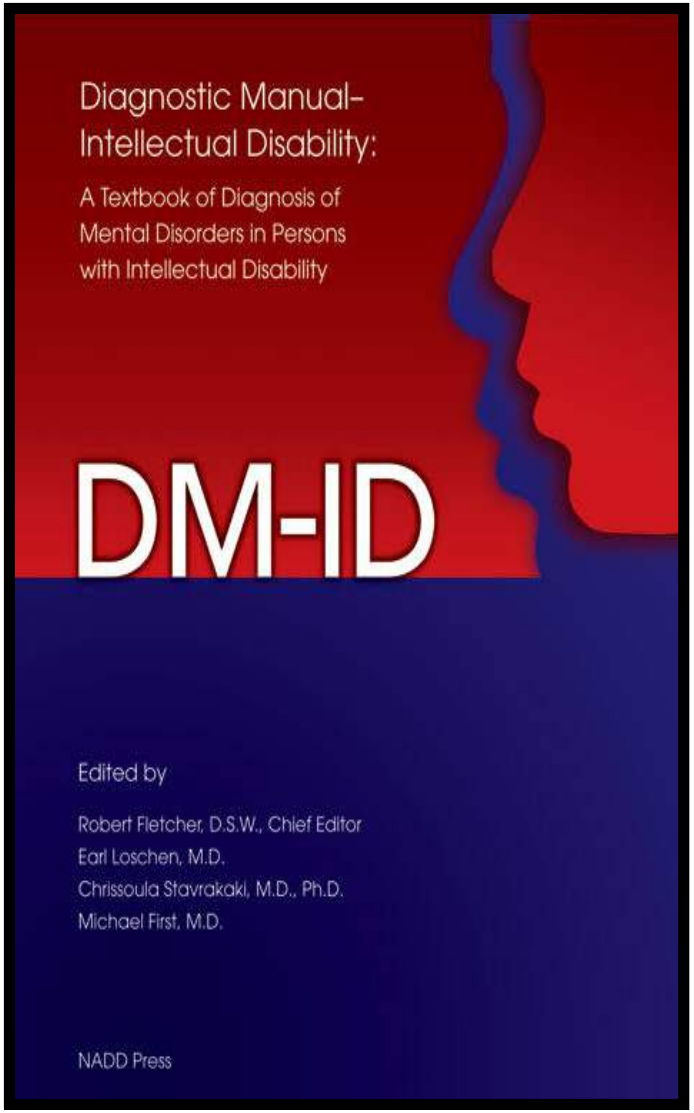
# Risk for Adults with ID

SAME RISK:

- general population

GREATER RISK:

- Down syndrome – over 40 yo
  - Starts 20 years sooner
  - 25% age 40; 65% age 60
- Head injury
  - particularly multiple injuries
- Family hx of Alzheimer disease



# Potential Early Signs

Onset will vary depending on type of dementia and individual person.

- Changes in activities of daily living and work habits are noticed first.
- Needing assistance for previously independent task
- Social withdrawal, lack of interest
- Sleep disturbances, gait changes, hallucinations
  - Lewy Body
- Getting lost inside or outside their residence

# Potential Early Signs:

Onset will vary depending on type of dementia and individual person.

- Forgetting names/words, planned events, location of objects, how to use common objects
- Increased frustration and lack of patience
- Changes in personality, e.g. more stubborn
- Epileptic Sz may occur (in early or late stages)
- Spatial awareness, e.g. curbs or steps
- Processing visual information-recognizing objects
- Lose of inhibitions

# Differential Diagnosis

## Delirium

- Develops over hours/days
- Fluctuates during day
- Temporary, often reversible

- Potential predisposing factors in ID population
  - Abrupt withdrawal of some long-term medication
  - Use of high dose psychotropic/anti-epileptic medications
  - Multiple medications
  - Age
  - Hospitalization
  - Constipation
  - Lack of sleep
  - Poor diet

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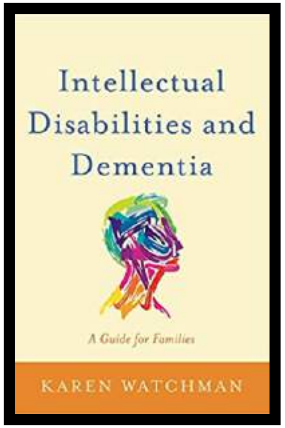


- Screening
  - Baseline
  - Ongoing
- Psychiatric Assessment
  - to rule out reversible causes of symptoms
    - E.g. Depression (may be first sign), etc.
- Medical Assessment
  - to rule out reversible causes of symptoms
    - E.g. Thyroid, etc.
- Diagnosis
  - Utilize ID relevant testing
    - E.g. nonverbal memory testing
- Symptom Management

# Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)

- Behavior rating scale
- Covers:  loss of memory, confusion, loss of skills, social withdrawal, behavioral changes, psychological symptoms, physical symptoms, sleep disturbance, and speech abnormalities.
- Incorporates carer's perspective

## PART 1: LEVEL OF 'BEST' ABILITY

**Please indicate the level of 'best' ability the person has, or has had, by ☑ the appropriate boxes.**

**SPEECH:**

- ❒ Could speak fluently and understandably
- ❒ Could make short sentences
- ❒ Could speak only a few words
- ❒ Could not speak much but used sign language
- ❒ Could not speak and did not use sign language

**DAILY LIVING SKILLS (e.g. Dressing, washing, eating etc.):**

- ❒ Could live independently with minor help
- ❒ Could live independently but needed a lot of help with self help skills
- ❒ Could not live independently and needed minor help with self help skills
- ❒ Could not live independently and needed a lot of help with self help skills

**Part 2:**
**43 questions about behavior or symptoms that are associated with dementia**

| | Always been the case | Always, but worse | New symptom | Does not apply |
|---|---|---|---|---|
| Does not know what to do with familiar objects | ☐ | ☐ | ☐ | ☐ |
| Appears insecure | ☐ | ☐ | ☐ | ☐ |
| Appears anxious or nervous | ☐ | ☐ | ☐ | ☐ |
| Appears depressed | ☐ | ☐ | ☐ | ☐ |
| Shows aggression (Verbal or physical) | ☐ | ☐ | ☐ | ☐ |
| Fits/ Epilepsy | ☐ | ☐ | ☐ | ☐ |
| Talks to self | ☐ | ☐ | ☐ | ☐ |

## PART 3

**Finally, please answer the following questions by ticking 'yes' or 'no'.**

| | Yes | No |
|---|---|---|
| Lost some skills (e.g. Brushing teeth) | ☐ | ☐ |
| Speaks (or signs) less | ☐ | ☐ |
| Seems generally more tired | ☐ | ☐ |
| Appears tearful, gets more easily upset | ☐ | ☐ |
| Appears generally slower | ☐ | ☐ |
| Slower speech | ☐ | ☐ |
| Appears more lazy | ☐ | ☐ |
| Walks slower | ☐ | ☐ |
| Generally appears more forgetful | ☐ | ☐ |
| Generally appears more confused | ☐ | ☐ |

# An adaption of the DSQIID:
# "some changes, including addition of health status segment

ntg
National Task Group on Intellectual Disabilities and Dementia Practices

# NTG-EDSD

v.1/2013.1

The **NTG-Early Detection Screen for Dementia**, adapted from the DSQIID*, can be used for the early detection screening of those adults who are suspected of or may be showing early signs of mild cognitive impairment or dementia. The NTG-EDSD is not an assessment or diagnostic instrument, but an administrative screen that can be used by staff and family caregivers to note functional decline and health problems and record information useful for further assessment, as well as to serve as part of the mandatory cognitive assessment review that is part of the Affordable Care Act's annual wellness visit for Medicare recipients. This instrument complies with Action 2.B of the US National Plan to Address Alzheimer's Disease.

It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. The form can be completed by anyone who is familiar with the adult (that is, has known him or her for over six months), such as a family member, agency support worker, or a behavioral or health specialist using information derived by observation or from the adult's personal record.

The estimated time necessary to complete this form is between 15 and 60 minutes. Some information can be drawn from the individual's medical/health record. Consult the NTG-EDSD Manual for additional instructions (www.aadmd.org/ntg/ screening).

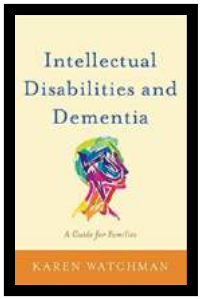
| | [27]Chronic Health Conditions* | Recent condition (past year) | Condition diagnosed in last 5 years | Lifelong condition | Condition not present |
|---|---|---|---|---|---|
| | **Bone, Joint and Muscle** | | | | |
| 1 | Arthritis | | | | |
| 2 | Osteoporosis | | | | |
| | **Heart and Circulation** | | | | |
| 3 | Heart condition | | | | |
| 4 | High cholesterol | | | | |
| 5 | High blood pressure | | | | |
| 6 | Low blood pressure | | | | |
| 7 | Stroke | | | | |
| | **Hormonal** | | | | |
| 8 | Diabetes (type 1 or 2) | | | | |
| 9 | Thyroid disorder | | | | |
| | **Lungs/breathing** | | | | |
| 10 | Asthma | | | | |
| 11 | Chronic bronchitis, emphysema | | | | |
| 12 | Sleep disorder | | | | |
| | **Mental health** | | | | |
| 13 | Alcohol or substance abuse | | | | |
| 14 | Anxiety disorder | | | | |
| 15 | Attention deficit disorder | | | | |
| 16 | Bipolar disorder | | | | |
| 17 | Dementia/Alzheimer's disease | | | | |
| 18 | Depression | | | | |
| 19 | Eating disorder (anorexia, bulimia) | | | | |
| 20 | Obsessive-compulsive disorder | | | | |
| 21 | Schizophrenia | | | | |
| 22 | Other: | | | | |
| | **Pain / Discomfort** | | | | |
| 23 | Back pain | | | | |
| 24 | Constipation | | | | |
| 25 | Foot pain | | | | |
| 26 | Gastrointestinal pain or discomfort | | | | |
| 27 | Headaches | | | | |
| 28 | Hip/knee pain | | | | |

# Diagnostic Overshadowing

Do NOT assume that present behavioral responses are merely “symptoms of dementia”.

**Conduct functional assessments** to determine what variables “activate” the behavior and which variables may by the “payoff”.

- “***Think Pain First***” rather than assuming changes are due to the person’s disability or progression of dementia.



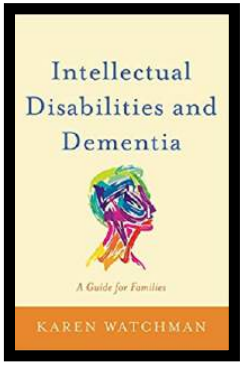
# COMMON "PROBLEM" BEHAVIORS AND SPECULATIONS ABOUT THEIR CAUSES

| BEHAVIOR | SUSPECTED CAUSE |
|---|---|
| Biting side of hand/whole mouth | • Sinus problems<br>• Ears/Eustachian tubes<br>• Eruption of wisdom teeth<br>• Dental problems<br>• Paresthesias/painful sensations (e.g., pins & Needles) in the hand |
| Biting thumbs/objects with front teeth | • Sinus problems<br>• Ears/Eustachian tubes |
| Biting with back teeth | • Dental<br>• Otitis (ear) |
| Fist jammed in mouth/down throat | • Gastroesophageal reflux<br>• Eruption of teeth<br>• Asthma<br>• Rumination<br>• Nausea |
| General Scratching | • Eczema<br>• Drug effects<br>• Liver/renal disorders<br>• Scabies |
| Head Banging | • Pain<br>• Depression<br>• Migraine<br>• Dental<br>• Seizure<br>• Otitis (ear ache)<br>• Mastoiditis (inflammation of bone behind the ear)<br>• Sinus problems<br>• Tinea capitis (fungal infection in the head) |

# Pain

- The person's brain may lose the ability to recognize and communicate pain sensations
  - Be aware of what is going on with the person at all times
  - Look for physical indicators the person may be in pain
    - Facial expressions
    - Posture
    - Favoring one side of the body
  - Look for other indicators
    - Increased vocalizations or moaning and groaning
    - Changes in mood or behavior, such as increase in SIB

# Pain Assessment




- Abbey Pain Scale
  - Assess non-verbal cues in people with dementia.
- DisDat
  - Checklist to observe and identify distress cues in people whose verbal communication is severely limited.
- Detective Work
  - Chair, clothing, laying/sitting too long, etc.

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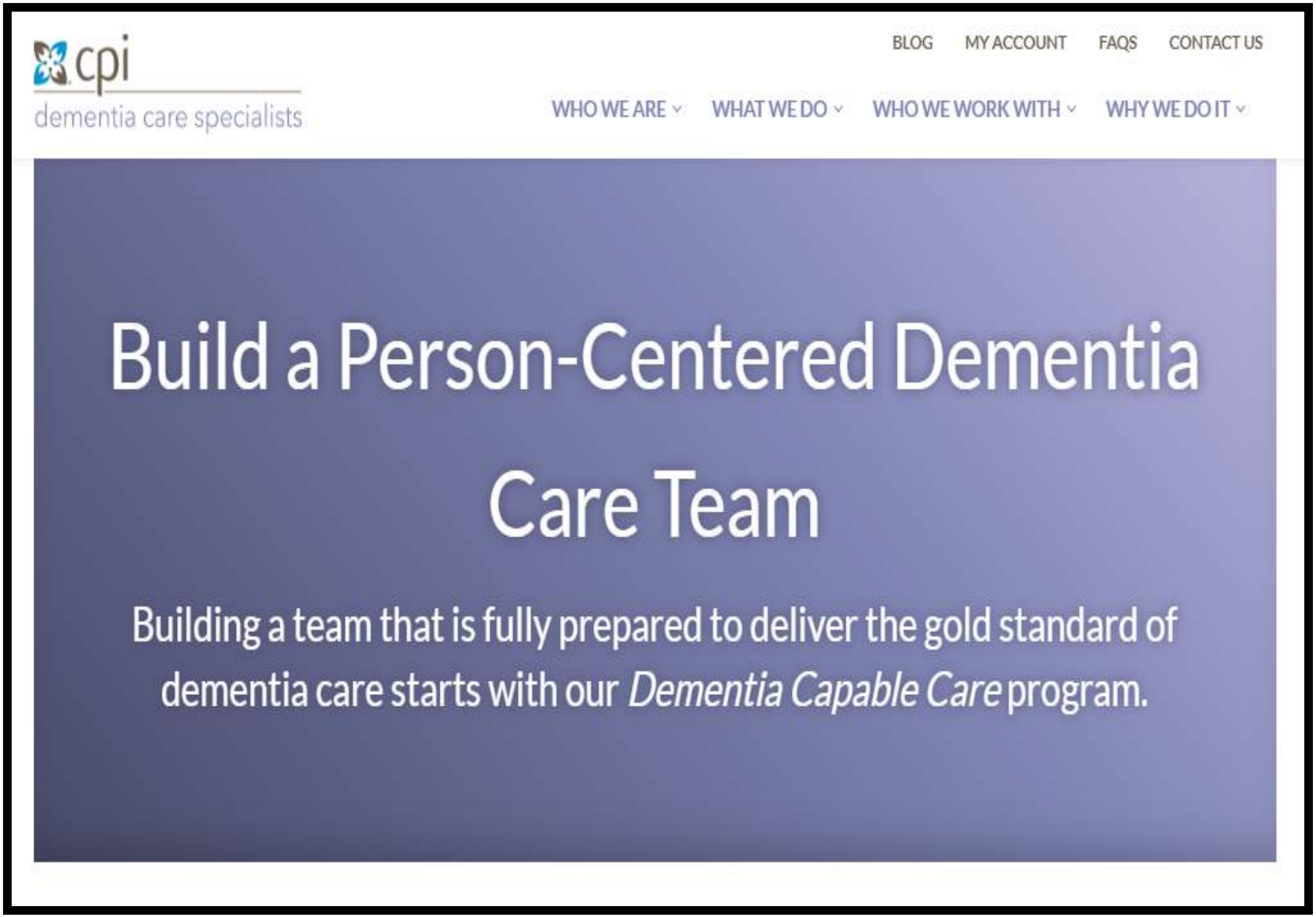
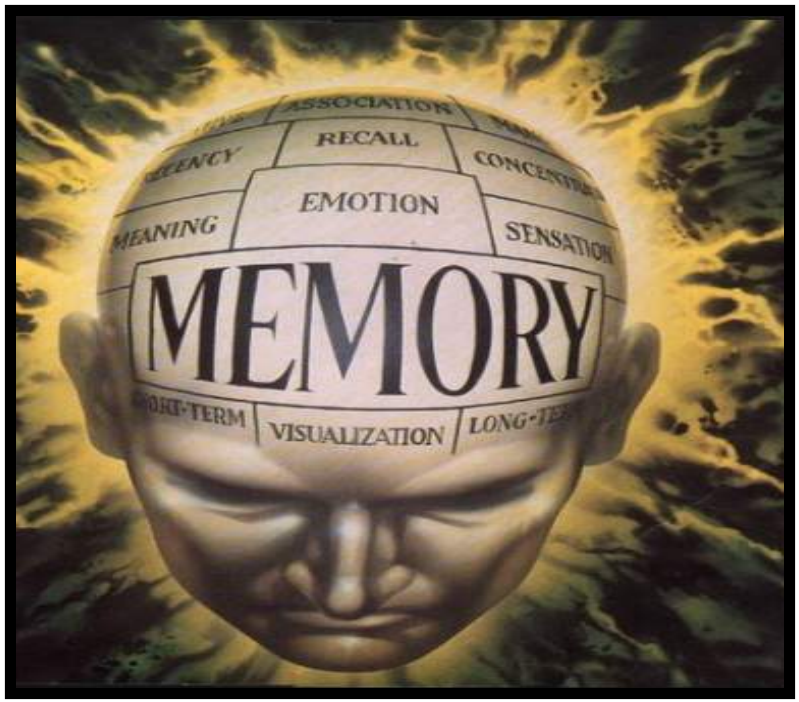
- PAINAD
  - Pain Assessment In Advanced Dementia Scale

- Ensure staff understand what is happening.
- Staff are IMPORTANT to the person; they may be the only support the individual has.
- Ensure the team realizes it may be time to reexamining expectations and focus behavioral management on prevention to avoid confrontation and difficulties.


cpi
dementia care specialists
BLOG
MY ACCOUNT
FAQS
CONTACT US
WHO WE ARE
WHAT WE DO
WHO WE WORK WITH
WHY WE DO IT
Build a Person-Centered Dementia Care Team
Building a team that is fully prepared to deliver the gold standard of dementia care starts with our *Dementia Capable Care* program.

When you ask the person to do something, break the request down into small, descriptive steps.

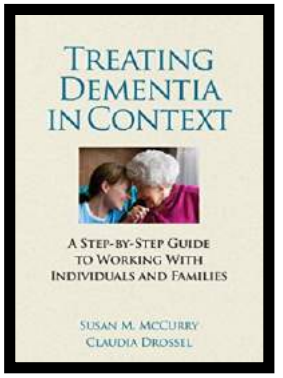
| Early On | As Disease Progresses |
| --- | --- |
| Sit down. | Bend your knees. Put your bottom on the chair. |
| Put it over there. | Put the magazine on the bed. |
| Get dressed. | Put your arm in the sleeve (touching the arm and holding the shirt sleeve open). |




# Memory

- Procedural, Episodic, Semantic
  - All effected, not necessarily at same time
- Remembering Certain Things and Not Other Things

# Erroneous Beliefs/Accusatory Behavior




- E.g. accuse others of stealing their belongings, talking about them, etc.
- If orientating the person to factual information no longer leads to a shift in the person's reasoning, the caregiver may have to learn to let the person be "right" regardless of content, quickly provide a plausible response, and not jeopardize the relationship.
- Focus is on long-term outcome, not being "right".

| Person | Staff |
|---|---|
| You have stolen my jeans! | No I did not. |
| You have stolen my jeans? | Oh, sorry. I think they are in the wash. Let me check on that for you. |

# Repetitive Questions

- Loss of the ability to form new memories
- If answer to the question is distressful, the person will experience the distress EACH TIME he/she hears the answer.

No: “You father passed away. We already talked about that.”

Yes: “Tell me about what your father. What did he like to do?”

# Resources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National Task Group on Intellectual Disabilities and Dementia Practices
WELCOME TO THE NTG
The 'NTG' is a coalition charged with ensuring that the interests of adults with intellectual and developmental disabilities who are affected by Alzheimer's disease and related dementias – as well as their families and friends – are taken into account as part of the National Plan to Address Alzheimer's Disease.
ntg
National Task Group on Intellectual Disabilities and Dementia Practices
We produce materials related to dementia, including practice guidelines, screening tools, education and training curricula and workshops, agency and family-based information, and other technical materials – as well provide technical assistance.
The NTG is affiliated with the American Academy of Developmental Medicine and Dentistry and the Rehabilitation Research and Training Center on Developmental Disabilities and Health at the University of Illinois at Chicago and other partners, such as various university centers and the Gerontology Division of the AAIDD. Read more about us.

# National Task Group on ID and Dementia Practices

## GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA

# Samples

- Color
  - Use color and contrast to create visual cues or reduce attention to specific areas throughout the home.
    - White light switch on dark switch plate
    - Dark toilet seat on white toilet
- Illumination
  - Use lighting to avoid shadows
    - Source of visual hallucinations
  - Reduce reflective surfaces (e.g. floors)

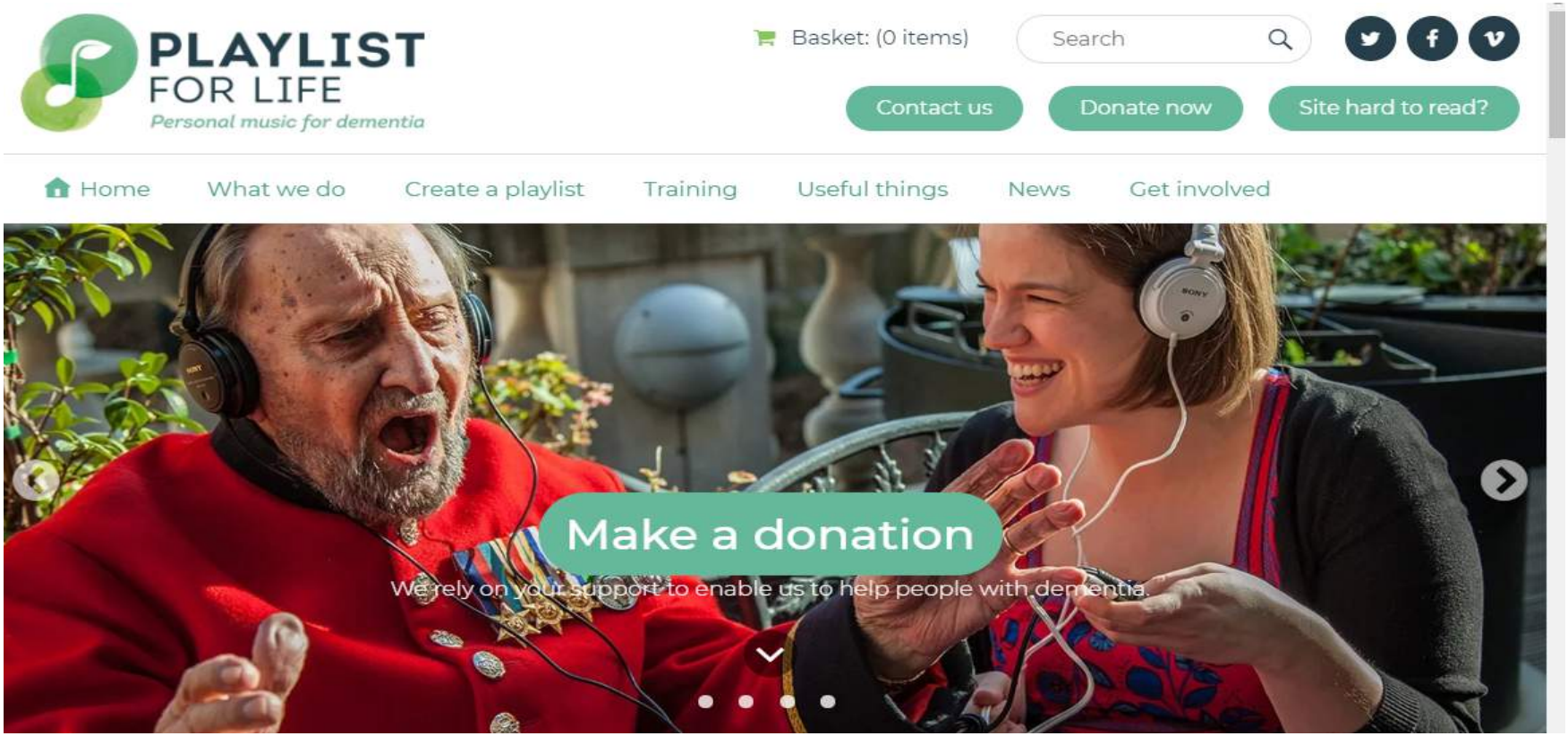
NTG-Guidelines for Structuring

# Day Programs

- Multi sensory; both stimulation and relaxing
- Support **existing** skills and memories


- Tailored to likes/dislikes and previous experiences
- Horticulture, art, music, aromatherapy, hair/makeup/personal grooming activities, trips in community, walks, exercise, massage, reminiscence
- Offered by staff trained in dementia care practices

NTG-Guidelines for Structuring




- The “right” playlist can be very powerful.
- Requires very little cognitive processing.
- Even in advanced stages of dementia, the person may be able to sing or move their hands/tap their feet.

- Music should NOT be kept on just for background noise. The person may find it aversive yet not be able to ask for it to be shut off.

Natural light can improve sleep and wellbeing.

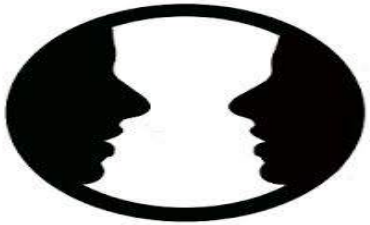
# Life Stories


- Create a detailed "Life Story" about the person by gathering info from family or people who know the person well.
- Include the person's preferences and stories about their past that they have enjoyed telling or talking about.
- Not always positive; may recall distressing memories.

# Your Vocal Communication

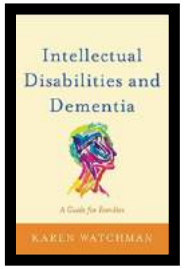
- Even when the person can no longer comprehend your words, **he will perceive your non vocal language**, especially as his ability to comprehend language diminishes.
- Make sure the person can see you and watch your face. **Smile and make eye contact!**
- Use gestures and visual prompts in addition to your words.

# Socialization - Interest



- The person may have diminished concentration or memory span, and have difficulty finding words, however, the desire to interact is often as strong as ever.
- Even when they lose their vocal skills, they can maintain their desire to be around other people, as long as the environment is not loud, extremely “busy” or overwhelming.

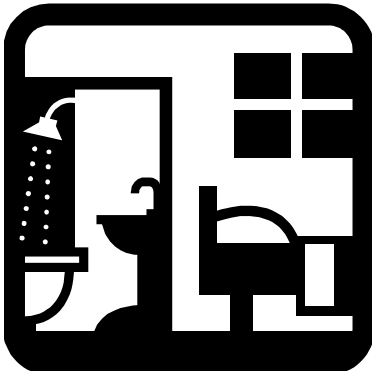
# Anti-Dementia Medication




- May slow the progression of the symptoms.
- Medication cannot cure dementia.
- Medication is NOT a replacement for environmental supports.
- Some heart conditions may rule out use.
- Few studies with people with ID-use caution
- Monitor changes for side effects:
  - Donepezil / pain, diarrhea, aggression, urinary incontinence

# Eliminate Hazards and Clutter

**Environmental Adaptations**



Walk through the person's living area, **often**, looking for tripping hazards or clutter and remove any items that may be considered a tripping hazard.

# Routines

Meal times, medication times, hygiene routines, are examples of activities that can often be scheduled at consistent times to help decrease the anxiety and increase independence.

# Providing Assistance

- It is important that we support the person, rather than “do for” the person, as much as possible.
- Doing “too much, too early” could result in the person losing skills.

# Maintaining Wellness

Physical Exercise

- Walking; Wii;, etc.

Cognitive Exercise

- Saying names of objects/people

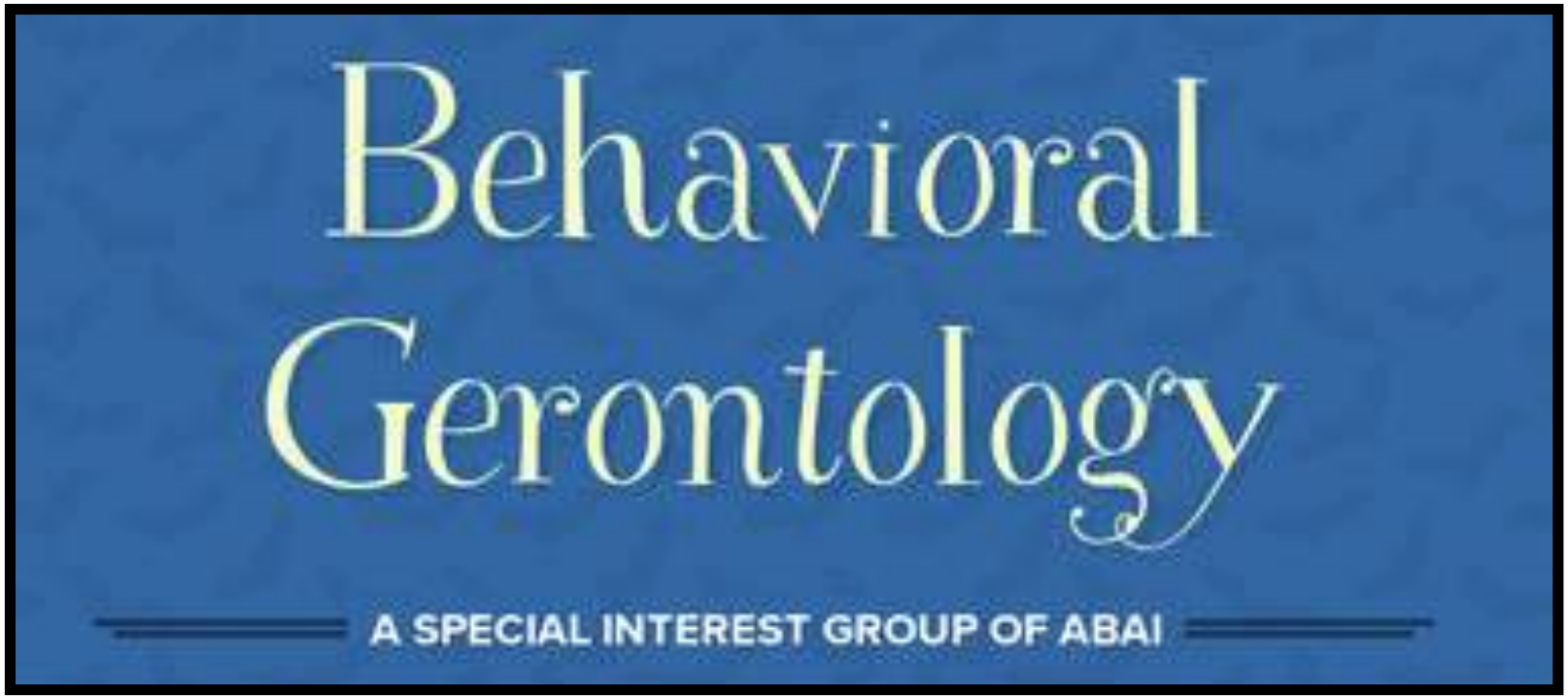
Nutrition

- Low-Fat, Low-Calorie, Low Cholesterol
- Diets rich in vegetables, fish, and folic acid

Hydration

Choking-modified diets; vigilant for triggers

Behavioral
Gerontologists



# Caring for the Care Giver

- Working with individuals experiencing cognitive functioning impairments can be stressful.
- Find a way to manage your stress in a healthy way.
- Ask your supervisor or peers to watch your interactions with the person and provide feedback.
- Help out coworkers when they seem to be having a challenging day with an individual.