National Task Group
on Intellectual Disabilities
and Dementia Practices

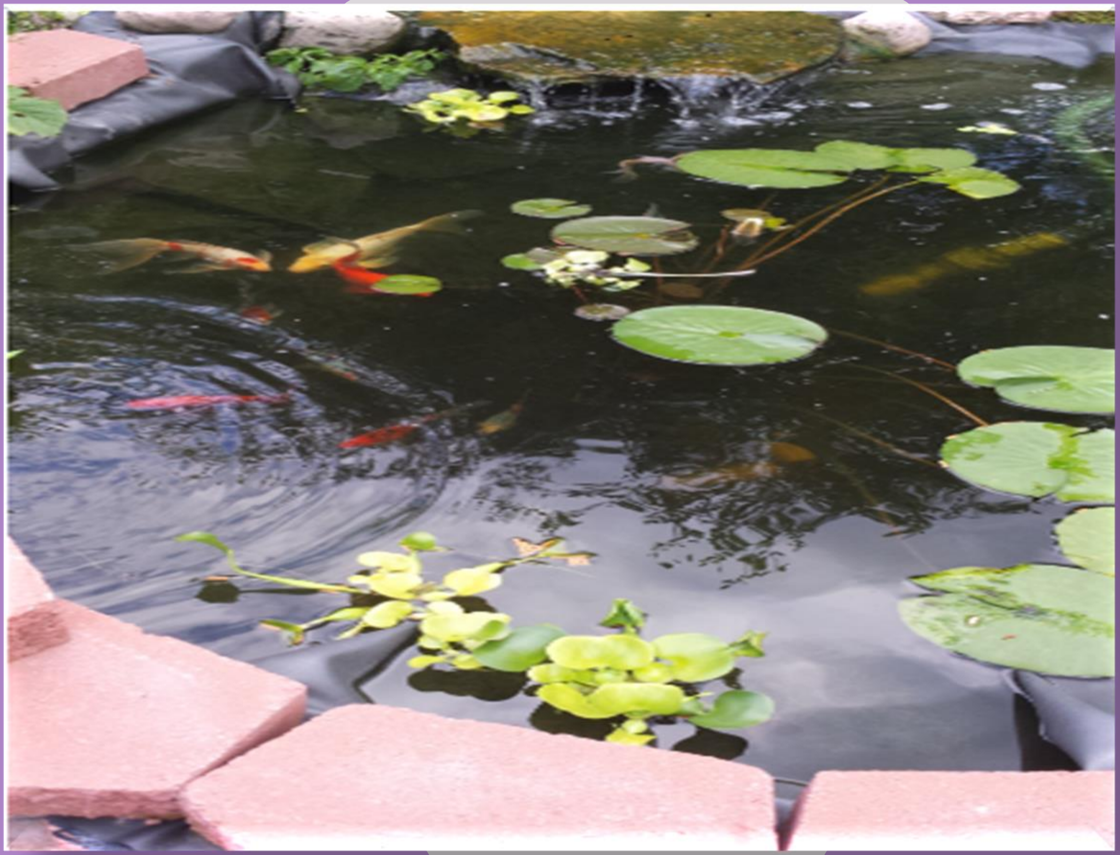
NTG Dementia Capable Care of Adults with Intellectual Disabilities & Dementia

DAY 1

Introduction to Workshop
Aging, ID & Dementia

MS. PIGGY BE IN THE MOMENT

KATHLEEN M. BISHOP, PH,D.



PUT AWAY YOUR CELL PHONES, TEXT MESSAGES, & WORRIES OF THE DAY…

LEARN FROM MS. PIGGY

ALBERT'S STORY

HISTORY:

- Albert was born in 1949 near Rochester, NY.
- He lived with parents and large extended family until 1992 when his mother passed away and he moved in with his aunts.
- Moved into a residence for adults with ID in early 2000 after the death of his aunts
- In 2011 Albert began demonstrating significant behavioral changes and loss in functioning
  - Health care advocacy by staff and family continued
  - Formally diagnosed with Alzheimer's disease in 2012
  - Informal caregivers have become his family and are doing their best to maintain quality of life and well-being for Albert

TO TEACH PRESENCE YOU MUST BE PRESENT IN THE MOMENT

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NEVER DISREGARD PROFESSIONAL MEDICAL ADVICE OR DELAY SEEKING MEDICAL TREATMENT BECAUSE OF SOMETHING YOU HAVE HEARD IN THIS WORKSHOP.

Overall Training Objectives

AFTER 2 DAYS OF TRAINING PARTICIPANTS WILL BE ABLE TO:

- Discuss information, characteristics, and effects of aging, dementia, and intellectual disability (ID).
- Discuss the importance of specialized care and supports for adults with ID, including screening, working with health care providers, systems challenges, daily health advocacy, and support management.
- Implement practices of quality caregiving for adults with ID and Alzheimer’s and related dementias.

Agenda

Day 1	Day 2	Day 3	Day 4
Welcome Derek Video Introduction to NTG Aging in ID Dementia in ID Intro Differential Diagnosis	Homework Review Alzheimers, DS, Stages Health Care Advocacy Early Screening (EDSD)	Homework Review Philosophical Shift Key Concepts of Care BPSD Behavioral Triggers	Homework Review Sensory Impairment Environmental Issues Derek Video

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VIDEO: SUPPORTING DEREK

Have you ever wondered
how the world might
look and sound
if you had dementia?

Introduction to NAPA, the NTG and the Dementia Capable Care Workshop

National Task Group
on Intellectual Disabilities
and Dementia Practices

Section Objectives

Participants will be able to recognize:

- The intent of National Alzheimer's Planning Act
- The function of the National Plan to Address Alzheimer's Disease
- The activities of the National Task Group

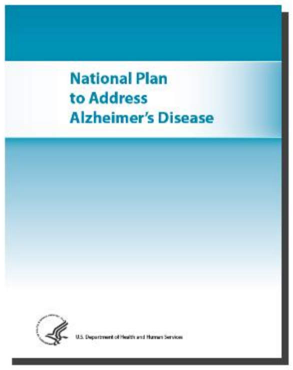
NAPA

National Alzheimer’s Project Act

National Plan to Address Alzheimer's Disease

The law calls for a National Plan for ADRD with input from a public-private Advisory Council on Alzheimer's Research, Care and Services.

The Advisory Council will make recommendations to HHS for priority actions to expand, coordinate, and condense programs in order to improve the health outcomes of people with ADRD and reduce the financial burden of these conditions on those with the diseases, their families, and society.



National Plan
to Address
Alzheimer's Disease

U.S. Department of Health and Human Services

Calls for…

☑ Issuance of practice guidelines for care and supports and expanded public education

☑ Promotion of assessment tool for detection of cognitive impairment as part of the Medicare annual wellness visit

☑ Enhanced supports for caregivers

☑ Expanded research

☑ Specific population focus, including ID

Why a National Training Curriculum?

National Plan
to Address
Alzheimer's Disease

WHAT'S HAPPENING
2014 Update of the National Plan
to Address Alzheimer's Disease

Select Actions Directly Related
To Intellectual Disabilities

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Addresses the provision in the 2014 Update of the National Plan to Address Alzheimer's Disease which calls for the *"Development of a curriculum on Alzheimer's disease for primary care practitioners so that providers have the necessary skills to provide high-quality dementia care."*

Action 2.A.5: Strengthen state aging, public health, and intellectual and developmental disability workforces.

NTG

National Task Group on Intellectual Disabilities and Dementia Practices

National Task Group on Intellectual Disabilities & Dementia Practices (NTG)

- Coalition of interested persons and organizations.
- Mission: Ensuring that the needs and 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 Alzheimer's Project Act (**NAPA).**
- **To access resources, visit** www.the-ntg.org

NTG Activities

- **An early detection-screening instrument (NTG-EDSD) & manual**
  - Various language versions available
  - Access at www.aadmd.org/ntg
- **Practice guidelines**
  - Community supports guidelines
  - Health practitioner assessment guidelines
  - Health advocacy guidelines
  - Community dementia care setting guidelines

NTG-EDSD

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The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias

Index

Alzheimer's and related dementias — p1
Dementia and persons with intellectual disability — p2
Assessment, diagnosis, and treatment — p6
Interacting with medical practitioners and health care providers... p9

'My Thinker's Not Working'
A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

Executive Summary to the Report of the National Task Group on Intellectual Disabilities and Dementia Practices

2012

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO; Michael S. Rafii, MD, PhD; Seth M. Keller, MD; Baldev K. Singh, MD; and Matthew P. Janicki, PhD

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

NTG Activities

- **Training and education activities**
  - Training workshops - webinars
  - Meetings with professional groups
  - Information for families (FAQ)
- **Linkages**
  - US Administration on Community Living
  - NASDDDS, N4A, NACDD & state activities
  - CARF & national program standards
  - The Arc, NDSS, Alzheimer's Association

NTG-EDSD

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National Task Group on Intellectual Disabilities and Dementia Practices

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

NTG's 'Thinker Document Recommendations


'My Thinker's Not Working'
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2012

- Early screening, health and wellness across the lifespan, and quality lifespan diagnostic services
- Formal (paid) and informal caregivers (family) also at risk with the intersection of the aging needs occurring
- Community and health care provider education
- Caregiver supports and services
- Increased research
- Health care advocacy
- Need for dementia capable services, supports, and advocacy
- Long term planning process needed that includes ID at the agency, regional, state, and federal level.
- Collaboration across networks

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ID and Healthy Aging

Health disparities and challenges

Developmental vs. Intellectual Disability

Developmental Disability

Umbrella Term: Can be cognitive or physical or both.

Severe & chronic. Disability occurs prior to birthdate of age 19 or 22 (depending on the state).

May or may not have low IQ.

Some developmental disabilities are largely physical.

- Example - cerebral palsy or epilepsy.

Can include a physical and intellectual disability.

- Example - Down syndrome or fetal alcohol syndrome.

Intellectual Disability

Disability related to cognitive (thought) processes.

Severe & chronic. Disability occurs prior to birthdate of age 19 or 22 (depending on the state).

Low IQ

The term intellectual disability covers the same population of individuals who were diagnosed previously with mental retardation.

Developmental disabilities and intellectual disabilities can co-occur.

What is Aging?

- Active process that occurs over an individual’s lifespan, from birth until death.
- Aging is unique to each person.
  - Marked by gains and losses within common patterns of aging.
- Conditions that impact aging:
  - Genetics
  - Lifestyle
  - Environment
  - Attitude

Adopt a Lifespan Approach

Based on the premise that what happens in childhood and young adulthood affects the quality of life in old age.

It’s never too late to make a difference, but the earlier we start the larger difference we can make.

Factors Impacting Healthy Aging

Healthy aging is impacted by the following factors:

- Poor lifespan health practices
- Long-term consequences of early-life therapeutic interventions
  - Ex. Cerebral Palsy
- Prolonged usage of medications adding to chronic conditions in older age (adverse drug reactions & polypharmacy)
  - Ex. Thorazine

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- Problems with accessing health services
  - Not having medical personnel familiar with ID
  - Not tracking risk conditions
- Age-associated pathologies
  - Dementia, cardiovascular disease, etc.
- Lack of exercise
- Poor nutrition and bad eating habits
  - Ex. Chewing, swallowing problems in Cerebral Palsy

Nutrition is Important

- Important determinant of health and well-being throughout the lifespan.
- Known risk factors for developing dementia:
    - Diabetes, obesity, vascular disease
- 10 lbs or more unintended weight loss (or 5% of body weight) over 6 – 12 months may be indicative of serious disease or illness.

Challenges to Healthy Aging in Adults with ID

Medical history is often incomplete or unknown.

- Staff turnover
- Family not available for information, historical documentation unavailable
- Health care provider turn over
- Providers not understanding baseline functioning of the presenting older adult with ID
    - IDEA: Video can provide a visual of the person over their lifespan.

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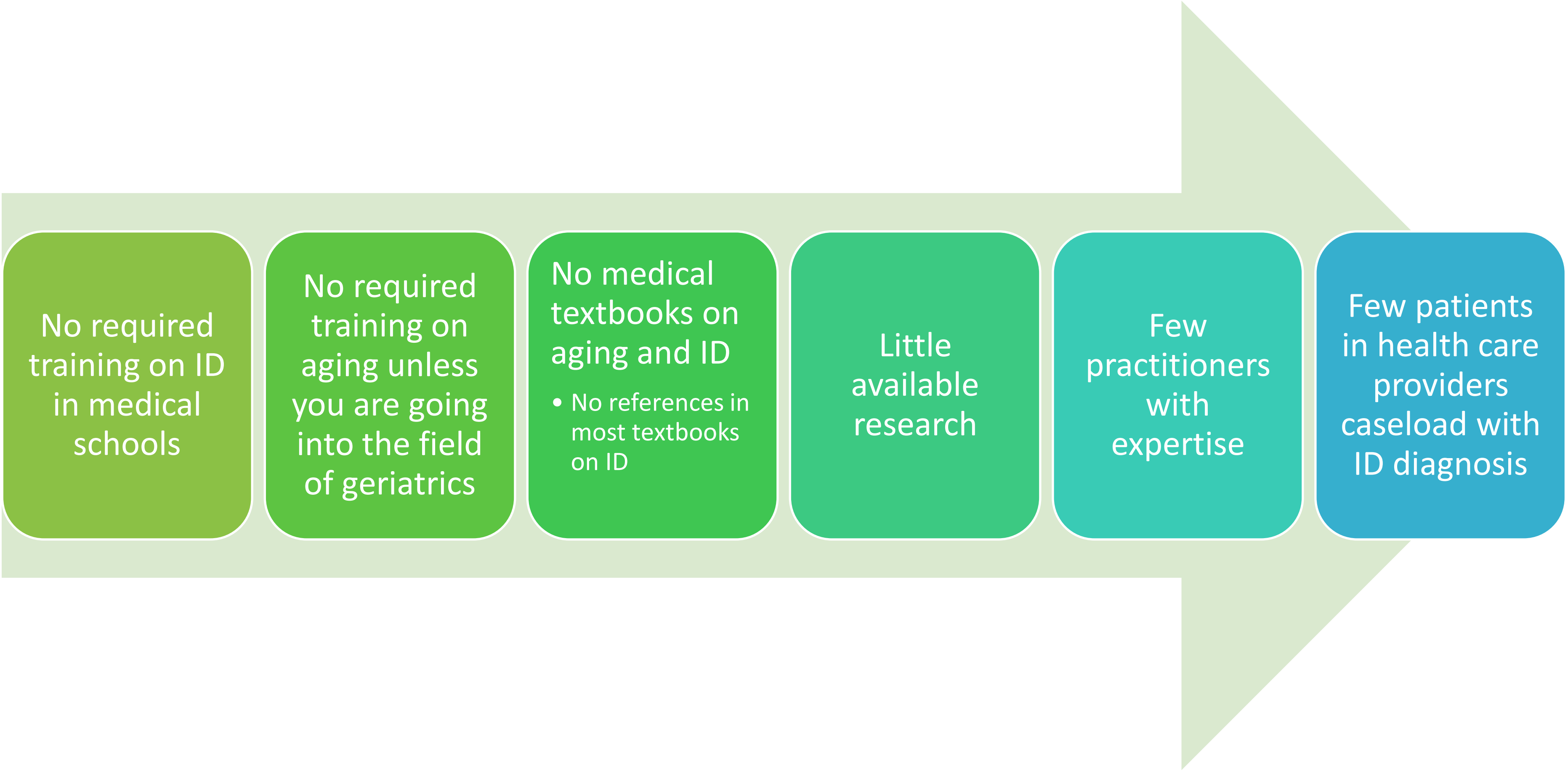
Lack of systems for health advocacy :

- Information provided for the appointment may not include all necessary information.
- Staff/family attending health care appointments may not be the most knowledgeable about the symptoms.

Health Care Disparities for Adults with ID



- No required training on ID in medical schools
- No required training on aging unless you are going into the field of geriatrics
- No medical textbooks on aging and ID
  - No references in most textbooks on ID
- Little available research
- Few practitioners with expertise
- Few patients in health care providers caseload with ID diagnosis

Introduction to Dementia and ID

National Task Group
on Intellectual Disabilities
and Dementia Practices

Dementia 101

Understanding the basics of dementia as it impacts adults with ID.

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!”

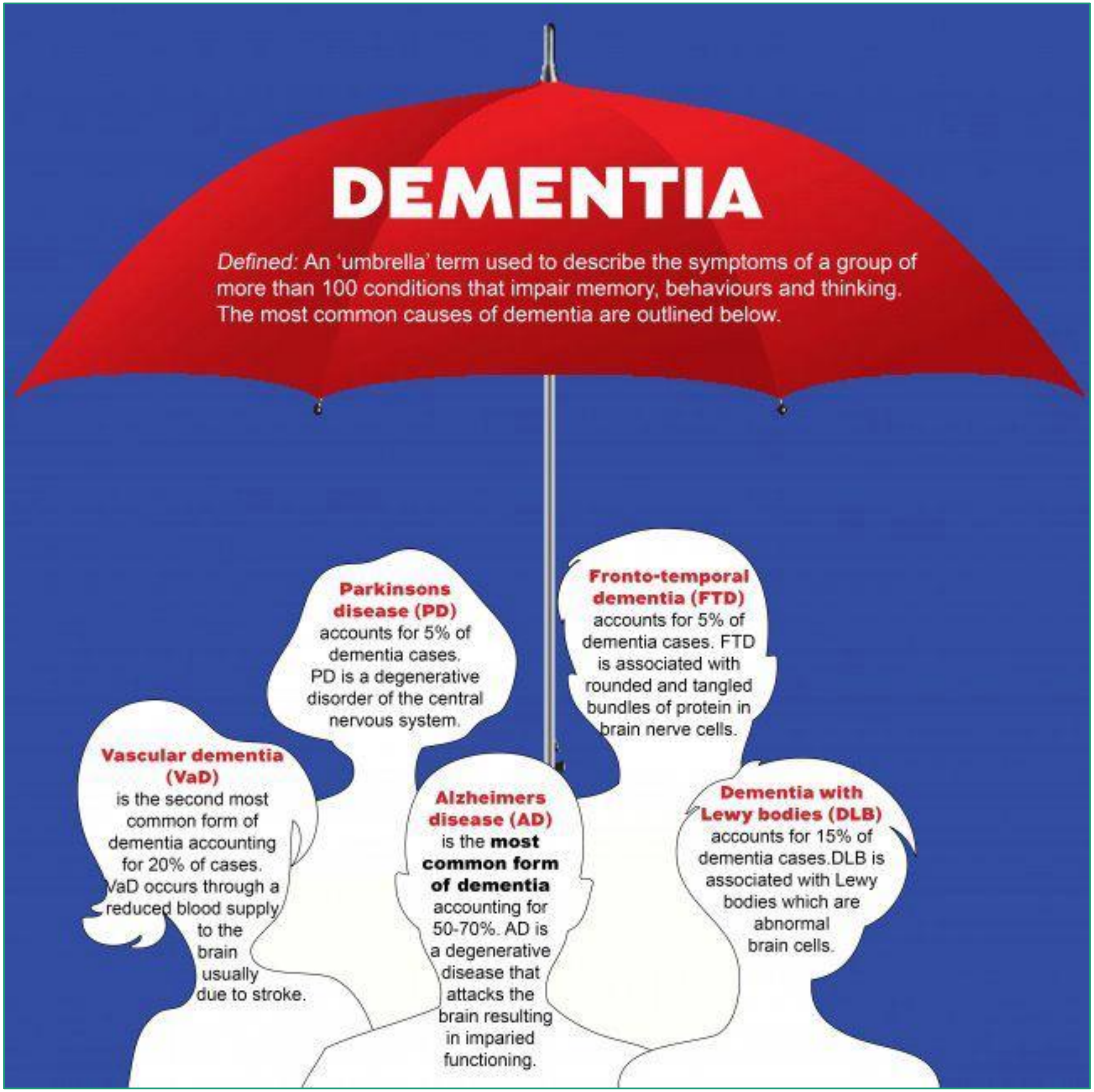
3. The condition we refer to as dementia may be caused by many things.
    a. Some may be **treatable** (Ex. Dehydration, B12 deficiency)
    b. Others are **irreversible** (Ex. Alzheimer’s, Vascular, Lewy body).

4. Dementia is **NOT part of normal aging**.

Irreversible Dementias

The symptoms we call “dementia” can have many different causes.

Alzheimer’s disease is the most common.



DEMENTIA

Defined: An ‘umbrella’ term used to describe the symptoms of a group of more than 100 conditions that impair memory, behaviours and thinking. The most common causes of dementia are outlined below.

Parkinsons disease (PD) accounts for 5% of dementia cases. PD is a degenerative disorder of the central nervous system.

Fronto-temporal dementia (FTD) accounts for 5% of dementia cases. FTD is associated with rounded and tangled bundles of protein in brain nerve cells.

Vascular dementia (VaD) is the second most common form of dementia accounting for 20% of cases. VaD occurs through a reduced blood supply to the brain usually due to stroke.

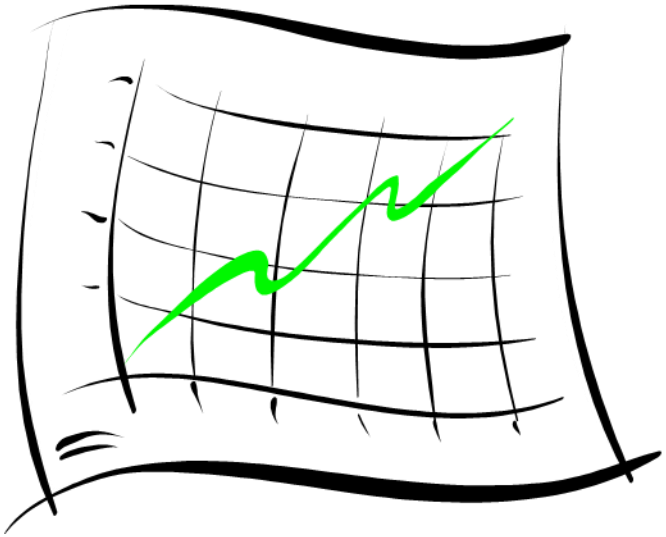
Alzheimers disease (AD) is the **most common form of dementia** accounting for 50-70%. AD is a degenerative disease that attacks the brain resulting in imparied functioning.

Dementia with Lewy bodies (DLB) accounts for 15% of dementia cases.DLB is associated with Lewy bodies which are abnormal brain cells.

Image: Dementia Forward

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!

Dementia Prevalence: ID vs. DS

Intellectual Disability

Age	Percentage
40+	3%
60+	6%
80+	12%

Down Syndrome

Age	Percentage
40+	22%
60+	56%

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. Mental Retardation: June 2000, Vol. 38, No. 3, pp. 276-288.

Prevalence of Dementia and Impact on Intellectual Disability Services.

Matthew P. Janicki and Arthur J. Dalton (2000) Prevalence of Dementia and Impact on Intellectual Disability Services. Mental Retardation: June 2000, Vol. 38, No. 3, pp. 276-288.

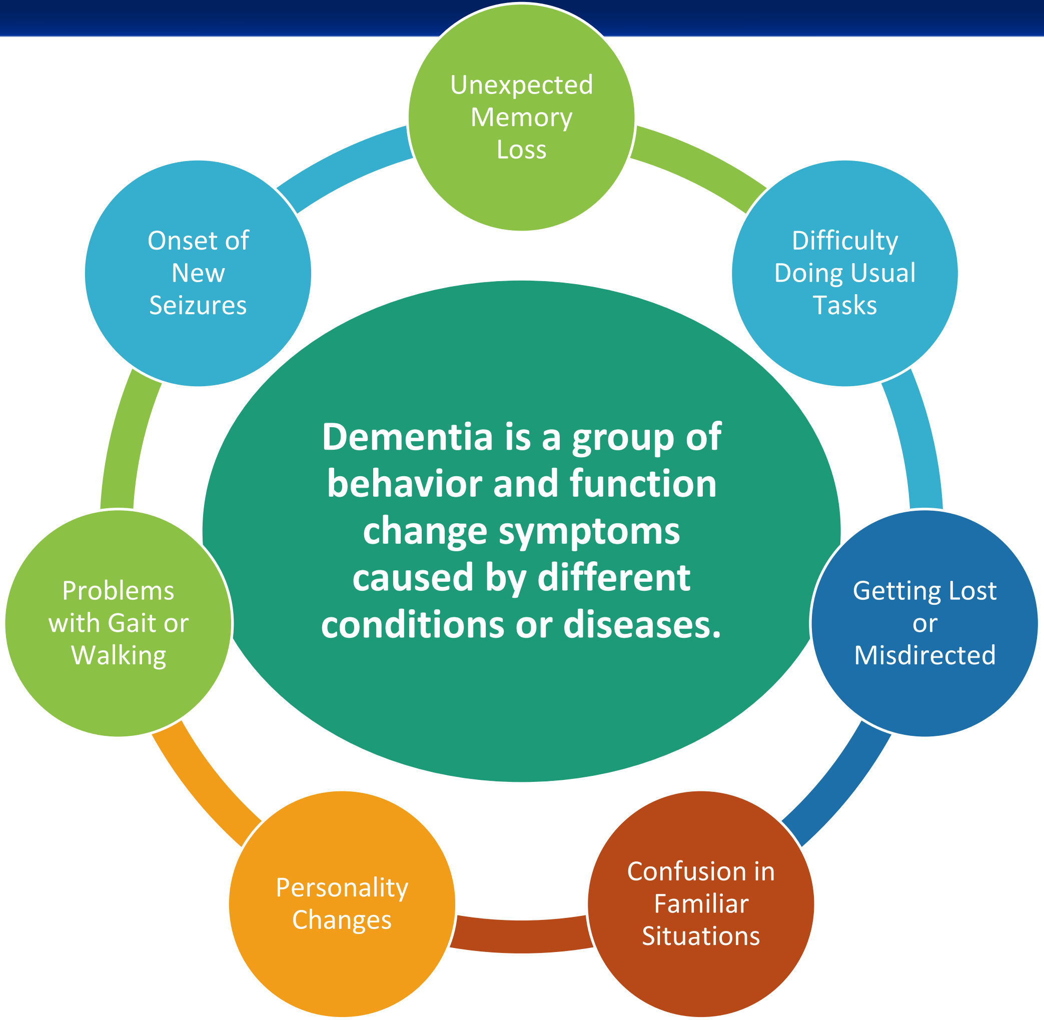
Increased lifespan = Increase in dementia.

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 notable and usually occur in a cluster



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

Unexpected Memory Loss

Difficulty Doing Usual Tasks

Getting Lost or Misdirected

Confusion in Familiar Situations

Personality Changes

Problems with Gait or Walking

Onset of New Seizures

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

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 Organizations
  - Alzheimer’s Association
  - Alzheimer’s Foundation
  - Other local Alzheimer’s and related dementia groups
- State and local Protection and Advocacy Networks
- Faith-based organizations
- Statewide or Community-based Respite/Caregiver Coalitions

Down Syndrome & Dementia

The unique challenges of dementia in adults with Down syndrome.

What is Down syndrome (DS)?

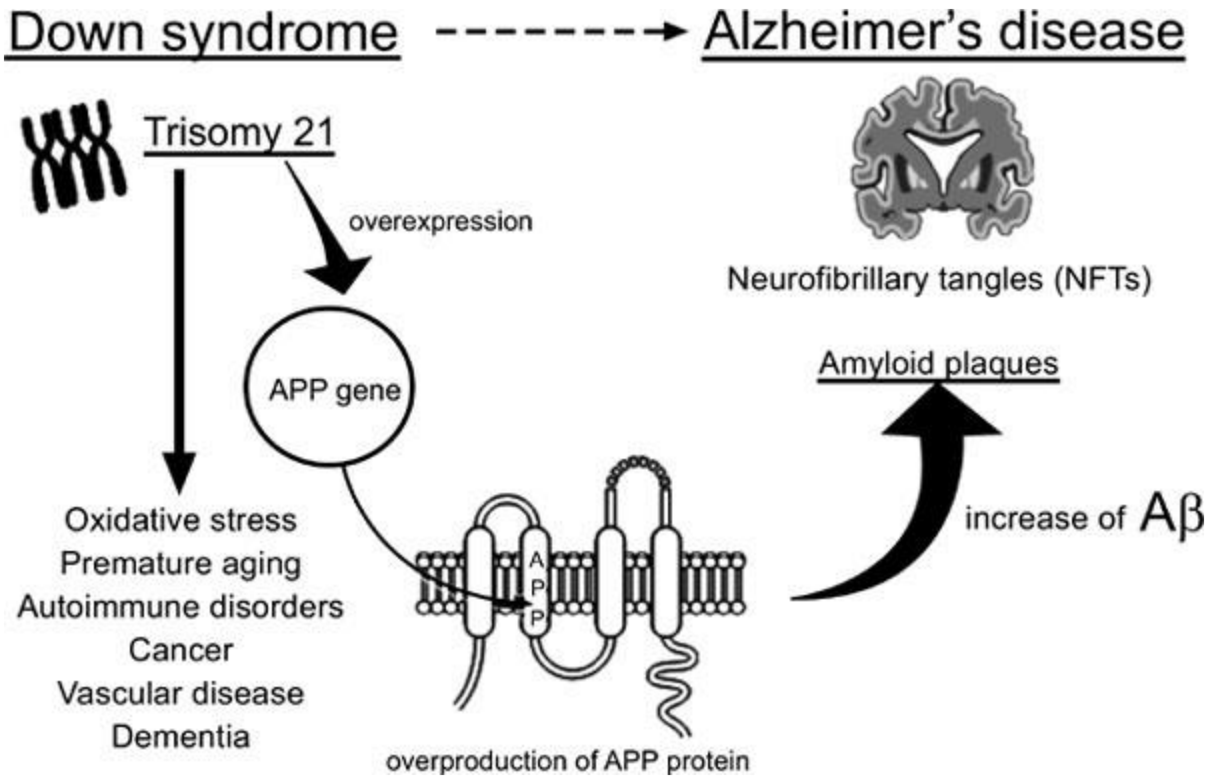
- First accurate description of a person with DS was published in 1866 by an English physician - John Langdon Down.
- DS is a developmental disability – intellectual impairment and physical abnormalities.
- DS occurs 1 in 750 live births.
- DS is caused by a genetic abnormality – an extra full or partial copy of chromosome 21 (Trisomy 21).
- Extra copy of genetic material alters the course of development and causes the characteristics associated with Down syndrome.
- common physical traits of Down syndrome are:
  - low muscle tone, small stature,
  - an upward slant to the eyes,
  - and a single deep crease across the center of the palm
  - each person with Down syndrome is a unique individual and may possess these characteristics to different degrees, or not at all

Premature Aging in Down Syndrome

- Life expectancy has continued to increase for people with Down syndrome.
- Aging increases risk for physical and cognitive changes for people with DS.
- Many individuals with DS age prematurely (age in their 50s).
- Adults with DS are at risk for diseases and changes about 20 years earlier than the general population.

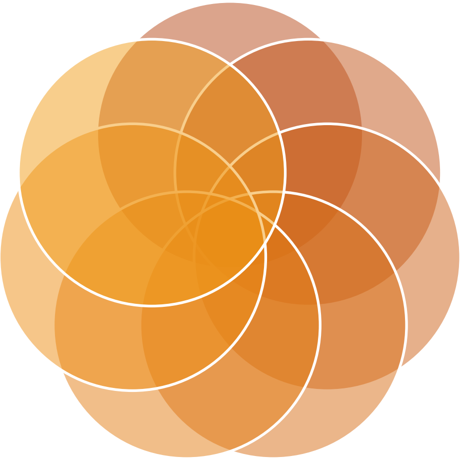
Why a focus on DS?

Down syndrome is one of the most significant risk factors for Alzheimer's disease.



Source: Bentham Science

Conditions That May Increase Risk of *“Dementia”* in Adults with DS



Hearing & visual impairment

Vitamin B12 deficiency

Seizures

Dehydration

Depression

Side Effects of Medications

Atypical Presentation of Alzheimer’s in DS

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

Diagnosing Dementia

The differential diagnosis

Health Care Barriers

- Clinicians lack specialized training
- Dementia assessment protocols are not well known.
- Primary care practitioners are often not familiar with ID generally and how dementia presents in adults with ID specifically.
- Diagnostic overshadowing

Normal Age-Related Memory Changes vs. Dementia

Typical Aging:	Symptoms of Dementia:
Complains about memory loss but able to provide detailed examples of forgetfulness	May complain of memory loss only if asked; unable to recall specific instances
Occasionally searches for words	Frequent word-finding pauses, substitutions
May have to pause to remember directions, but doesn't get lost in familiar places	Gets lost in familiar places and takes excessive time to return home
Remembers recent important events; conversations are not impaired	Notable decline in memory for recent events and ability to converse
Interpersonal social skills are at the same level as they've always been	Loss of interest in social activities; may behave in socially inappropriate ways

Must rise to the level of impairing ability to function in everyday life.

Adapted from: *The American Medical Association*

Regression vs Alzheimer’s

- Catatonia
- Young adults, adolescents
- Rapid regression with loss of independence and daily skills
- Cause unknown
- Occurs regardless of the cognitive level (severe, moderate, or mild intellectual disability)
- Present with - psychiatric symptoms (catatonia, depression, delusions, stereotypies, etc.), partial or total loss of independence in activities of daily living (dressing, toilet, meals, and continence), language impairment (silence, whispered voice, etc.), and loss of academic skills
- Potential trigger – severe emotional distress prior to regression
- Females more often than males
- Partial or complete recovery 50% of cases in one study
- Benzodiazepines, SSRIs, ECT

www.ncbi.nlm.nih.gov/pmc/articles/PMC5483630/

Differential Diagnosis

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

Two Stage Process:

- Establish that the symptoms are present – the easy part
- Determine the cause of those symptoms – the challenge

Not all dementia is irreversible!

Traditional Screening Tools Not Useful

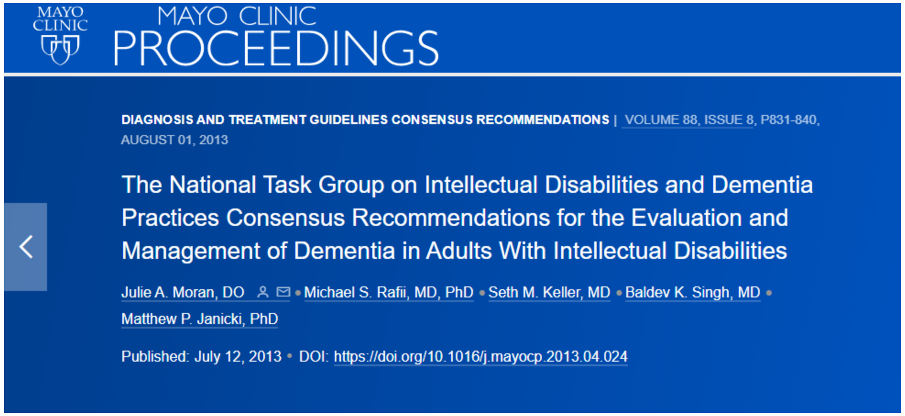
Traditional screening instruments for detecting dementia in the general population are designed for people with average baseline intelligence and are not useful for detecting cognitive impairment in adults with DS.

Example:

- Mini-Mental Status Exam (MMSE)
  - ✓ Ex. Count backwards from 100's by 7's

Alternative:

- NTG – EDSD (will be covered in afternoon session)



MAYO CLINIC PROCEEDINGS

DIAGNOSIS AND TREATMENT GUIDELINES CONSENSUS RECOMMENDATIONS | VOLUME 88, ISSUE 8, P831-840, AUGUST 01, 2013

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO • Michael S. Rafii, MD, PhD • Seth M. Keller, MD • Baldev K. Singh, MD • Matthew P. Janicki, PhD

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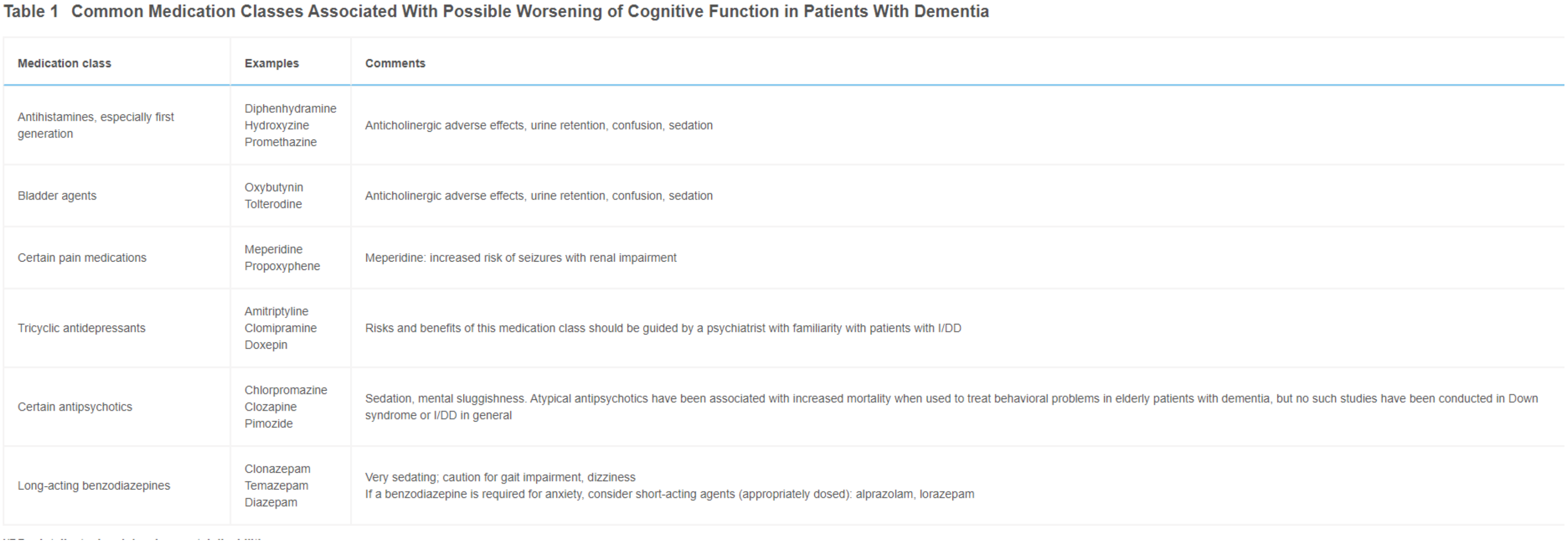


Table 1 **Common Medication Classes Associated With Possible Worsening of Cognitive Function in Patients With Dementia**

Medication class	Examples	Comments
Antihistamines, especially first generation	Diphenhydramine Hydroxyzine Promethazine	Anticholinergic adverse effects, urine retention, confusion, sedation
Bladder agents	Oxybutynin Tolterodine	Anticholinergic adverse effects, urine retention, confusion, sedation
Certain pain medications	Meperidine Propoxyphene	Meperidine: increased risk of seizures with renal impairment
Tricyclic antidepressants	Amitriptyline Clomipramine Doxepin	Risks and benefits of this medication class should be guided by a psychiatrist with familiarity with patients with I/DD
Certain antipsychotics	Chlorpromazine Clozapine Pimozide	Sedation, mental sluggishness. Atypical antipsychotics have been associated with increased mortality when used to treat behavioral problems in elderly patients with dementia, but no such studies have been conducted in Down syndrome or I/DD in general
Long-acting benzodiazepines	Clonazepam Temazepam Diazepam	Very sedating; caution for gait impairment, dizziness If a benzodiazepine is required for anxiety, consider short-acting agents (appropriately dosed): alprazolam, lorazepam

https://www.mayoclinicproceedings.org/action/showFullTableHTML?isHtml=true&tableId=tbl1&pii=S0025-6196%2813%2900371-6

Essentials of a Diagnostic Workup

- Medication review – especially polypharmacy, anticholinergics, antipsychotics
- History and physical (including psychiatric, personal, past medical and family histories and mental state assessment)
- Lab tests

  Evidence supports the following tests:
  - Complete blood cell count
  - Serum electrolytes
  - Glucose
  - BUN/creatinine
  - Vitamin B12 levels
  - Vitamin D - deficiency is highly prevalent in people with intellectual disabilities, partly because of insufficient exposure to sunlight.
  - Folate (folic acid, B9), especially if:
    - Long term use of antipsychotics
    - Epilepsy - anticonvulsants other than sodium valproate tend to lower serum folate level
  - Thyroid function tests
  - Liver function tests
  - Celiac screening if DS - blood sample to be taken to test for antibodies
- MRI and/or CT scan to detect lesions that could result in cognitive impairment.

www.tools.aan.com/professionals/practice/pdfs/dementia_guideline.pdf

Resources

DETECTION, DIAGNOSIS AND MANAGEMENT OF DEMENTIA

DIAGNOSIS AND TREATMENT GUIDELINES
Consensus Recommendations

The National Task Group on Intellectual Disabilities and Dementia Practices Consensus Recommendations for the Evaluation and Management of Dementia in Adults With Intellectual Disabilities

Julie A. Moran, DO; Michael S. Rafii, MD, PhD; Seth M. Keller, MD; Baldev K. Singh, MD; and Matthew P. Janicki, PhD

Detection, Diagnosis and Management of Dementia

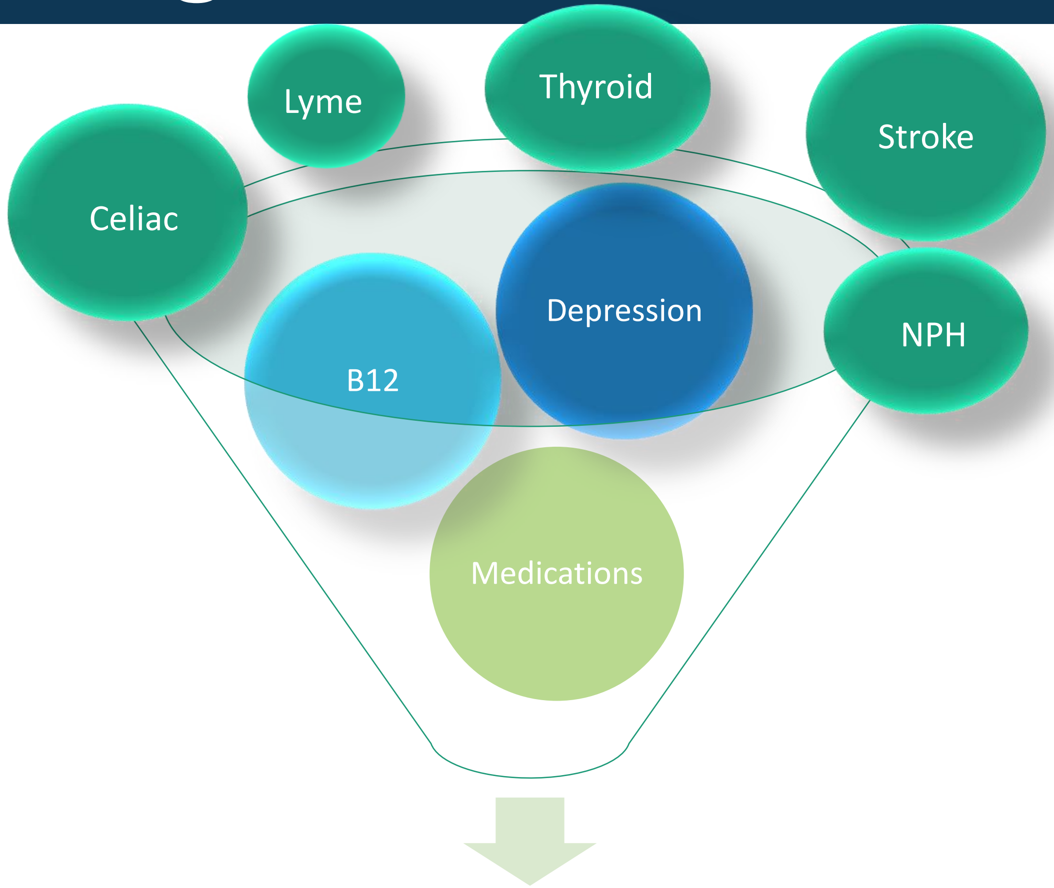
American Academy of Neurology

https://neurology.uams.edu/wp-content/uploads/sites/49/2018/03/Dementia-diagnosis.pdf

NTG Consensus Recommendations for the Evaluation and Management of Dementia in Adults with ID

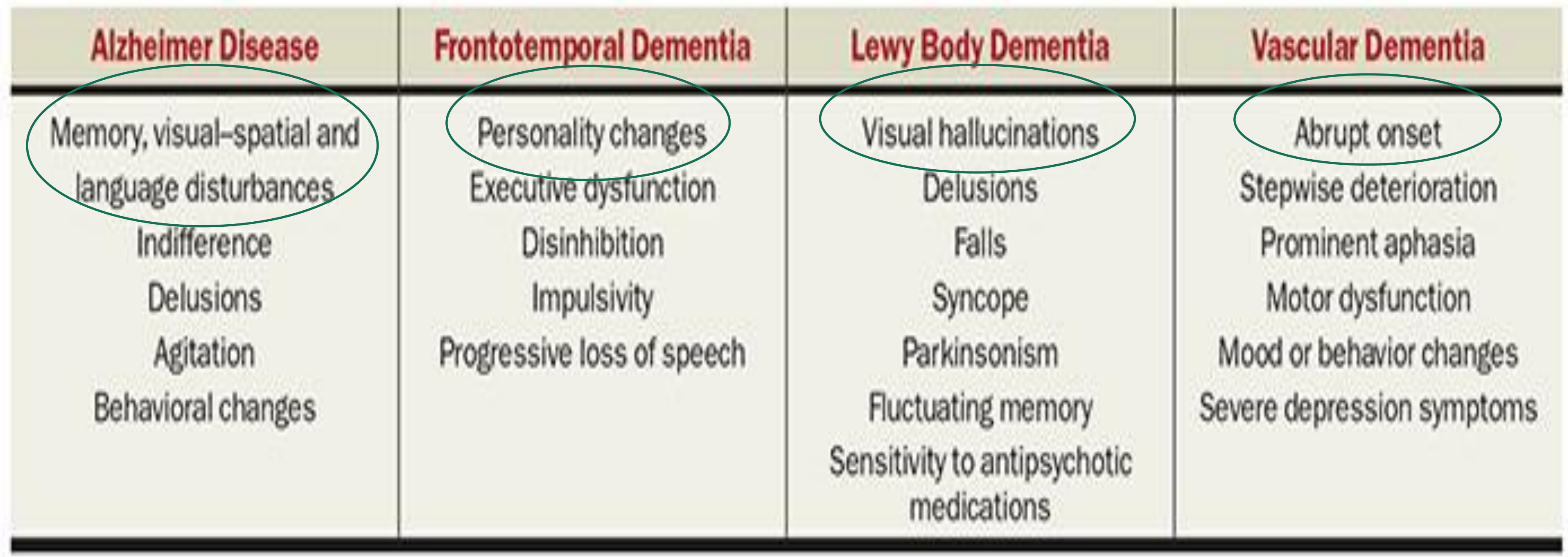
https://www.the-ntg.org/publications

Alzheimer's is a diagnosis of exclusion



Probable Alzheimer's

Clinical Features of Various Dementias



Alzheimer Disease	Frontotemporal Dementia	Lewy Body Dementia	Vascular Dementia
Memory, visual-spatial and language disturbances	Personality changes	Visual hallucinations	Abrupt onset
Indifference	Executive dysfunction	Delusions	Stepwise deterioration
Delusions	Disinhibition	Falls	Prominent aphasia
Agitation	Impulsivity	Syncope	Motor dysfunction
Behavioral changes	Progressive loss of speech	Parkinsonism	Mood or behavior changes
		Fluctuating memory	Severe depression symptoms
		Sensitivity to antipsychotic medications	

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

Treatment Considerations

- **Lewy body** – Sensitivity to certain antipsychotics.
- **Fronto-temporal:** Does not respond to common Alzheimer's medications such as Aricept and may have an adverse reaction.
- **Vascular dementia:** FDA has not approved any drugs specifically to treat symptoms of vascular dementia, but there is some clinical trial evidence that certain drugs approved to treat AD may also offer a modest benefit in people diagnosed with vascular dementia.
    - Also important - Substantial evidence that treatment of risk factors may improve outcomes and help postpone or prevent further decline.

The Three D's

Dementia

Gradual over months to years

Delirium

★

Sudden onset, hours to days

Depression

"Pseudodementia"

Recent unexplained change in mood that lasts for over 2 weeks

Medications for Alzheimer’s

- **Aricept*** (Donepezil)
- **Namenda**** (Memantine)
- **Exelon*** (Rivastigmine)
- **Razadyne*** (Galantamine)

- Often used together for moderate to severe AD.
- Statistically significant improvement in cognition and global function for patients treated with NAMENDA XR 28 mg plus an AChEI compared to placebo plus an AChEI

- **Namzaric – NEW 2015**. Extended release.
  - Namenda + Aricept
  - Approved for the treatment of moderate to severe dementia of the Alzheimer's type
  - Capsule can be opened to sprinkle onto food

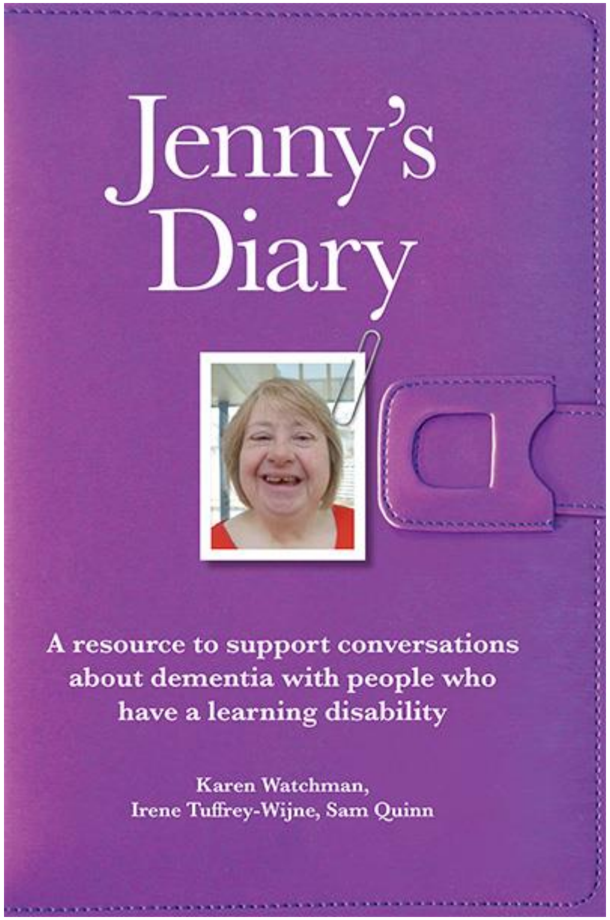
* Cholinesterase inhibitors are prescribed to treat symptoms related to memory, thinking, language, judgment and other thought processes in early to moderate AD. Delay worsening of symptoms for 6 to 12 months, on average, for about half the people who take them.

** Regulates the activity of glutamate, a different messenger chemical involved in learning and memory. Delays worsening of symptoms for some people temporarily.

Jenny's Diary

- Part 1 opens dialogue about why Jenny is behaving differently, and how she can be supported to live as well as possible with dementia.
- Part 2 suggests how to have a conversation with Jenny about her diagnosis of dementia.
- Part 3 contains guidance to talk about dementia with George, Jenny's partner.

http://www.uws.ac.uk/jennysdiary/



Homework Assignment

Thanks to the NTG volunteers who made this training possible.

National Task Group
on Intellectual Disabilities
and Dementia Practices

Homework Review

A Bit More on Alzheimer's Disease & Down Syndrome

Why Focus on Alzheimer's?

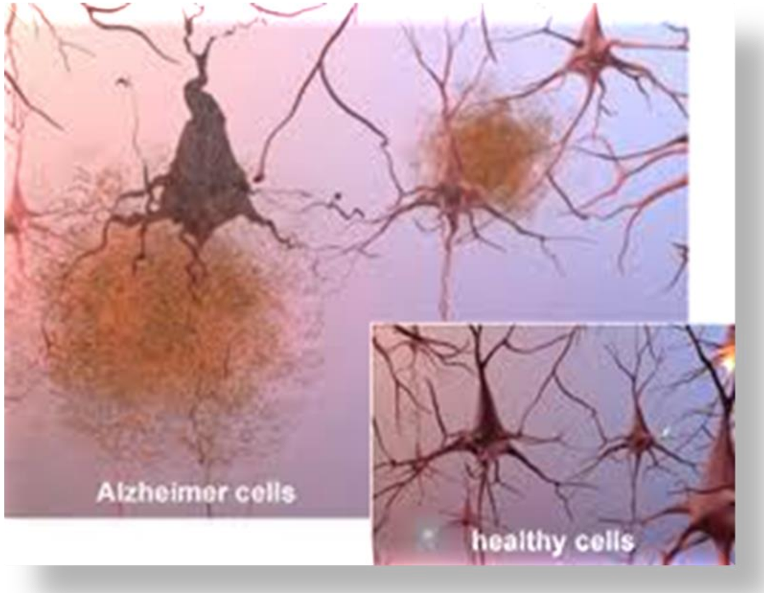
1. Most common form of dementia
2. People with DS have a greatly increased risk.
3. Alzheimer's often presents differently in people with Down syndrome (and possibly other forms of ID).

Common presenting symptoms:

- Abrupt onset of seizure activity
- Behavioral and personality change
- Short term memory impairment less common

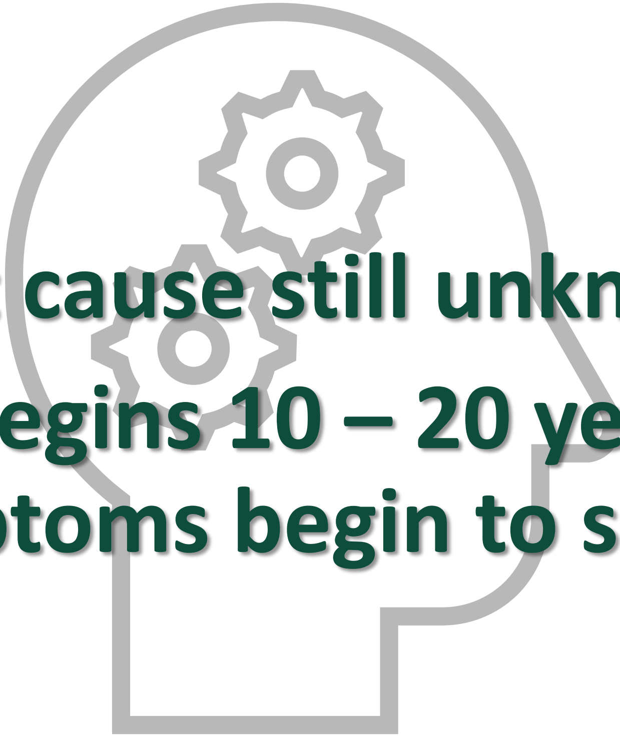
Just as in the general population, the course and symptom presentation is unpredictable and unique to the individual.

Alzheimer’s disease



- Most common form of dementia.
- Comes on slowly.
- Short term memory loss.
- Generalized brain atrophy.
  - Shrinks by 30% by time of death.
- Amyloid plaques and neurofibrillary tangles.

What Causes Alzheimer’s?



Exact cause still unknown.

Damage begins 10 – 20 years before symptoms begin to show!

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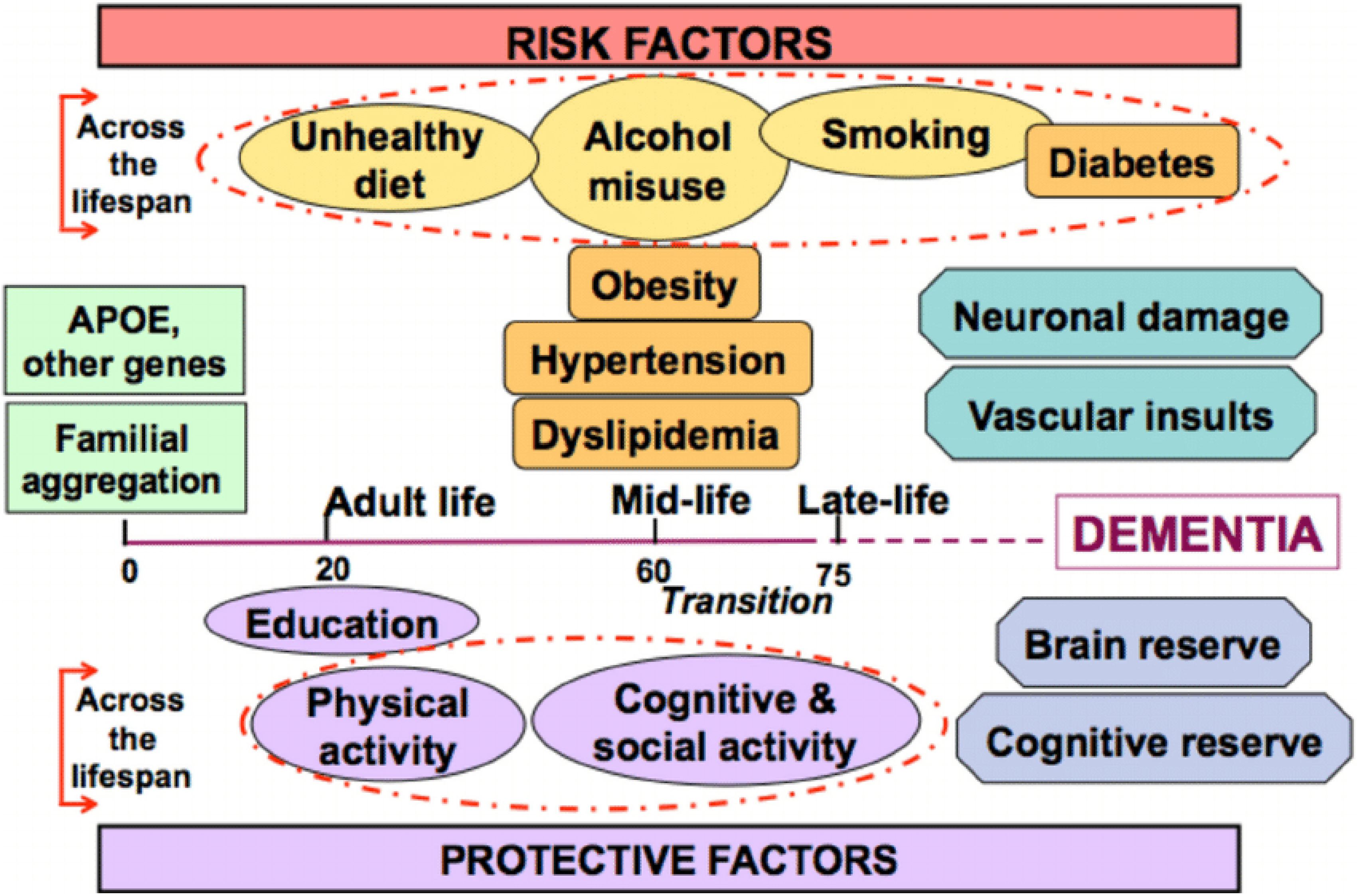


RISK FACTORS

Across the lifespan

Unhealthy diet

Alcohol misuse

Smoking

Diabetes

Obesity

Hypertension

Dyslipidemia

APOE, other genes

Familial aggregation

Neuronal damage

Vascular insults

Adult life

Mid-life

Late-life

0

20

60

75

Transition

DEMENTIA

Education

Across the lifespan

Physical activity

Cognitive & social activity

Brain reserve

Cognitive reserve

PROTECTIVE FACTORS

Source: Sindi, Shireen & Mangialasche, Francesca & Kivipelto, Miia. (2015). Advances in the prevention of Alzheimer's Disease. F1000Prime Reports. 7. 10.12703/P7-50).

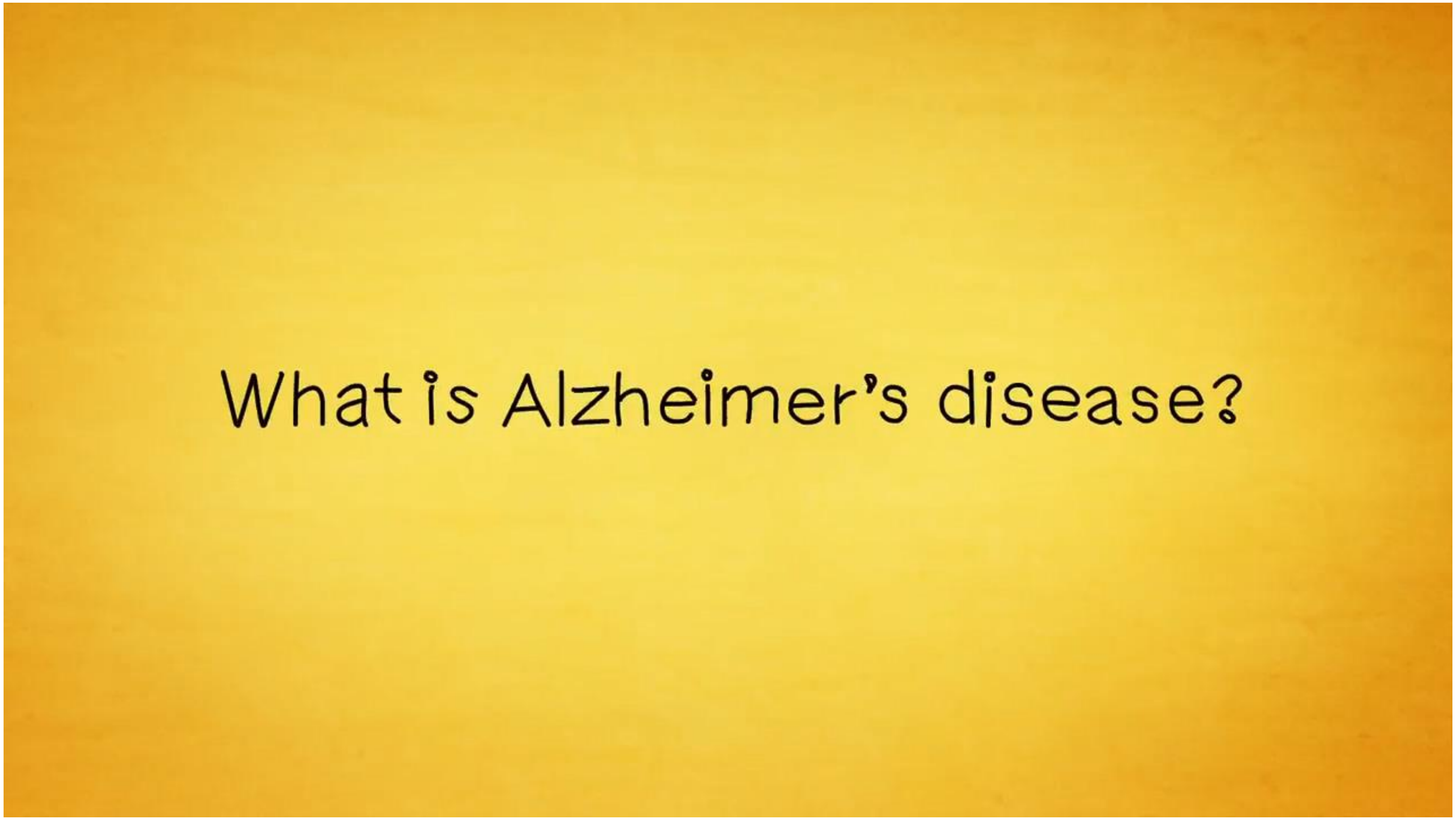
Continued

- Most people with Alzheimer’s disease have “late-onset” Alzheimer’s.
  - After age 65.
- Early-onset Alzheimer’s is a rare form of the disease.
  - Age 30 to 60
  - Less than 5 percent of all people who have Alzheimer’s disease.
- Individuals with Down syndrome develop Alzheimer’s at a younger age than the general population.

Mild Cognitive Impairment (MCI)

- Memory problems greater than those expected for age.
- Do not experience the personality changes or other problems that are characteristic of AD.
- Serious enough to be noticed by the individuals experiencing them or to other people…but ***not severe enough to interfere with ability to function in daily life.***
- Because the changes caused by MCI are not *severe enough to affect daily life*, a person with MCI does not meet diagnostic guidelines for dementia.

How does Alzheimer’s disease progress?



Stage Related Changes in Alzheimer's

Early Stage	Middle Stage	Late Stage
• Confusion and memory loss • Disorientation in space • Problems with routine tasks • Changes in personality and judgment	• Difficulties with ADLs • Anxiety, paranoia, agitation and other compromising behaviors • Sleep difficulties • Difficulty recognizing familiar people	• Loss of speech • Loss of appetite, weight loss • Loss of bladder and bowel control • Loss of mobility • Total dependence on others • Death

End-of-Life

Recognizing Signs of End-of-Life

Final Two-to-Three Months

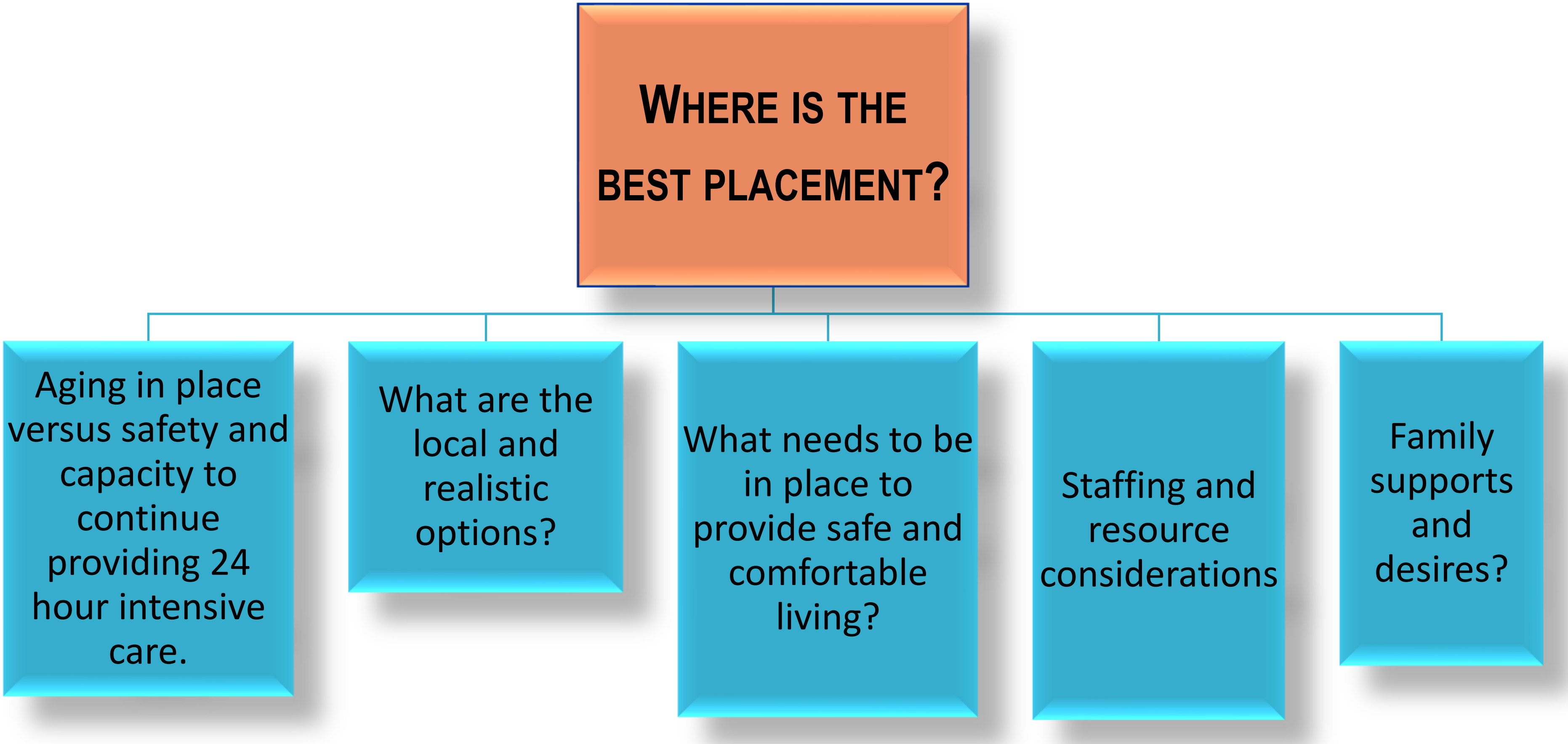
- Speech limited to six words or less per day
- Difficulty in swallowing or choking on liquids or food
- Unable to walk or sit upright without assistance
- Incontinence

Final Days/Weeks

- Hands, feet, arms and legs may be increasingly cold to the touch
- Inability to swallow
- Terminal agitation or restlessness
- An increasing amount of time asleep or drifting into unconsciousness
- Changes in breathing, including shallow breaths or periods without breathing for several seconds or up to a minute

Source: Crossroads Hospice

Aging in Place



WHERE IS THE BEST PLACEMENT?

Aging in place versus safety and capacity to continue providing 24 hour intensive care.

What are the local and realistic options?

What needs to be in place to provide safe and comfortable living?

Staffing and resource considerations

Family supports and desires?

"Ageing in place is only an appropriate long-term option if the support level continues to increase
on an individual basis. It may mean that the person is able to remain in their own accommodation, but this should not be assumed."

People with a learning disability and dementia: reducing marginalization. Karen Watchman. Vol 2 No 6 December 2013/January 2014 Australian Journal of Dementia Care.

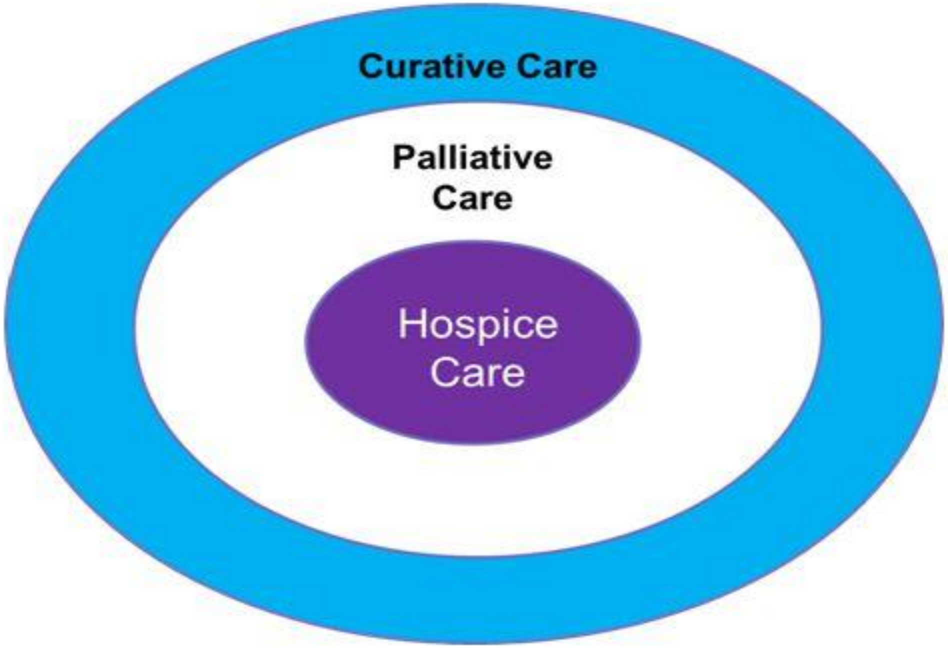
Hospice vs. Palliative Care

Palliative Care

- **Any time during illness**
- May be combined with curative care
- Independent of insurer
- Complementary therapies often included

Hospice

- **Prognosis of < 6 mo**
- Focus on comfort care
- Medicare hospice benefit
- Volunteers integral & required aspect of the program



"Hospice is for the predictably dying"

Hospice Criteria for Dementia

Most programs use the following as a standard in assessing if a dementia patient is appropriate for Medicare hospice services:

- **The patient has a stage 7 ranking on the Functional Assessment Staging (FAST) scale.**
  The FAST scale consists of 16 items that rank the progression of dementia symptoms. For example, a ranking at stage 7 means a patient suffers from incontinence and is unable to dress, bathe, walk, or use the restroom without help. They are also unable to speak meaningfully or express their own thoughts.
- **Other illnesses presently exist alongside the patient's dementia.**
  Also known as "comorbidities," these are an important part of hospice eligibility. Dementia comorbidities can include sepsis, severe weight loss, pneumonia, pressure ulcers and fever. A present comorbidity is often an enrollment requirement, and the patient is required to have received treatment for that comorbidity within the last year.

"Dementia patients who died with hospice vs. those who died without hospice have better pain control, are less likely to die in a hospital, and their families have greater satisfaction with end-of-life care"

Susan Mitchell, MD, senior scientist at the Institute for Aging Research, Hebrew SeniorLife in Boston.

"A lack of appreciation of the nature of dementia leads to misguided and often overly aggressive end-stage treatment."

Greg Sachs, MD. Indiana University Center for Aging Research

Memory loss is an early hallmark of dementia. But experts in the field say dementia is more accurately defined as fatal brain failure: a terminal disease, like cancer, that physically kills patients, not simply a mental ailment that accompanies older age.

Experts Redefine Dementia as a Terminal Disease – TIME.

"We forget the brain does everything for us — controls the heart, the lungs, the gastrointestinal tract, the metabolism.“

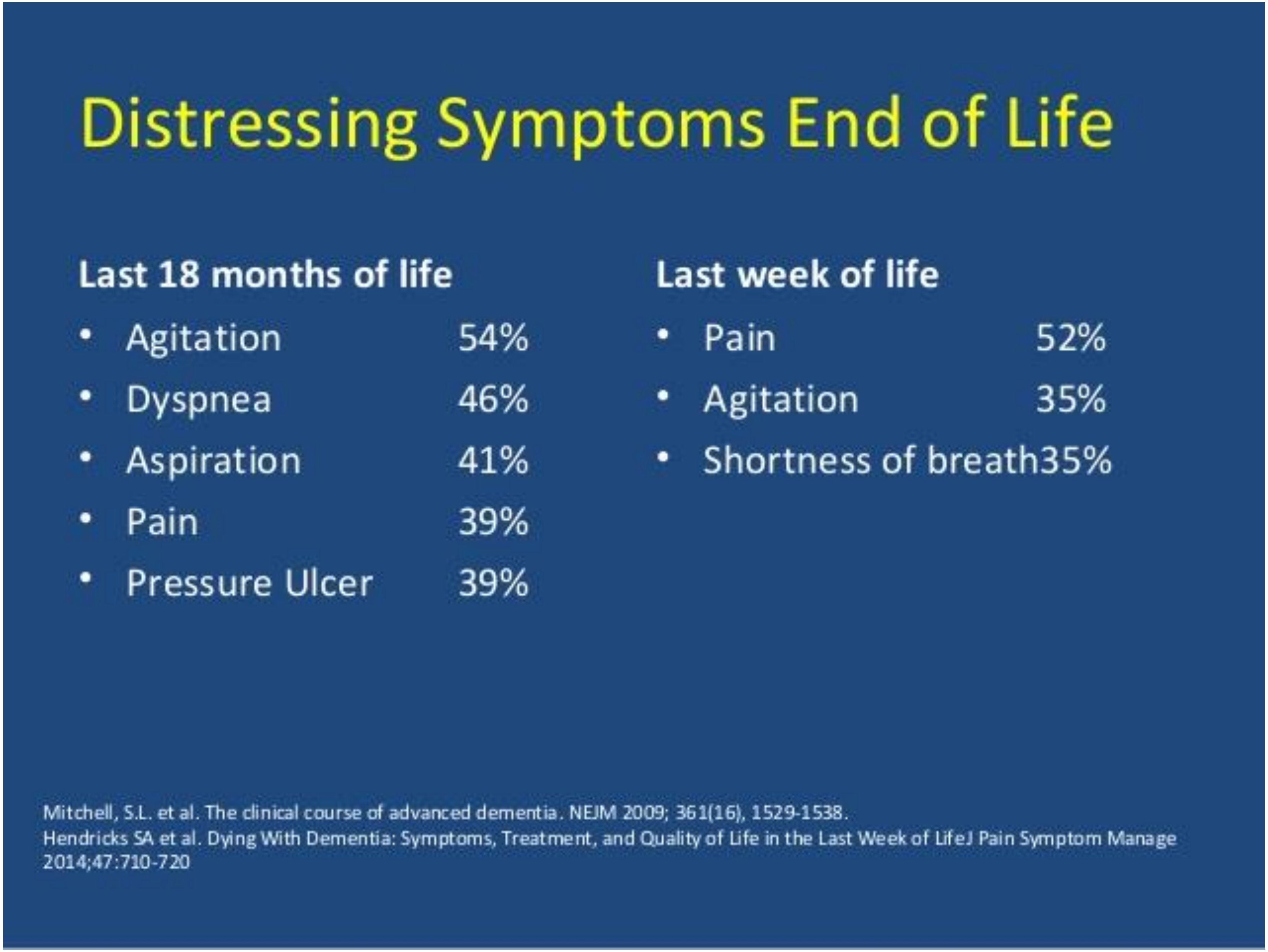
Dr. Claudia Kawas
Professor of neurology
University of California, Irvine

- Often aggressive treatment as opposed to palliative care.
- Research has shown that a large percentage of people in end-stage dementia are sent to the emergency room, hospitalized, tube-fed or given IV nutrition during the last three months of life.
- These interventions can themselves cause distress and pain while providing, at best, questionable benefit and minimal prolongation of life.

How do you know whether a patient with end-stage dementia is experiencing pain or suffering when the patient has lost the ability to communicate verbally?

- Assume that patients with dementia experience some pain.
  - Observe end-stage patients who cannot talk for pain behaviors, such as grimacing, resisting movement, agitation, and restlessness.
  - Before giving the patient a tranquilizer, a trial of analgesics should be attempted to see if the agitation or restlessness resolves.

Source: R. Sean Morrison, MD, director of the National Palliative Care Research Center, Brookdale Department of Geriatrics and Adult Development, Mount Sinai School of Medicine, New York City



Distressing Symptoms End of Life

Last 18 months of life

Agitation	54%
Dyspnea	46%
Aspiration	41%
Pain	39%
Pressure Ulcer	39%

Last week of life

Pain	52%
Agitation	35%
Shortness of breath	35%

Mitchell, S.L. et al. The clinical course of advanced dementia. NEJM 2009; 361(16), 1529-1538.
Hendricks SA et al. Dying With Dementia: Symptoms, Treatment, and Quality of Life in the Last Week of LifeJ Pain Symptom Manage 2014;47:710-720

Tube Feeding

Loss of the swallowing reflex in advanced dementia is a sign of brain deterioration.

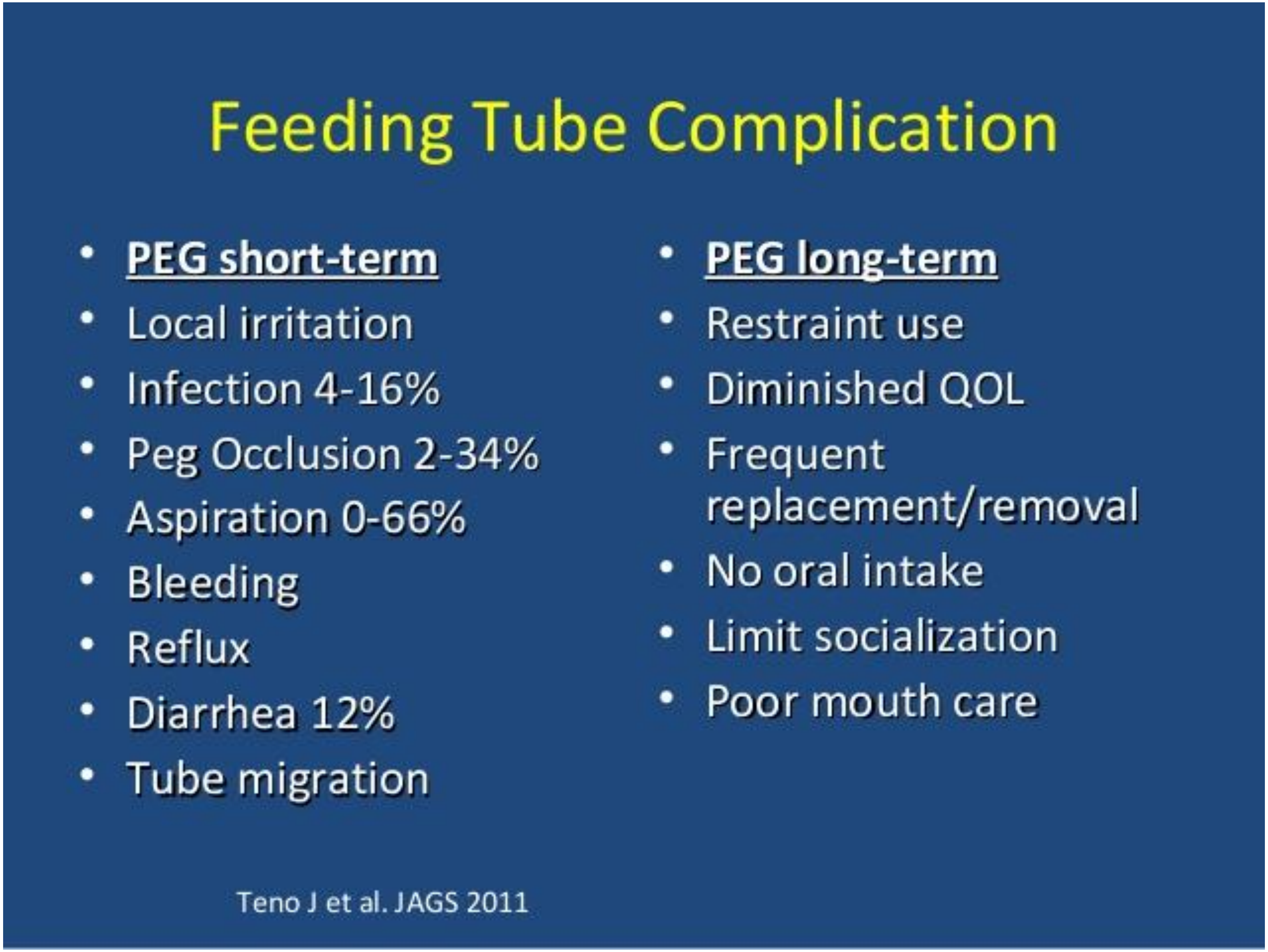
Studies have shown that feeding tubes are of unproven benefit in ensuring adequate nutrition, preventing pressure sores, preventing aspiration pneumonia, providing comfort, improving functional status, or extending life in patients with advanced dementia.

Position Statement of the Alzheimer's Association

The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer's disease or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth.

The Association emphasizes that assisted oral feeding (hand feeding) should be available to all persons with advanced Alzheimer's disease. Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding.

www.alz.org/documents_custom/statements/Assisted_Oral_Tube_Feeding.pdf



Feeding Tube Complication

- **PEG short-term**
- Local irritation
- Infection 4-16%
- Peg Occlusion 2-34%
- Aspiration 0-66%
- Bleeding
- Reflux
- Diarrhea 12%
- Tube migration

- **PEG long-term**
- Restraint use
- Diminished QOL
- Frequent replacement/removal
- No oral intake
- Limit socialization
- Poor mouth care

Teno J et al. JAGS 2011

Research on Tube Feeding

- Does not usually improve nutritional status
- Does not prevent or lower the incidence of aspiration pneumonia
- No evidence to suggest reduces skin breakdown or the likelihood of pressure sores.
- No difference in longevity between persons with advanced Alzheimer's disease who are tube fed and those provided with assistance in oral feeding.
- Tube feeding has been associated with increased diarrhea and related discomfort.
- Can also result in greatly increased use of physical restraints to prevent individuals from pulling the tubes out of their abdomens.

www.alz.org/documents_custom/statements/Assisted_Oral_Tube_Feeding.pdf

Summary

- Focus on comfort, not life prolongation
  - Feeding tubes not recommended
- Consider palliative care and hospice
  - Palliative care is available at any stage
- Connect through the senses
  - Touch – hand, foot massage
  - Smell – favorite perfume, aromatherapy
  - Sight – videos of calming scenes
  - Hearing – talk to the person, favorite music

Health Care Advocacy

Section Objectives

Participants will be able to:

- List steps of health care advocacy.
- Discuss the process of conducting quality observations for health care advocacy.
- Be able to apply this information to a sample case study to make appropriate recommendations for follow-up.
- Understand that while caregivers are not responsible for the assessment and diagnosis their input is essential for an accurate and helpful diagnosis/intervention.

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

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

There are often interventions that make a difference in quality of life and health.

Staff and family are the experts about individuals with ID.

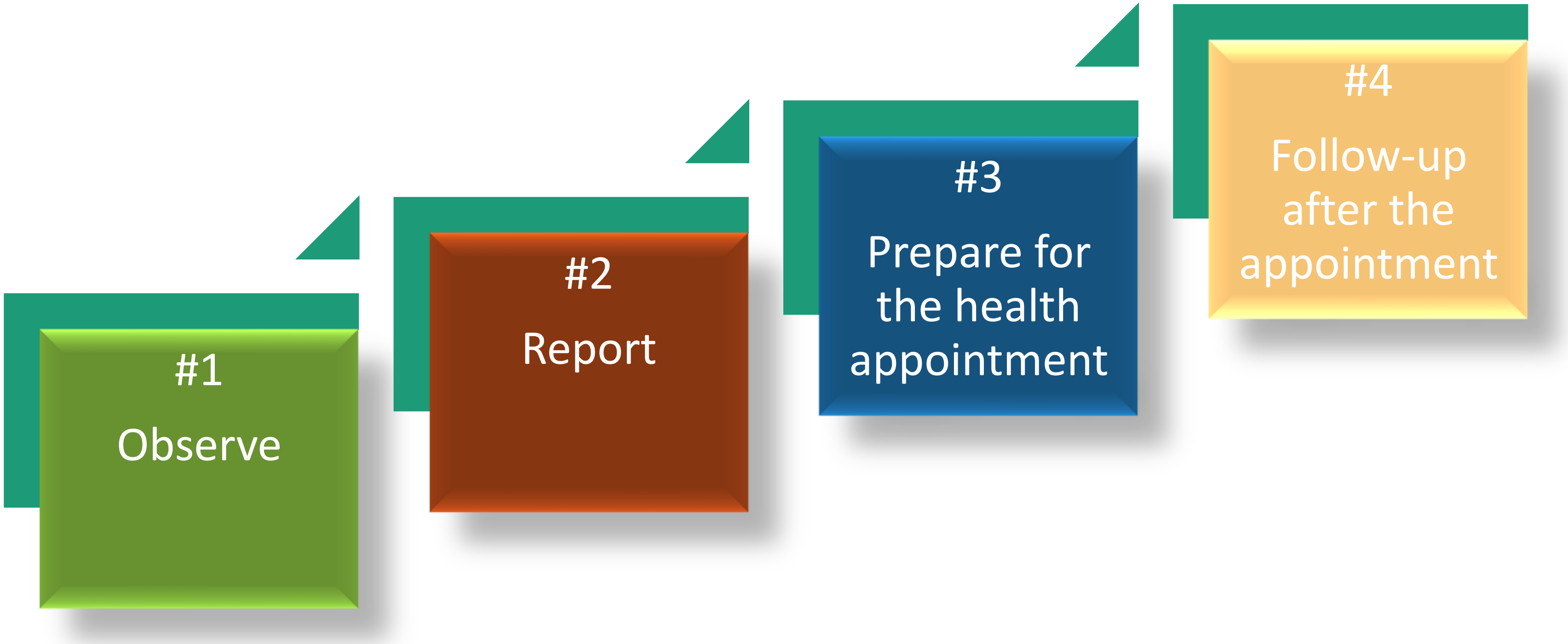
- To recognize current changes and symptoms knowing the person across the lifespan is the best resource.

Health care is an art, not a science!

Why do people with ID and dementia need an advocate?

- 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

#2

Report

#3

Prepare for the health appointment

#4

Follow-up after the appointment

First…

#1. Observe

- Functional and behavioral changes observed are 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 wake/sleep patterns
- Diarrhea/constipation

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

Then…

#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!

Be proactive

#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

Always rule out potentially 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 the 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.
  - Beers List
    www.americangeriatrics.org/files/documents/beers/PrintableBeersPocketCard.pdf
  - 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!

Be persistent! Be an advocate!

Early Screening for Dementia (EDSD)

The early identification of signs and symptoms of cognitive impairment and dementia is an important first step in managing the course of the disease and providing quality care.

ntg

National Task Group on Intellectual Disabilities and Dementia Practices

Establish a Baseline to Identify Future Change in Function

Why is it important to identify changes in function early?

- Signal the need for a more comprehensive evaluation and help in **identifying the cause** of the functional decline,
- Result in **treatments or interventions** that reverse functional change, or
- Introduce a period of **greater surveillance** to check for other areas of decline or change, and
- Inform future **changes to program, supports, supervision**.

Change in Skills Over Time is Meaningful

EDSD Purpose: Monitor and screen for any changes in health/ cognitive function over time.

- Items that make up the NTG-EDSD are **associated with the changes typically observed in dementia**.
- Screening tool…**not a diagnostic tool**.
  - A screening tool does not help establish the origins of change; but, it is useful in substantiating change.
- Establishes a **baseline assessment** for persons who are at risk of developing dementia prior to the onset of the disorder. (Zeilinger, Esralew et al.)
- Can also be used in the **detection of other conditions that might otherwise remain untreated**.
- **No formal training** needed.

The Scotland study also determined the EDSD was useful in sharing information between staff and family carer.

*“In some circumstances, **information about individual health conditions were only discovered after completion of the NTG-EDSD, despite the individual using services and being known to staff for a number of years.** This shows just how multiple and complex an individual with learning disabilities needs can be, and how it is possible for staff and services to be unaware of certain conditions or issues if there is no clear method of communicating this information.”*

The NTG-EDSD has proved to be a useful tool in prompting carers and staff to be aware of all of these needs.

EDSD

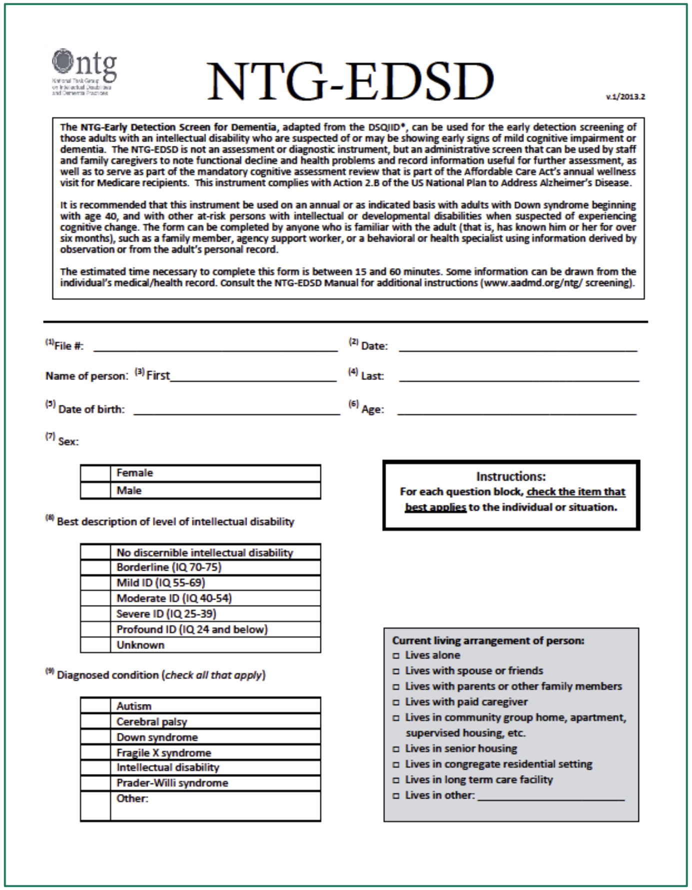
Adapted from:

- Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007), and
- Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)

15 – 60 minutes to complete

Down Syndrome age 40 then annually
Non-DS begin at age 50

Video as an adjunct



NTG-EDSD

v.1/2013.2

The NTG-Early Detection Screen for Dementia, adapted from the DSQIID*, can be used for the early detection screening of those adults with an intellectual disability 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).

(1) File #: ______________________ (2) Date: ______________________

Name of person: (3) First______________________ (4) Last: ______________________

(5) Date of birth: ______________________ (6) Age: ______________________

(7) Sex:

	Female
	Male

Instructions:
For each question block, check the item that best applies to the individual or situation.

(8) Best description of level of intellectual disability

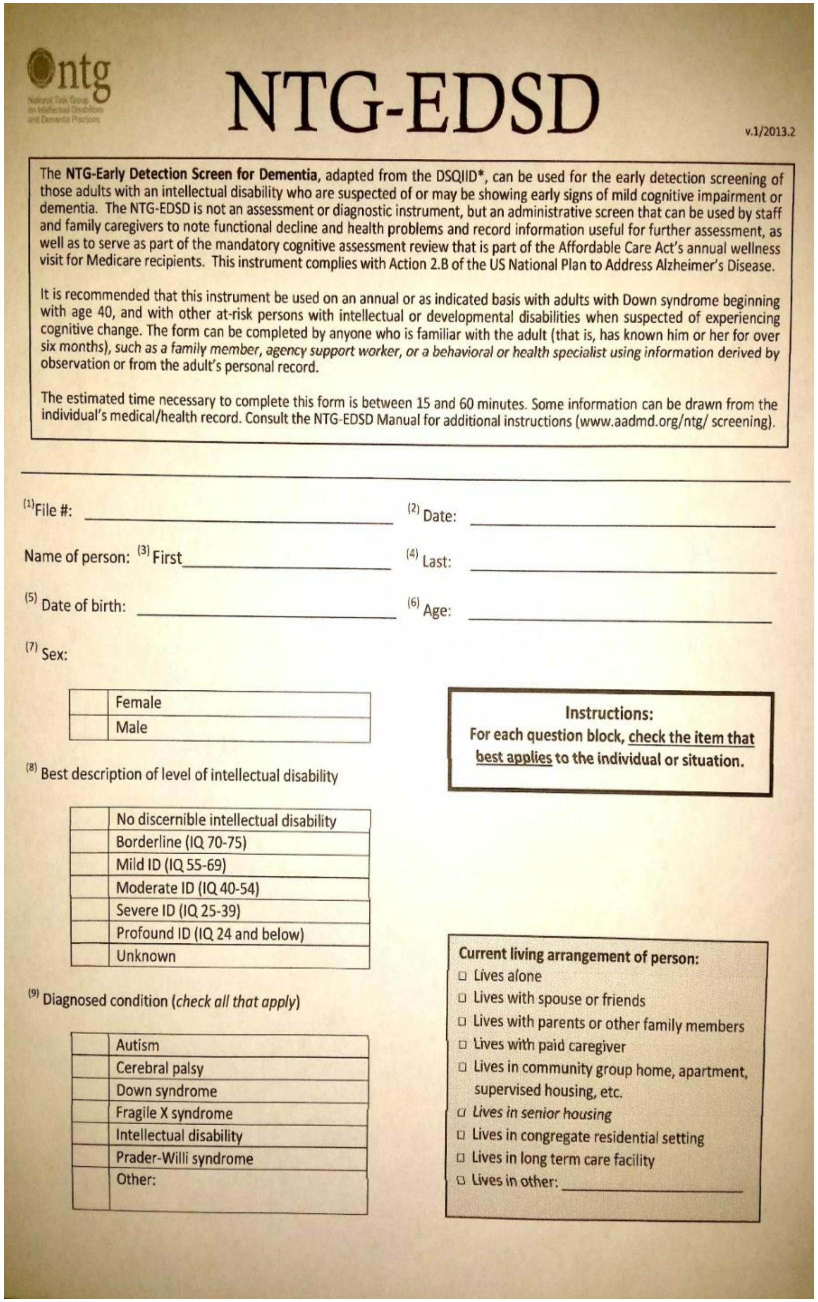
	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:
☐ Lives alone
☐ Lives with spouse or friends
☐ Lives with parents or other family members
☐ Lives with paid caregiver
☐ Lives in community group home, apartment, supervised housing, etc.
☐ Lives in senior housing
☐ Lives in congregate residential setting
☐ Lives in long term care facility
☐ Lives in other: ______________________

Tool & manual available online in multiple languages:
www.aadmd.org/ntg/screening



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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).

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(1) File #: ____________________ (2) Date: ____________________

Name of person: (3) First____________________ (4) Last: ____________________

(5) Date of birth: ____________________ (6) Age: ____________________

(7) Sex:

	Female
	Male

Instructions:
For each question block, <u>check the item that best applies</u> to the individual or situation.

(8) Best description of level of intellectual disability

	No discernible intellectual disability
	Borderline (IQ 70-75)
	Mild ID (IQ 55-69)
	Moderate ID (IQ 40-54)
	Severe ID (IQ 25-39)
	Profound ID (IQ 24 and below)
	Unknown

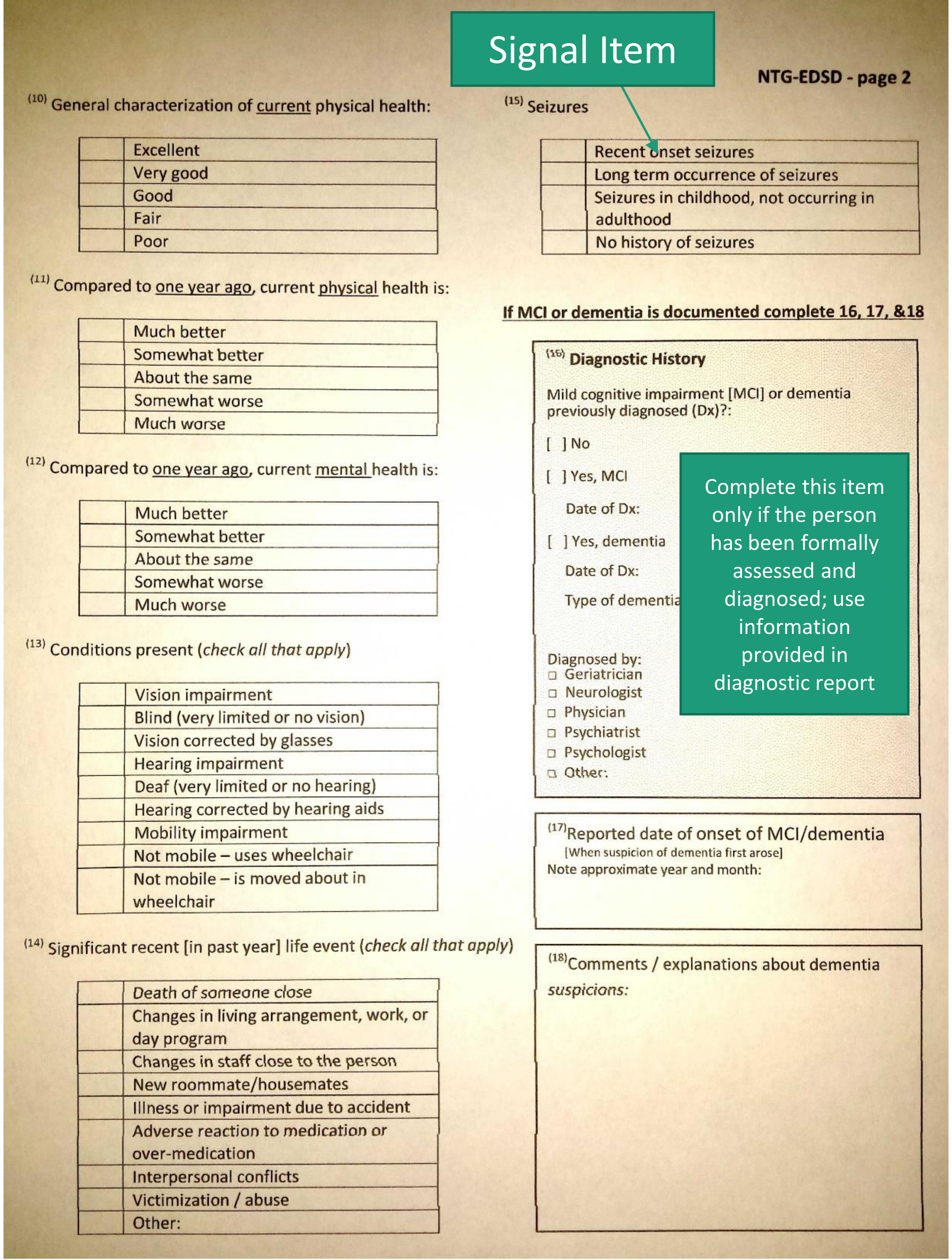
(9) Diagnosed condition (*check all that apply*)

	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

Current living arrangement of person:

- ☐ Lives alone
- ☐ Lives with spouse or friends
- ☐ Lives with parents or other family members
- ☐ Lives with paid caregiver
- ☐ Lives in community group home, apartment, supervised housing, etc.
- ☐ *Lives in senior housing*
- ☐ Lives in congregate residential setting
- ☐ Lives in long term care facility
- ☐ Lives in other: ____________________

Draw from any previously completed assessments (or estimate if none ever done)



NTG-EDSD - page 2

(10) General characterization of current physical health:

	Excellent
	Very good
	Good
	Fair
	Poor

(11) Compared to one year ago, current physical health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(12) Compared to one year ago, current mental health is:

	Much better
	Somewhat better
	About the same
	Somewhat worse
	Much worse

(13) Conditions present (*check all that apply*)

	Vision impairment
	Blind (very limited or no vision)
	Vision corrected by glasses
	Hearing impairment
	Deaf (very limited or no hearing)
	Hearing corrected by hearing aids
	Mobility impairment
	Not mobile – uses wheelchair
	Not mobile – is moved about in wheelchair

(14) Significant recent [in past year] life event (*check all that apply*)

	Death of someone close
	Changes in living arrangement, work, or day program
	Changes in staff close to the person
	New roommate/housemates
	Illness or impairment due to accident
	Adverse reaction to medication or over-medication
	Interpersonal conflicts
	Victimization / abuse
	Other:

Signal Item

(15) Seizures

	Recent onset seizures
	Long term occurrence of seizures
	Seizures in childhood, not occurring in adulthood
	No history of seizures

If MCI or dementia is documented complete 16, 17, &18

(16) **Diagnostic History**

Mild cognitive impairment [MCI] or dementia previously diagnosed (Dx)?:

[ ] No

[ ] Yes, MCI

Date of Dx:

[ ] Yes, dementia

Date of Dx:

Type of dementia

Diagnosed by:
- ☐ Geriatrician
- ☐ Neurologist
- ☐ Physician
- ☐ Psychiatrist
- ☐ Psychologist
- ☐ Other:

Complete this item only if the person has been formally assessed and diagnosed; use information provided in diagnostic report

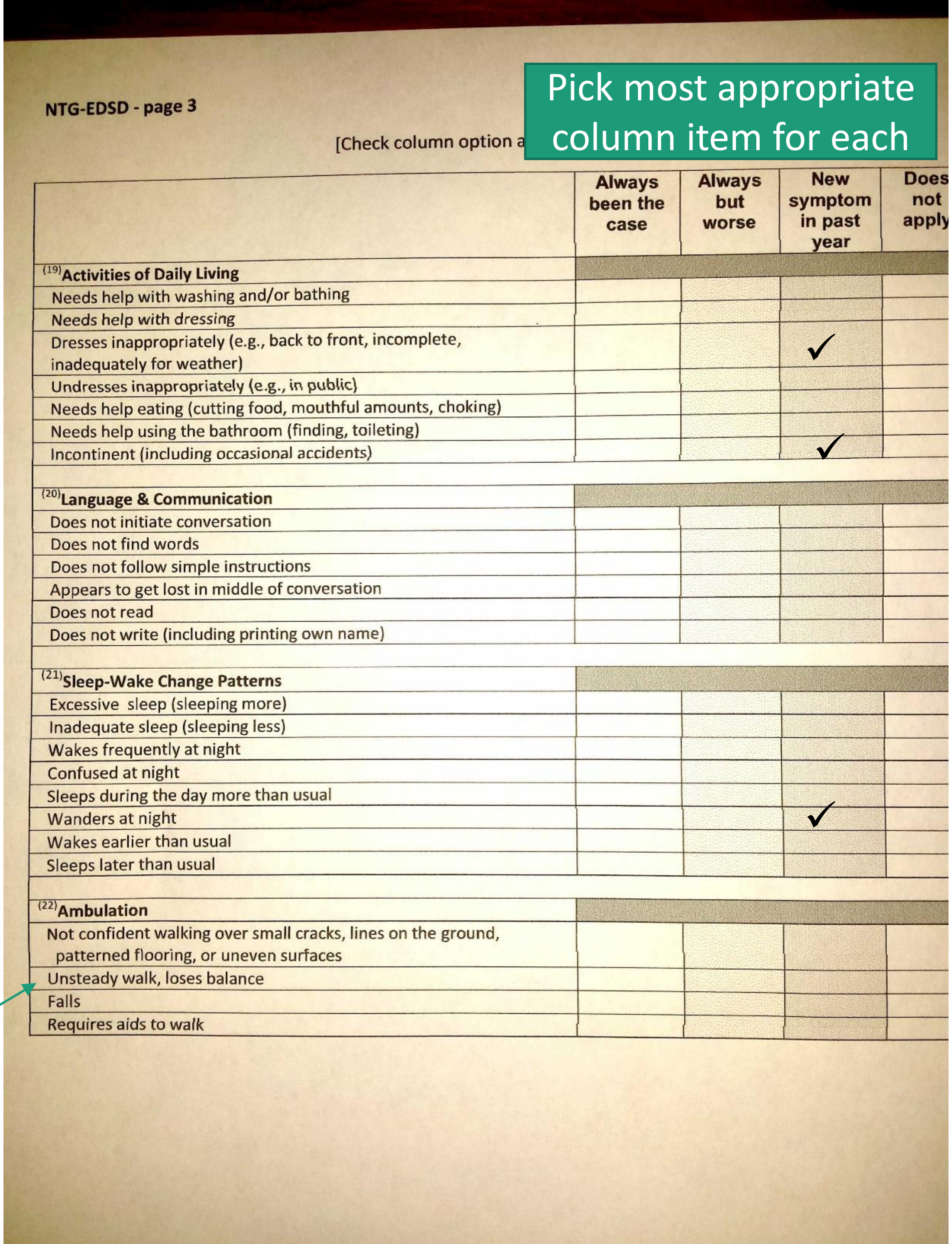
(17) Reported date of onset of MCI/dementia

[When suspicion of dementia first arose]

Note approximate year and month:

(18) Comments / explanations about dementia *suspicions:*

Pick most appropriate column item for each

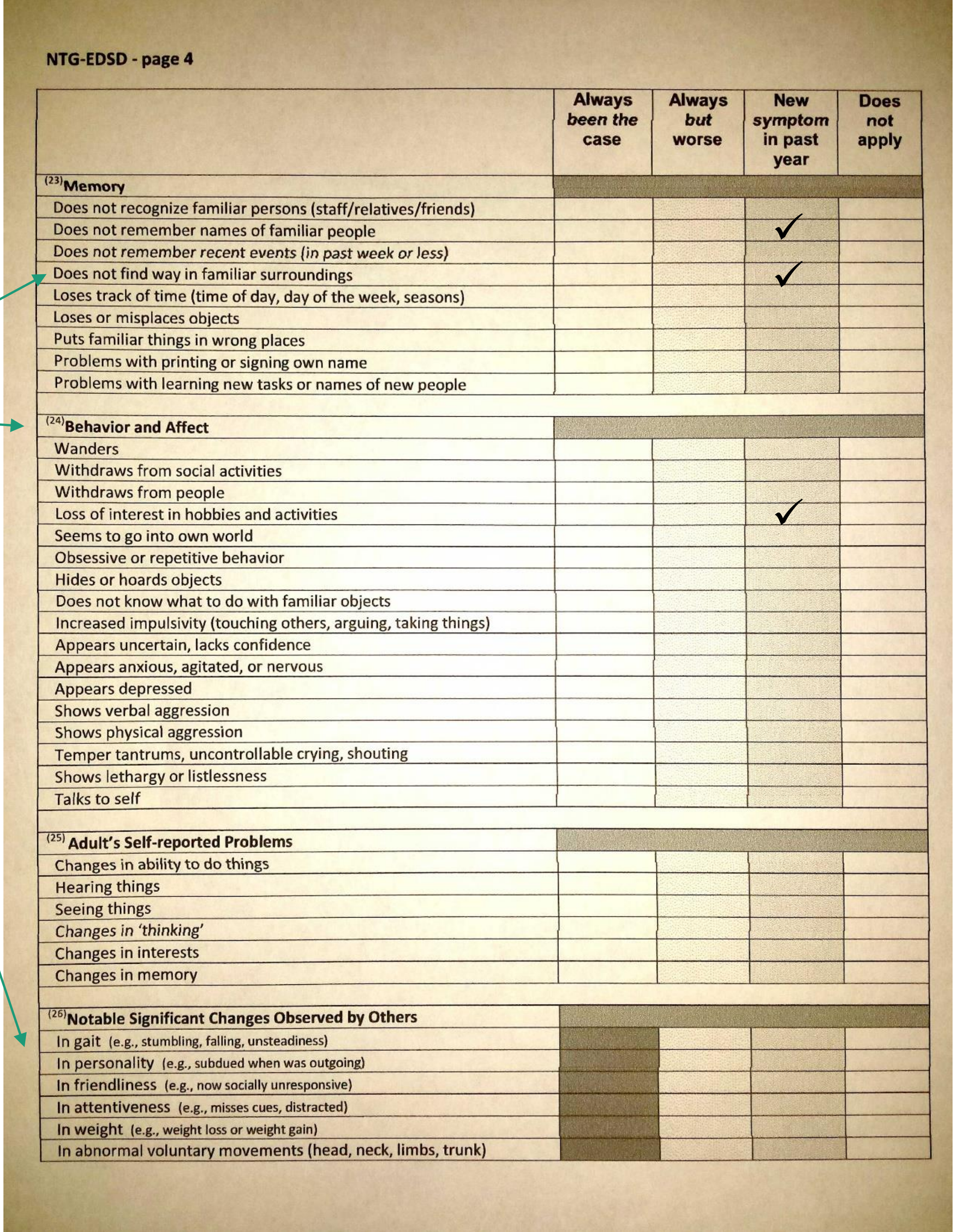


NTG-EDSD - page 3

[Check column option a

	Always been the case	Always but worse	New symptom in past year	Does not apply
(19) Activities of Daily Living				
Needs help with washing and/or bathing				
Needs help with dressing				
Dresses inappropriately (e.g., back to front, incomplete, inadequately for weather)			✓	
Undresses inappropriately (e.g., in public)				
Needs help eating (cutting food, mouthful amounts, choking)				
Needs help using the bathroom (finding, toileting)				
Incontinent (including occasional accidents)			✓	
(20) Language & Communication				
Does not initiate conversation				
Does not find words				
Does not follow simple instructions				
Appears to get lost in middle of conversation				
Does not read				
Does not write (including printing own name)				
(21) Sleep-Wake Change Patterns				
Excessive sleep (sleeping more)				
Inadequate sleep (sleeping less)				
Wakes frequently at night				
Confused at night				
Sleeps during the day more than usual				
Wanders at night			✓	
Wakes earlier than usual				
Sleeps later than usual				
(22) Ambulation				
Not confident walking over small cracks, lines on the ground, patterned flooring, or uneven surfaces				
Unsteady walk, loses balance				
Falls				
Requires aids to walk				

Signal Item

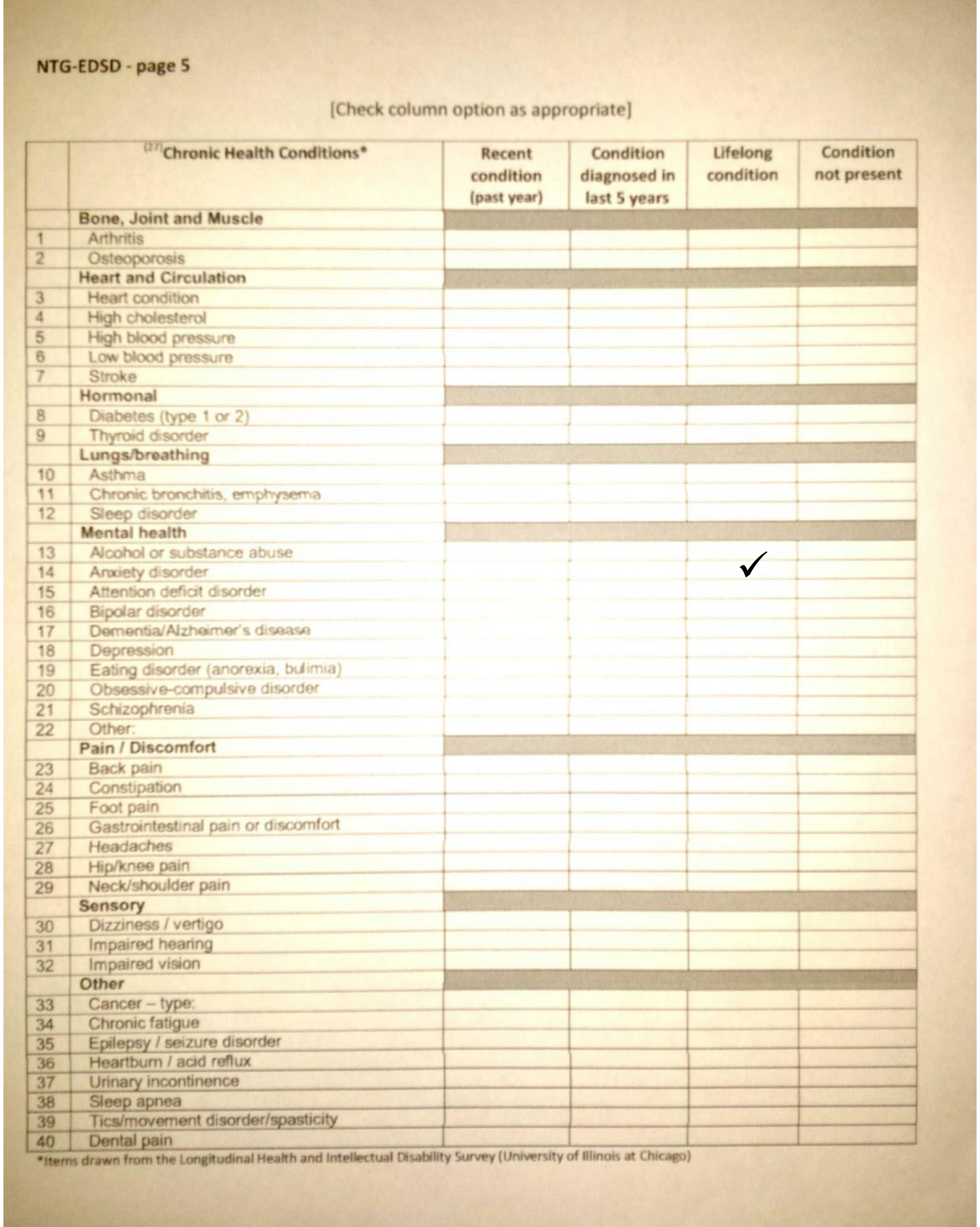


NTG-EDSD - page 4

	Always *been the* case	Always *but* worse	New *symptom* in past year	Does not apply
(23) Memory				
Does not recognize familiar persons (staff/relatives/friends)				
Does not remember names of familiar people			✓	
Does not remember recent events *(in past week or less)*				
Does not find way in familiar surroundings			✓	
Loses track of time (time of day, day of the week, seasons)				
Loses or misplaces objects				
Puts familiar things in wrong places				
Problems with printing or signing own name				
Problems with learning new tasks or names of new people				
(24) Behavior and Affect				
Wanders				
Withdraws from social activities				
Withdraws from people				
Loss of interest in hobbies and activities			✓	
Seems to go into own world				
Obsessive or repetitive behavior				
Hides or hoards objects				
Does not know what to do with familiar objects				
Increased impulsivity (touching others, arguing, taking things)				
Appears uncertain, lacks confidence				
Appears anxious, agitated, or nervous				
Appears depressed				
Shows verbal aggression				
Shows physical aggression				
Temper tantrums, uncontrollable crying, shouting				
Shows lethargy or listlessness				
Talks to self				
(25) Adult's Self-reported Problems				
Changes in ability to do things				
Hearing things				
Seeing things				
Changes in 'thinking'				
Changes in interests				
Changes in memory				
(26) Notable Significant Changes Observed by Others				
In gait (e.g., stumbling, falling, unsteadiness)				
In personality (e.g., subdued when was outgoing)				
In friendliness (e.g., now socially unresponsive)				
In attentiveness (e.g., misses cues, distracted)				
In weight (e.g., weight loss or weight gain)				
In abnormal voluntary movements (head, neck, limbs, trunk)				

Signal Item

Draw from any previously completed medical evaluations or current health notes in record

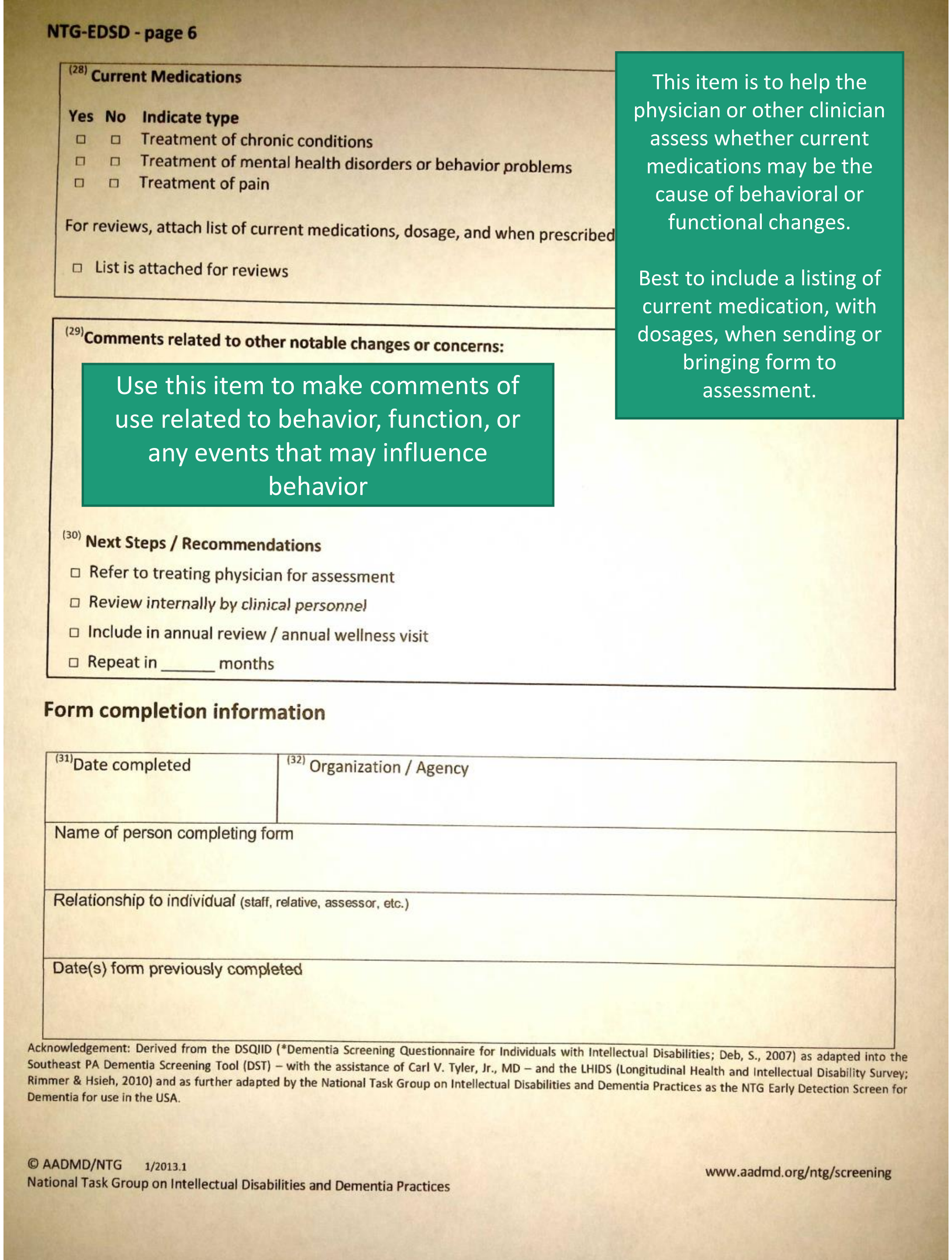


NTG-EDSD - page 5

[Check column option as appropriate]

	(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				
29	Neck/shoulder pain				
	Sensory				
30	Dizziness / vertigo				
31	Impaired hearing				
32	Impaired vision				
	Other				
33	Cancer – type:				
34	Chronic fatigue				
35	Epilepsy / seizure disorder				
36	Heartburn / acid reflux				
37	Urinary incontinence				
38	Sleep apnea				
39	Tics/movement disorder/spasticity				
40	Dental pain				

*Items drawn from the Longitudinal Health and Intellectual Disability Survey (University of Illinois at Chicago)



NTG-EDSD - page 6

(28) Current Medications

Yes	No	Indicate type
☐	☐	Treatment of chronic conditions
☐	☐	Treatment of mental health disorders or behavior problems
☐	☐	Treatment of pain

For reviews, attach list of current medications, dosage, and when prescribed

☐ List is attached for reviews

This item is to help the physician or other clinician assess whether current medications may be the cause of behavioral or functional changes.

Best to include a listing of current medication, with dosages, when sending or bringing form to assessment.

(29) Comments related to other notable changes or concerns:

Use this item to make comments of use related to behavior, function, or any events that may influence behavior

(30) Next Steps / Recommendations

☐ Refer to treating physician for assessment

☐ Review internally by *clinical personnel*

☐ Include in annual review / annual wellness visit

☐ Repeat in ______ months

Form completion information

(31) Date completed	(32) Organization / Agency
Name of person completing form	
Relationship to individual (staff, relative, assessor, etc.)	
Date(s) form previously completed	

Acknowledgement: Derived from the DSQIID (*Dementia Screening Questionnaire for Individuals with Intellectual Disabilities; Deb, S., 2007) as adapted into the Southeast PA Dementia Screening Tool (DST) – with the assistance of Carl V. Tyler, Jr., MD – and the LHIDS (Longitudinal Health and Intellectual Disability Survey; Rimmer & Hsieh, 2010) and as further adapted by the National Task Group on Intellectual Disabilities and Dementia Practices as the NTG Early Detection Screen for Dementia for use in the USA.

National Task Group on Intellectual Disabilities and Dementia Practices

www.aadmd.org/ntg/screening

Homework Assignment

Thanks to the NTG volunteers who made this training possible.

www.aadmd.org/ntg/curriculum

ntg

National Task Group
on Intellectual Disabilities
and Dementia Practices

National Task Group on Intellectual Disabilities and Dementia Practices

NTG Dementia Capable Care of Adults with Intellectual Disabilities & Dementia

DAY 3

Philosophy of Care

Behavioral & Psychiatric Symptoms of Dementia

Homework Review

Shift in Philosophy

Rehabilitation to Habilitation

Caring for Someone with Dementia Requires a Shift in Thinking.

Skills gained over a lifetime are now lost.

Goals Change

Lifespan Goals

- Sensory stimulation & challenge
- Novelty & exposure to new information
- Skill building
- Increases independence
- Choices and opportunities
- Normalization

Goals with Dementia

- Balance of ease of use with limited sensory stimulation
- Predictable, consistent routine
- Maintain function and social interaction as much as possible
- Limited choices – may be one at a time
- Support and failure free activities

Source: Kathleen Bishop, PhD

Adapt activities so they are “failure free.”

Adapt activities to suit the needs and capacity of the person.

Focus on simple activities which reinforce self-esteem while relieving boredom and frustration.

Emphasis is on remaining abilities, not losses.

Tips for 'Failure Free Activities'

Examples:

- **Limiting choices to one at a time** based on previous known preferences.
- **Provide gentle guidance** and hand over hand assistance if the person is struggling with previous learned skills.
- **Break tasks down into single step directions** waiting for completion of each step before proceeding to the next step.
- **Positive body language** and calm, gentle tone of voice.
- **Distract** when upset with positive comments or diversional activities.

Focus on remaining abilities… not the losses.

More Shifting Concepts

Normalization

Tasks and activities based on the social norms of the culture.

Age Appropriate or “Meaning” Appropriate

Participate in activities and use items that are designed for their own age group.

i.e. dolls, stuffed animals

Key Concepts in Dementia Care

Knowledge and skills needed for dementia capable care.

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 Concept in Dementia Care #1

Maintenance Support

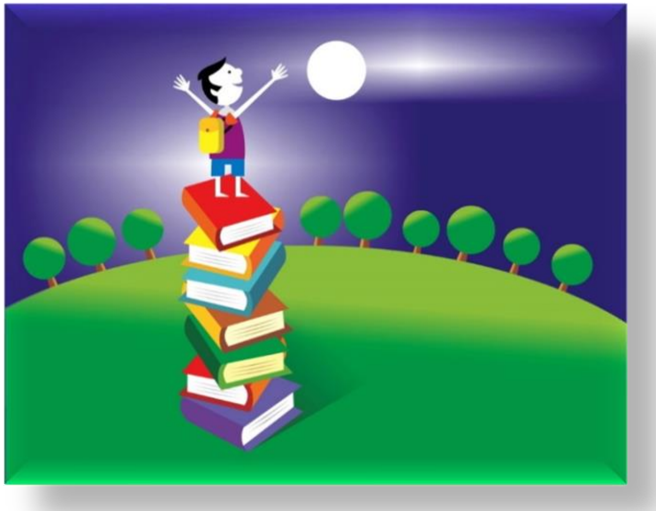
- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
  - A few minutes of pro-action can eliminate hours of reaction.
- Focus is on **support of remaining abilities**.
  - Respect changing needs of the person
  - Provide meaningful, failure-free activity.
  - Allow 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 #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.



Key Concept in Dementia Care #3

Validate

- 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 then the logic that leads to them.

Key Concept in Dementia Care #4

To Reorient or Not Reorient

- Best practice in dementia care: Do not correct or try to "reorient" the person.
- Requires staff to shift their care philosophy…

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."

~~Re~~orientation Tips

Whose reality is it?

- **Memory Regression:**
  - No longer make sense of the present.
  - Memories of years past become the new reality.
  - May re-live past events.
- **“Therapeutic Fiblets”**: To avoid frustration and increasing agitation you must enter their reality. *Don’t argue.* ***This is <u>not lying</u>, it is <u>respecting their reality</u>.***

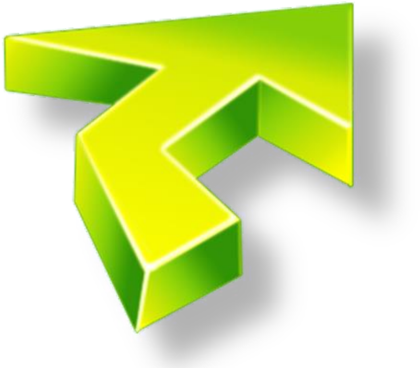
Wouldn’t you be upset if someone told you your parent was dead if you were sure they were alive?

Key Concept in Dementia Care #5
REDIRECTION

Distract AND Divert

- Distract and redirect to minimize or avoid outbursts and challenging behaviors.
- Redirect with gentle distraction or by suggesting a desired activity.
    - Food, drink, favorite activity
- Smile and 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."*

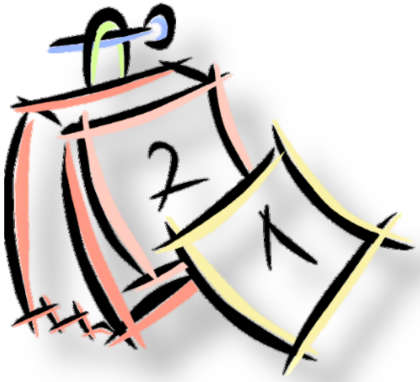
Example:

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.



Summary

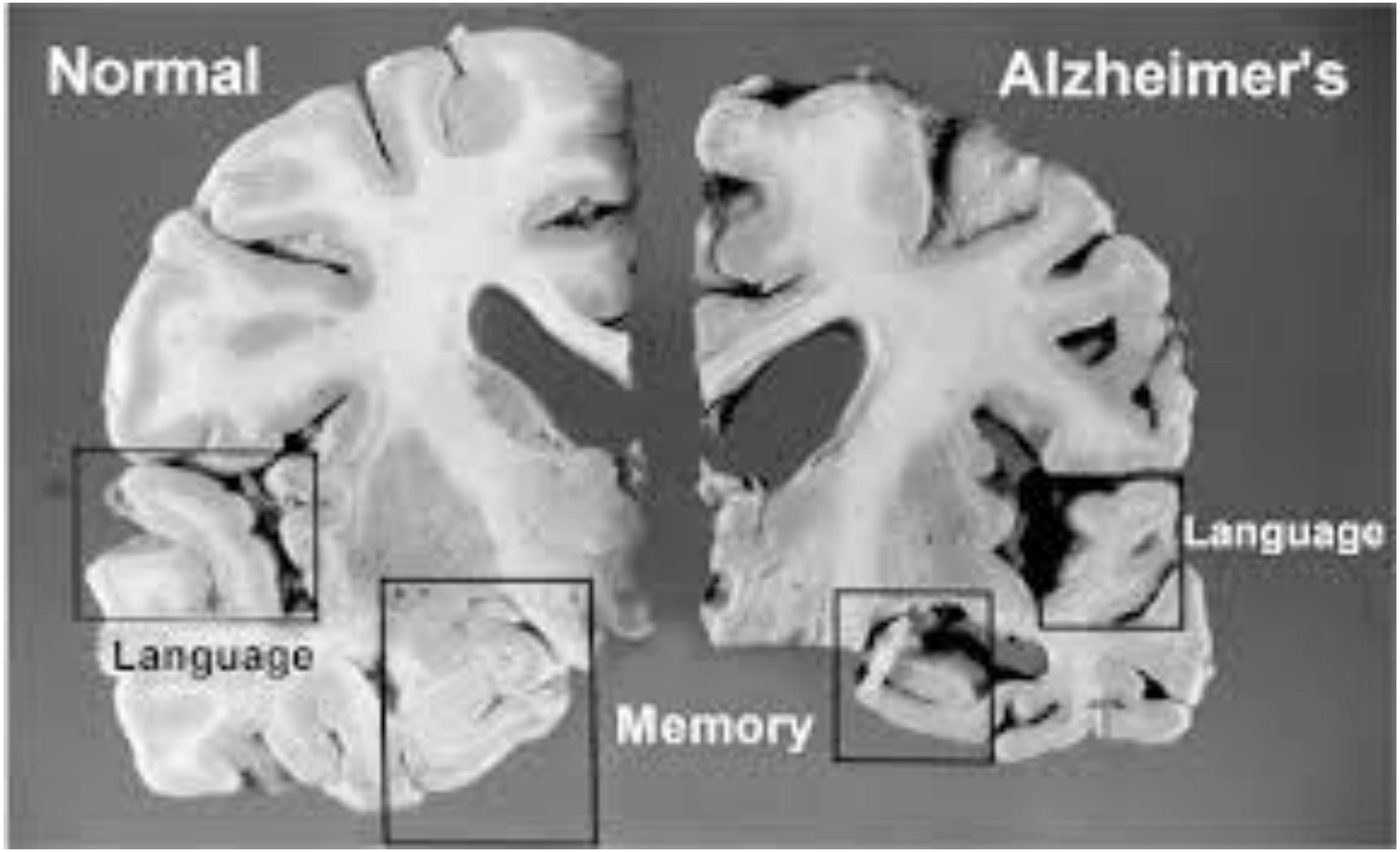
There are tools adapted from dementia care in the general population that can help improve the quality of life for an adult with ID & dementia.

Setting the Stage for Understanding the Behavioral and Psychological Symptoms of Dementia

Why do people with dementia do the things they do?

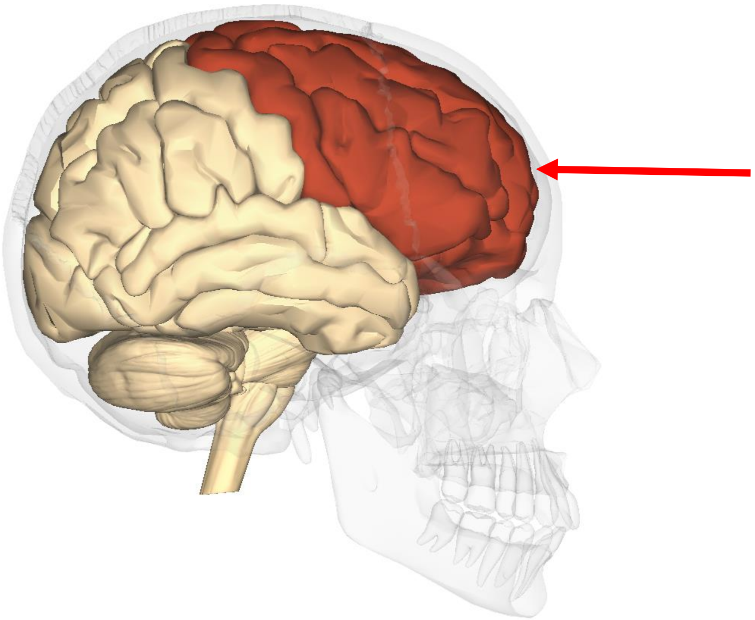
Understanding behaviors based on damage to the frontal lobe, limbic system and other areas of the brain.

Alzheimer's Disease



Importance of the Frontal Lobe

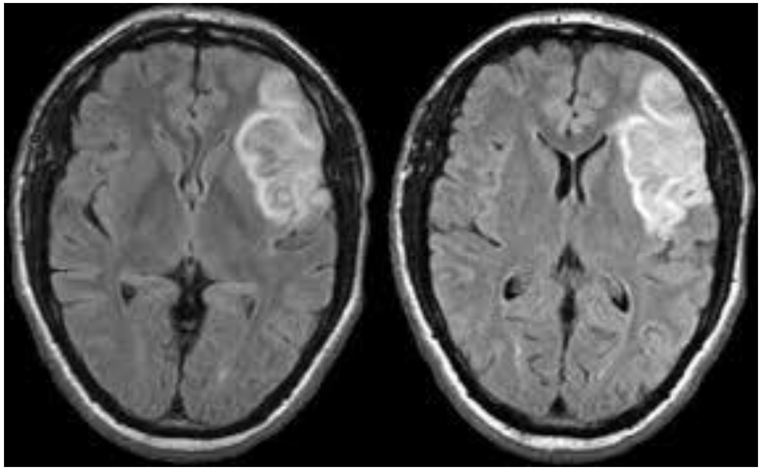
“Command and Control Center”



In most forms of dementia, especially AD, this is the first part of the brain that is damaged.

Other Forms of Dementia that may Damage the Frontal Lobe

Frontal Temporal Dementia



Stroke – left frontal lobe

Alzheimer's

Frontal Lobe… The 8 Executive Functions

1. **Inhibition** - The ability to stop one's own behavior at the appropriate time, including stopping actions and thoughts. The flip side of inhibition is impulsivity; if you have weak ability to stop yourself from acting on your impulses
2. **Shift** - The ability to move freely from one situation to another and to think flexibly in order to respond appropriately to the situation.
3. **Emotional Control** - The ability to modulate emotional responses by bringing rational thought to bear on feelings.
4. **Initiation** - The ability to begin a task or activity and to independently generate ideas, responses, or problem-solving strategies.

Adapted from: What Is Executive Functioning? Joyce Cooper-Kahn and Laurie Dietzel

Continued…

5. **Working memory** - The capacity to hold information in mind for the purpose of completing a task.

6. **Planning/Organization** - The ability to manage current and future- oriented task demands.

7. **Organization of Materials** - The ability to impose order on work, play, and storage spaces.

8. **Self-Monitoring** - The ability to monitor one's own performance and to measure it against some standard of what is needed or expected. “Insight”

Think About How You Got Here Today.

How many of these Executive Functions did you use?

Inhibition

Shift

Emotional Control

Initiation

Working Memory

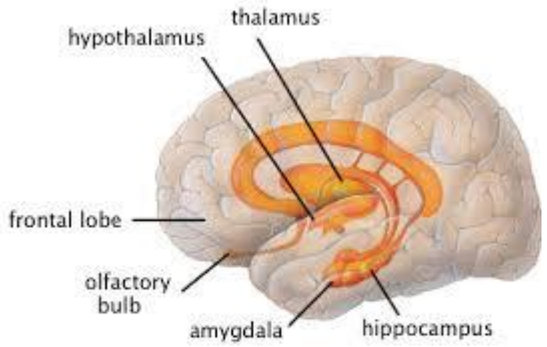
Planning/Organization

Organization of Materials

Self-Monitoring

Limbic System

Controls emotions like fear and anger.
Control of aggressive behavior.
Regulates eating.
Responds to pain or pleasure.



- Oldest and most primitive area of brain.
- Helps control numerous emotional, voluntary, endocrine and visceral responses to our environments that we all experience daily.
- Controls how we respond to stress.

Adapted from: What is the limbic system. Jillian Levy, CHHC. 2016

Damage to Limbic System Causes

- **Disinhibited behavior:** This means someone doesn’t consider the risk of behaviors and ignores social conventions/rules.
- **Increased anger and violence:** This is commonly tied to amygdala damage.
- **Hyperarousal:** Amygdala damage, or damage to parts of the brain connected to the amygdala, can cause increased fear and anxiety.
- **Hyperorality/Kluver-Bucy Syndrome:** This is characterized by amygdala damage that can lead to increased drive for pleasure, hypersexuality, disinhibited behavior and insertion of inappropriate objects in the mouth.
- **Appetite dysregulation:** Destructive behaviors tied to hyperorality or thalamus dysfunction can include overeating, binge eating or emotional eating.
- **Trouble forming memories:** Hippocampal damage can include short-term or long-term memory loss. Learning is often greatly impacted by hippocampal damage, since it depends on memory.
- **Disorientation and changes in moods.**

Adapted from: What is the limbic system. Jillian Levy, CHHC. 2016

The 7 A's

Each A relates to a part of the brain.	
Amnesia	Initially short term memory, eventually even long term memory.
Agnosia	Can no longer recognize things using your senses. Unable to recognize faces or familiar objects. May not be able to understand what you see or hear.
Aphasia	Loss of ability to speak, understand, read or write. Can lead to withdrawal or misunderstandings.
Apraxia	Loss of the ability to tell your body how to carry out purposeful movement.
Altered Perception	Misinterpreting the information your senses give you.
Anosognosia	Inability to understand that something has changed and is wrong with you. Unable to see the changes in abilities that others see.
Apathy	Loss of initiative.

Communication Tips

Tips and strategies for successful interactions.

Communication and Dementia

- Communicating our needs, wishes and feelings is vital – not only to maintain our quality of life, but also to preserve our sense of identity.
- Communication is more than verbal. It is also gestures, facial expressions and touch.
- As the disease progresses and language skills are lost nonverbal communication becomes more important.

Body Language

People with dementia are very adept at reading body language:

- Identify yourself.
    - Never assume the person knows who you are.
- Remain patient and calm.
- Don’t stand over someone – this can feel intimidating.
    - Try to stay below their eye level.
- Smile!
- If the person is comfortable with body contact patting or holding the person’s hand can be reassuring.

Keys to Successful Communications

- Don’t argue, don’t reason
- Enter their reality
- Speak slowly
- Yes or no questions/choices
- Short, simple sentences
- One step at a time
- Use statements instead of questions
  - Instead of *‘are you hungry?’* try, *‘it’s time to eat.’*
- Quiet voice – a loud voice conveys anger
- Pick your battles
- Distract AND Divert
- Don’t take it personally

BPSD:
Behavioral and Psychiatric Symptoms of Dementia

Behavior is communication.

Behavior is Communication

Common Behaviors

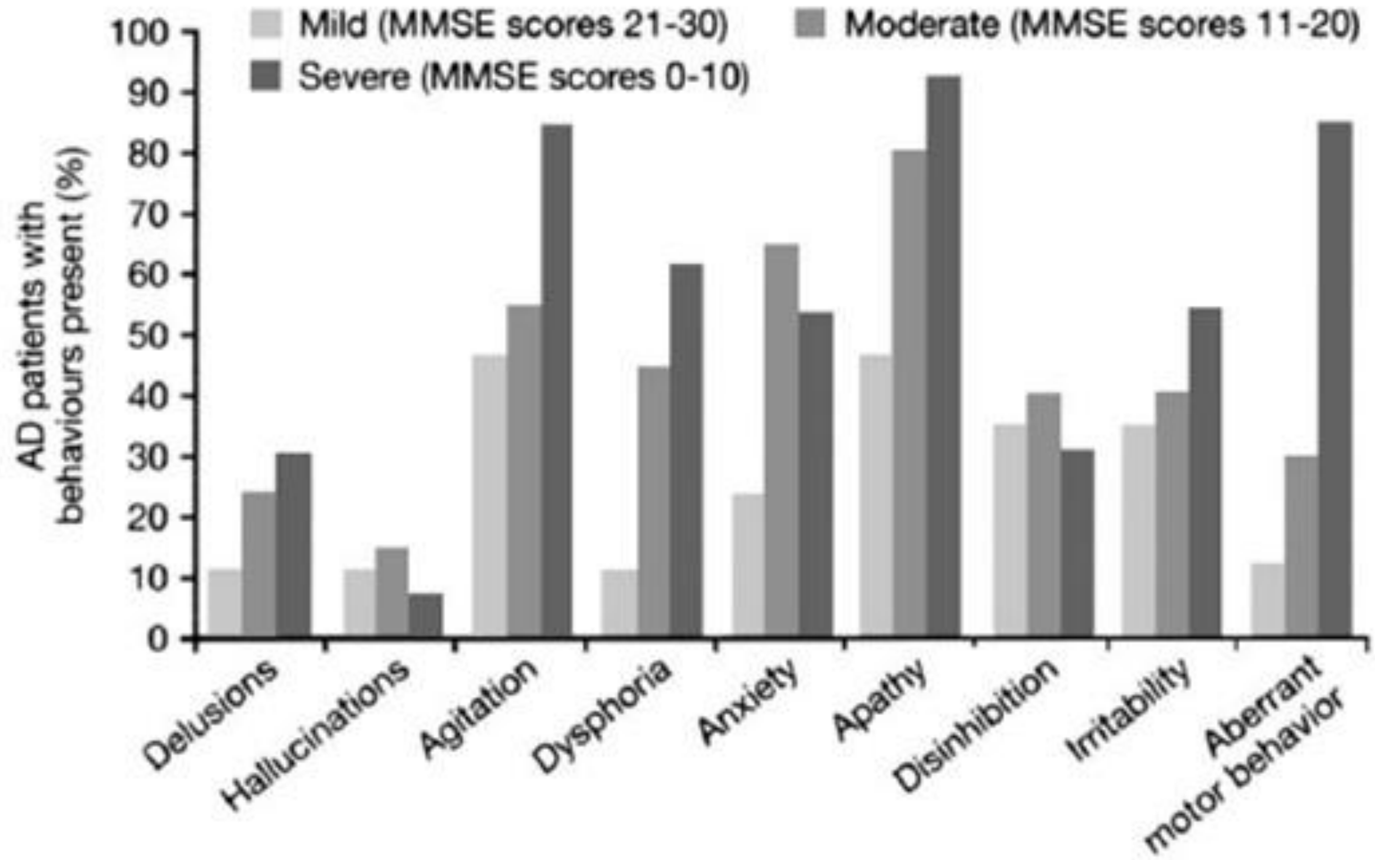


Figure 1. Presence of neuropsychiatric symptoms in patients with AD according to severity of disease (Adapted from Mega et al., 1996).

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?

Behaviors just come right out of the blue…or do they?

ABC Model

Antecedent

Behavior

Consequence

A-B-C Model

Scenario

Joe is 75 and suffers from behavioural and psychological symptoms of dementia. His aimless wandering is perceived as intrusiveness. When confronted he becomes aggressive.

A = Activating Event

Joe wanders into co-resident's room. Co-resident orders Joe out.

B = Behaviour

Joe responds with verbal aggression.

C = Consequence

Staff assess the situation and talk to Joe in a warm and friendly manner that is respectful and maintains dignity. Staff use communication techniques aimed at diffusing the aggressive situation.

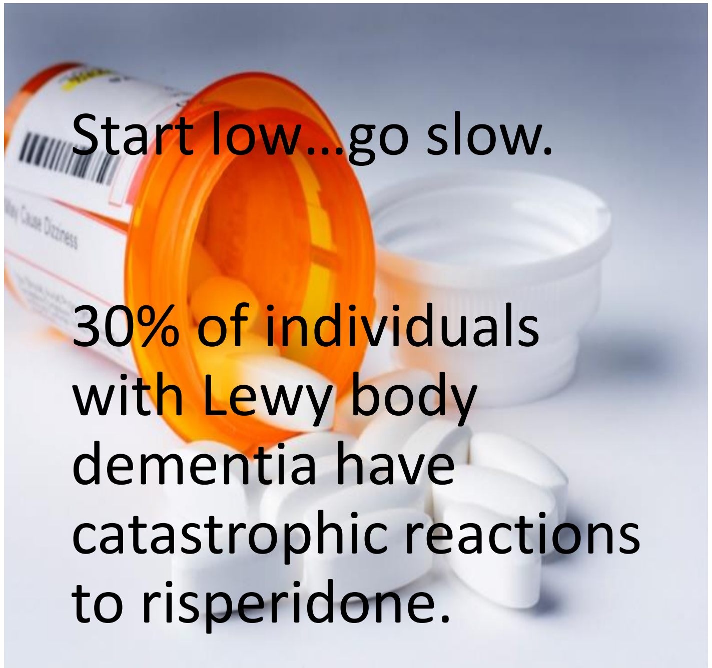
D = Decide & Debrief

Joe's aggression de-escalates and staff and others undergo debriefing.

By not confronting Joe in his anger and by using appropriate communication techniques, the **(C)** moves to **(D)** rather than **(A)**, allowing staff to distract him with an activity rather than an **(A)** activating event. The circle is broken.

Source: Bendigo Health. Behaviour Advisory Service (Aged Care) (2001) *Behaviour Assessment Guide*. Alzheimer's Association South Australia.

Antipsychotics a last resort.



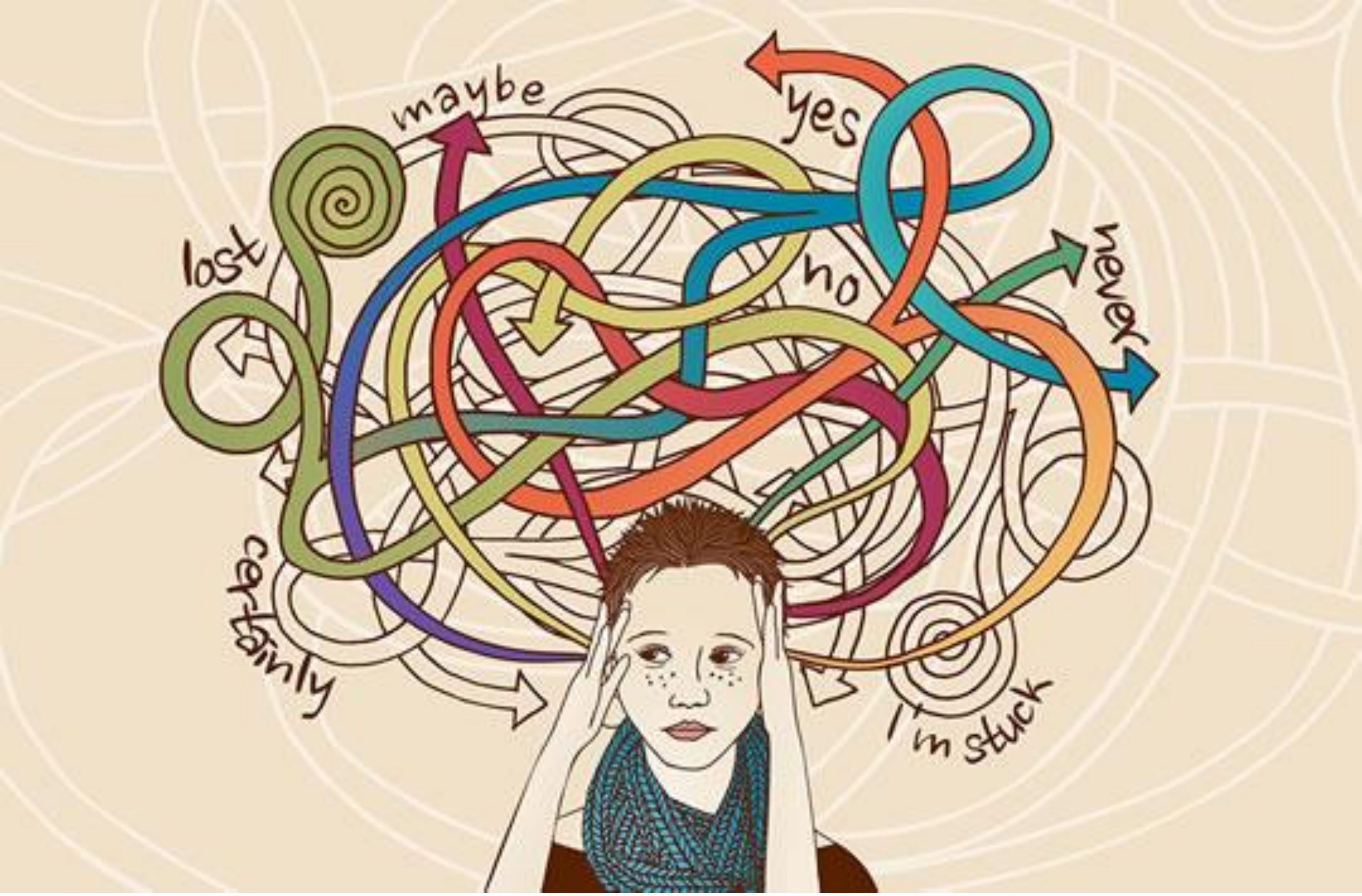
Start low…go slow.

30% of individuals with Lewy body dementia have catastrophic reactions to risperidone.

The National Partnership to Improve Dementia Care, a public (CMS) -private coalition, today established a new national goal of reducing the use of antipsychotic medications in long-stay nursing home residents by 25 percent by the end of 2015, and 30 percent by the end of 2016.

- Initial focus is on reducing the use of antipsychotic medications.
- Larger mission is to enhance the use of non-pharmacologic approaches and person-centered dementia care practices.

Common Behaviors



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.

Cause(s):

- Pain (studies suggest that 50% 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 mellitus**. (McGinn, 2005.)
- Is it something in the environment? Caregiver interaction?
- Quiet music, lollipop
- ECT

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.

Anger

Anxiety can look a lot like anger.

Hallucinations – false perceptions (see, hear, smell, taste, feel)

Causes:

- Prior history of severe mental illness, i.e. schizophrenia
- Vision, hearing impairments
- Lewy body dementia
- Change in medications
- Delirium
- Pain
- Dehydration

Strategies:

- Ask them to point to what they see…is it glare, a reflection?
- Look for physical cause
- Ignore if harmless
- Don't argue
- Reassure, distract
- Check hearing aid batteries
- Medication if upsetting (after rule out treatable causes)

Whose problem is it??

Delusions…false ideas

(suspicion, paranoia, jealousy, accusations)

Causes:

- Sensory deficits
- Memory loss
- Unfamiliar environment
- Misperception of environment

Don't automatically dismiss the belief! Just because the person may have dementia doesn't necessarily mean everything they say is untrue!!

Strategies:

- Don't challenge the belief
- 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.

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 (ex. 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.
- Lack of flexibility: The source of the distress is often the caregiver imposing his or her duty to get someone clean; even when that person is reluctant or distressed.

Strategies:

- Stick to familiar routine.
- Respect modesty.
- Use dry shampoo for hair washing.
- Towel or bed bath as alternative.
- Try again later

Bathing and Showering

Would I be agreeable to bathing or showering at this time of day or in this environment or with this approach?

- Take heart, no one had ever died from “Failure to Bathe syndrome.”
- Confusion, fear, too many steps, don’t understand the need
- Tips:
  - Offer an incentive, “let’s freshen up and then we will…”
  - Look at the environment – handheld shower, contrast, shower chair, water temperature, favorite music
  - Past history - abuse
  - Privacy and modesty
  - Get everything ready ahead of time
  - Time of day – honor past routines
  - Communication – speak slowly, describe each step, calm

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.

WHO HAS TO CHANGE? WE DO!

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.

Behavioral Triggers

The 4 major precipitants of behavior.

1.

Is it something I did? (caregiver interaction)

Caregiver Interaction/Communication

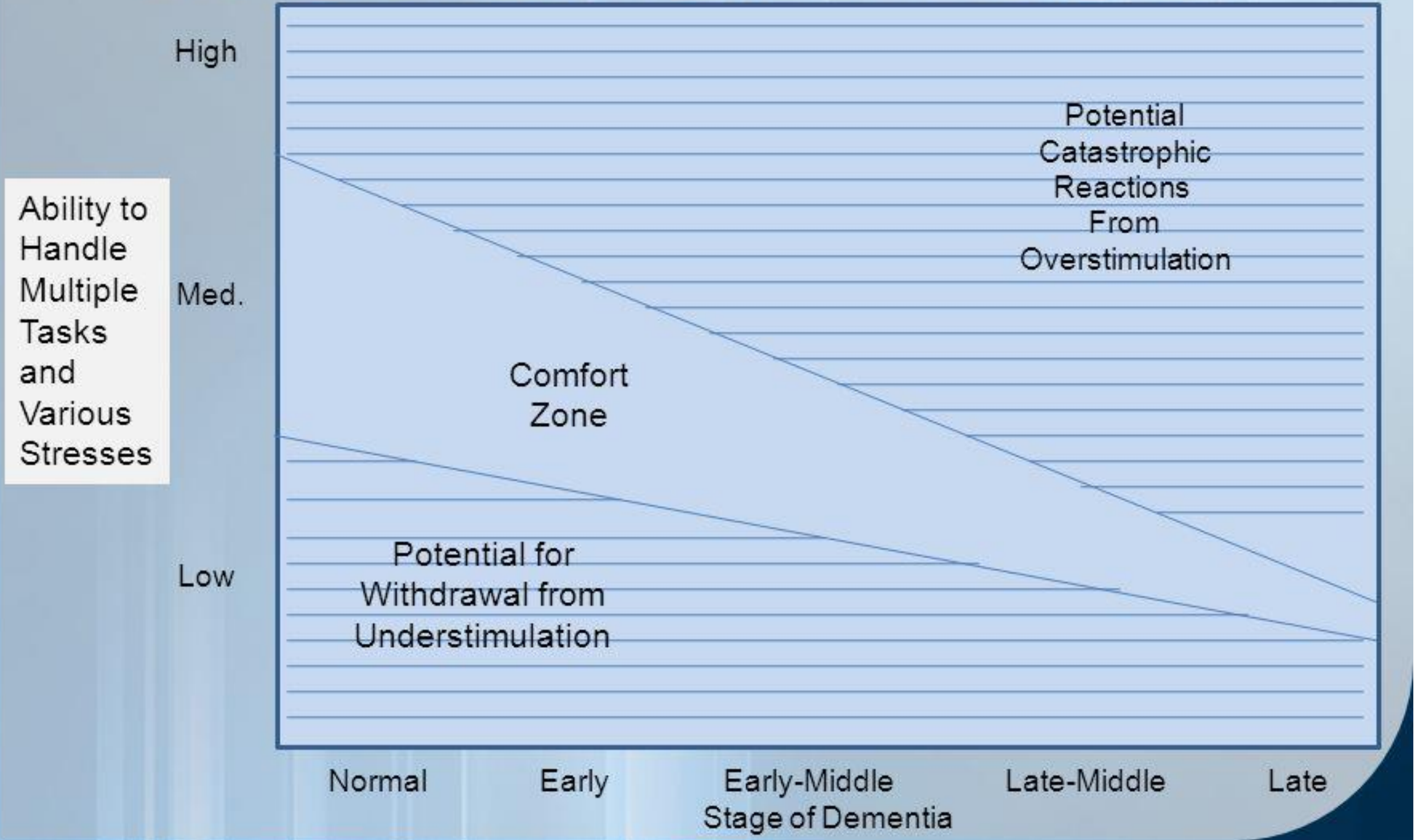
Is it something I did?

- Attitude – relaxed or anxious?
- Body language – tense?
- Tone of voice – cheerful or demanding?
- Facial expression – smiling?

EMORY

NELL HODGSON WOODRUFF SCHOOL OF NURSING

Progressively Lowered Stress Threshold in Dementia



2.
Is it pain?

Frequently the underlying cause of behavioral symptoms, which can lead to inappropriate treatment with antipsychotic medications.

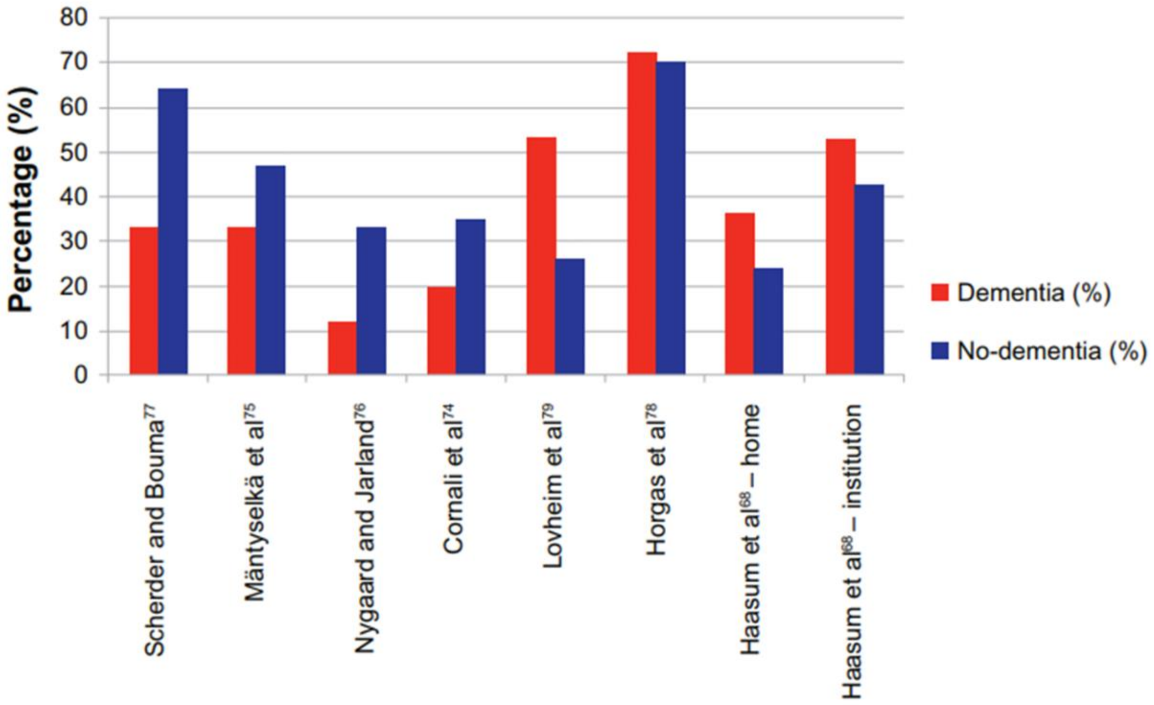


Figure 2 Studies on the prevalence (in %) of analgesic use in patients with dementia compared with in cognitively unimpaired patients (no dementia).

Acterberg, W. et al. Pain Management in Patients with Dementia. Clinical Interventions in Aging 2013:8

Pain

- Pain is thought to be one of the most important causal factors of BPSD. Assessment and treatment of pain in people with dementia.*Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, Ballard C., Nat Rev Neurol. 2012 Apr 10; 8(5):264-74.*
- Assessment of pain is particularly challenging due to the loss of communication ability.
- Pain processing is not diminished in Alzheimer's. Pain sensitivity and fMRI pain-related brain activity in Alzheimer's disease. *Cole LJ, Farrell MJ, Duff EP, Barber JB, Egan GF, Gibson SJ., Brain. 2006 Nov; 129(Pt 11):2957-65.*
- May require a higher dosage of pain medication to achieve the pain relief that would normally be expected in a cognitively healthy adult. Loss of expectation-related mechanisms in Alzheimer's disease makes analgesic therapies less effective.*Benedetti F, Arduino C, Costa S, Vighetti S, Tarenzi L, Rainero I, Asteggiano G., Pain. 2006 Mar; 121(1-2):133-44.*

More on Pain

- 50% of peoples with dementia are regularly in pain.
  Assessment and treatment of pain in people with dementia.*Corbett A, Husebo B, Malcangio M, Staniland A, Cohen-Mansfield J, Aarsland D, Ballard C., Nat Rev Neurol. 2012 Apr 10; 8(5):264-74.*

- The elderly in general, but especially those with dementia, receive less pain medication than their cognitively healthy counterparts, even in the same painful situations – for example, after a hip fracture. A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture.*Morrison RS, Siu AL., J Pain Symptom Manage. 2000 Apr; 19(4):240-8.*
  - Advanced dementia patients received one-third the amount of opioid analgesia as compared to cognitively intact subjects.

Common Pain Behaviors in Cognitively Impaired Persons

1. **Facial expressions.** Slight frown; sad, frightened face Grimacing, wrinkled forehead Closed or tightened eyes Any distorted expression Rapid blinking

2. **Verbalizations, vocalizations.** Sighing, moaning, groaning Grunting, chanting, calling out Noisy breathing Asking for help Verbally abusive

3. **Body movements.** Rigid, tense body posture, guarding Fidgeting Increased pacing, rocking Restricted movement Gait or mobility changes

4. **Changes in interpersonal interactions.** Aggressive, combative, resisting care Decreased social interactions Socially inappropriate, disruptive Withdrawn

5. **Changes in activity patterns or routines.** Refusing food, appetite change Increase in rest periods Sleep, rest pattern changes Sudden cessation of common routines Increased wandering

6. **Mental status changes.** Crying or tears Increased confusion Irritability or distress

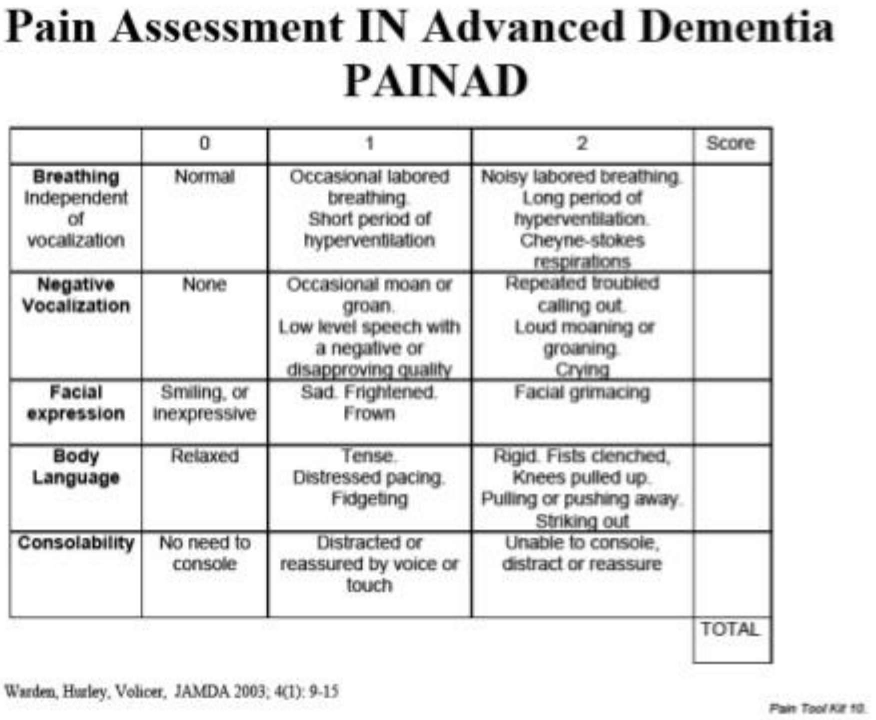
Source: AGS Panel on Persistent Pain in Older Persons. The management of persistent pain in older persons. J Am Geriatr Soc. 2002;50(Suppl 6): S205–S224.

Assess

- Does this person have any **known medical conditions** that may produce pain:
    - Ex. Arthritis, migraines, osteoporosis, stomach problems
- Has there been a **recent change in medications**?
    - Ex. New medication or increased dosage – side effects?
- Could there be the onset of a **new acute illness**?
    - Urinary tract infection, impaction, pneumonia can cause delirium and produce a sudden change in mental status. Delirium is a medical emergency.
- Is the person **too hot, too cold, clothes uncomfortable, need to change their position**, etc.
- Are they in **emotional pain**?
    - Ex. Frustrated at being expected to do a task that is beyond their ability, scared, feeling threatened, depressed, anxious?

Pain Assessment
IN Advanced Dementia- PAINAD

- Nurse, CNA
- For behavioral symptoms suggestive of pain, assess at least every 8 hours
- Observe the older adult for 3-5 minutes during activity/with movement (such as bathing, turning, transferring).



Pain Assessment IN Advanced Dementia
PAINAD

	0	1	2	Score
Breathing Independent of vocalization	Normal	Occasional labored breathing. Short period of hyperventilation	Noisy labored breathing. Long period of hyperventilation. Cheyne-stokes respirations	
Negative Vocalization	None	Occasional moan or groan. Low level speech with a negative or disapproving quality	Repeated troubled calling out. Loud moaning or groaning. Crying	
Facial expression	Smiling, or inexpressive	Sad. Frightened. Frown	Facial grimacing	
Body Language	Relaxed	Tense. Distressed pacing. Fidgeting	Rigid. Fists clenched, Knees pulled up. Pulling or pushing away. Striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	
				TOTAL

Warden, Hurley, Volicer, JAMDA 2003; 4(1): 9-15

Pain Tool Kit 10.

Dis-DAT: Disability Distress Assessment Tool

http://prc.coh.org/PainNOA/Dis%20DAT_Tool.pdf

- each person has their own ‘vocabulary’ of distress signs and behaviors
- identify distress cues…not pain
- NOT a scoring tool - provides a record against which subtle changes can be compared
- information can be transferred with the client or patient to any environment
- document a person’s usual content cues, thus enabling distress cues to be identified more clearly
- when to use DisDAT:
  - When the team believes the client is NOT distressed - baseline assessment document - transfer document for other teams
  - When the client IS distressed - use to compare the present signs and behaviors with previous observations documented on DisDAT.

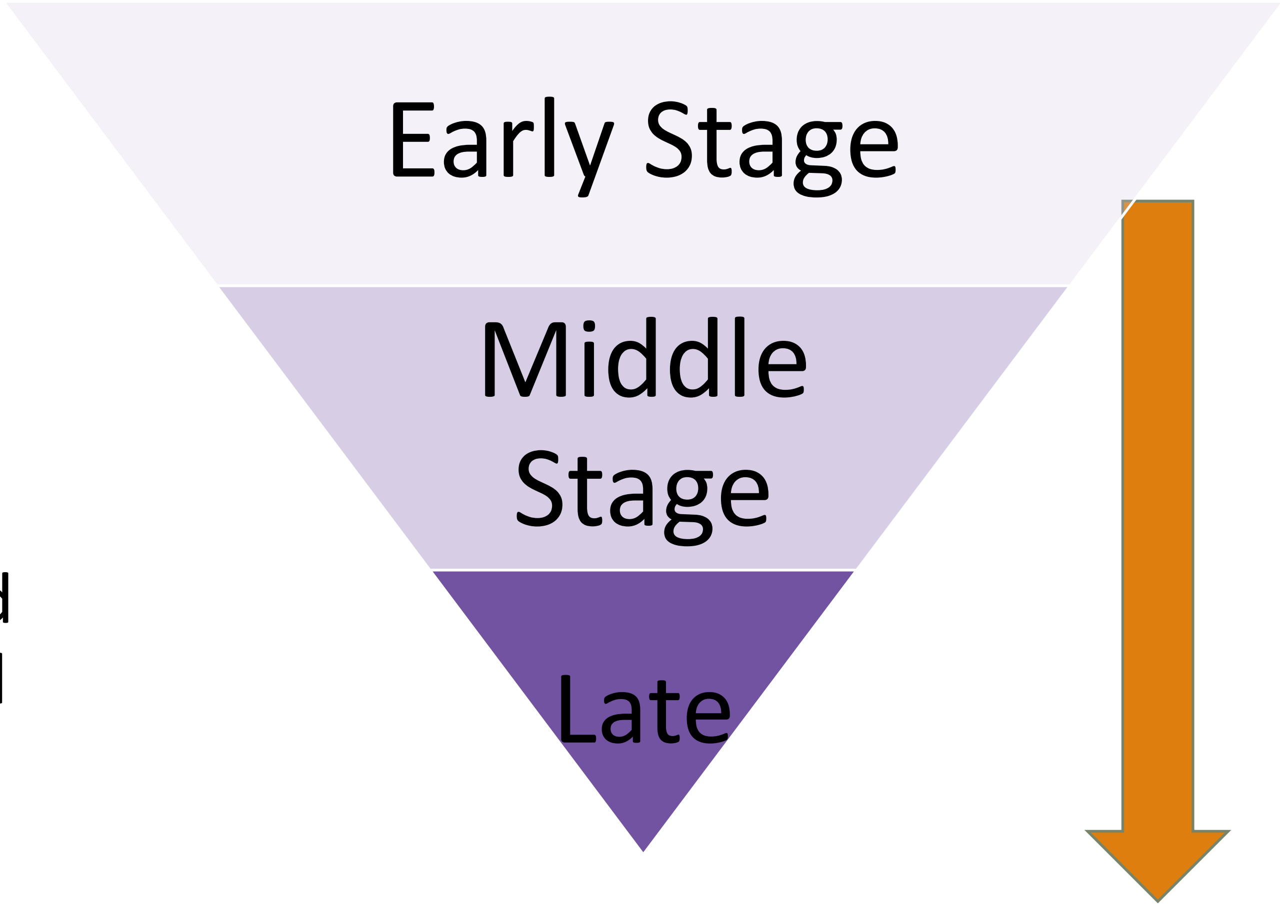
3.
Could it be something in the environment?

More on this shortly…

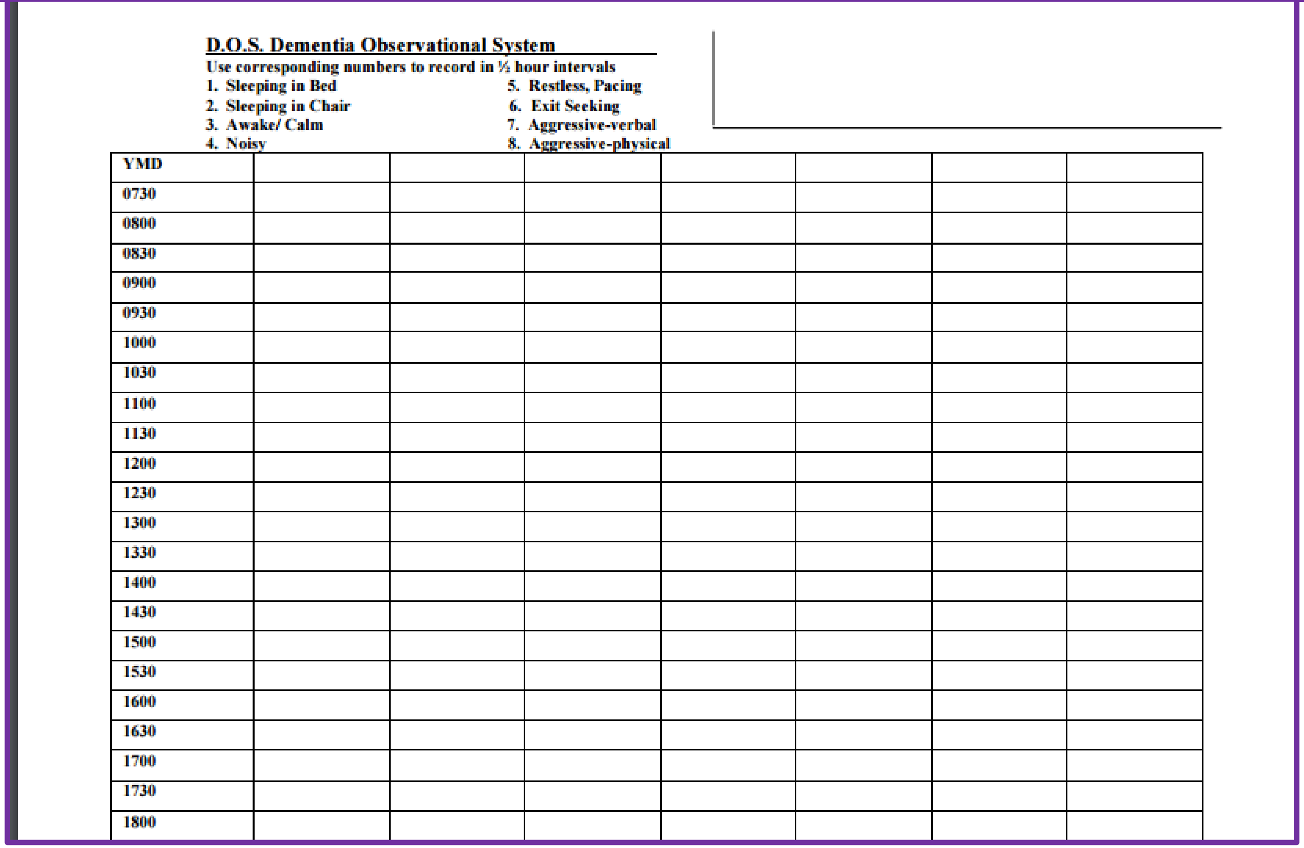
4.
Is the task too difficult?

Task

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



Document



D.O.S. Dementia Observational System

Use corresponding numbers to record in ½ hour intervals

1. Sleeping in Bed
2. Sleeping in Chair
3. Awake/ Calm
4. Noisy
5. Restless, Pacing
6. Exit Seeking
7. Aggressive-verbal
8. Aggressive-physical

YMD							
0730							
0800							
0830							
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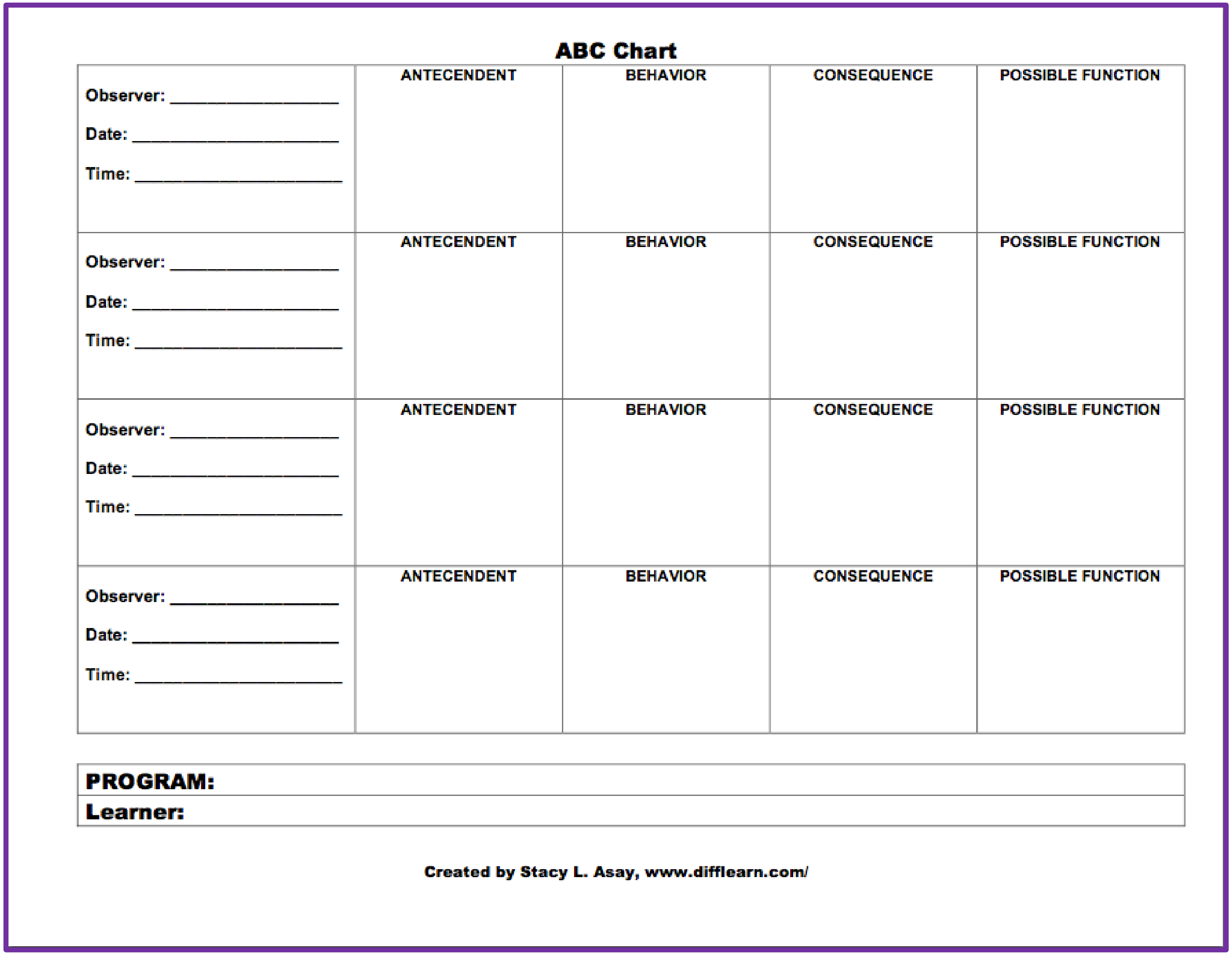
http://pieceslearning.com/wp-content/uploads/2016/08/Dementia-Observational-System-0730_Standardized.pdf



ABC Chart

Observer: ________________ **Date:** ____________________ **Time:** ____________________	**ANTECENDENT**	**BEHAVIOR**	**CONSEQUENCE**	**POSSIBLE FUNCTION**
Observer: ________________ **Date:** ____________________ **Time:** ____________________	**ANTECENDENT**	**BEHAVIOR**	**CONSEQUENCE**	**POSSIBLE FUNCTION**
Observer: ________________ **Date:** ____________________ **Time:** ____________________	**ANTECENDENT**	**BEHAVIOR**	**CONSEQUENCE**	**POSSIBLE FUNCTION**
Observer: ________________ **Date:** ____________________ **Time:** ____________________	**ANTECENDENT**	**BEHAVIOR**	**CONSEQUENCE**	**POSSIBLE FUNCTION**

PROGRAM:
Learner:

Created by Stacy L. Asay, www.difflearn.com/

Homework Assignment

Thanks to the NTG volunteers who made this training possible.

www.aadmd.org/ntg/curriculum

National Task Group
on Intellectual Disabilities
and Dementia Practices

NTG Dementia Capable Care of Adults with Intellectual Disabilities & Dementia

DAY 4

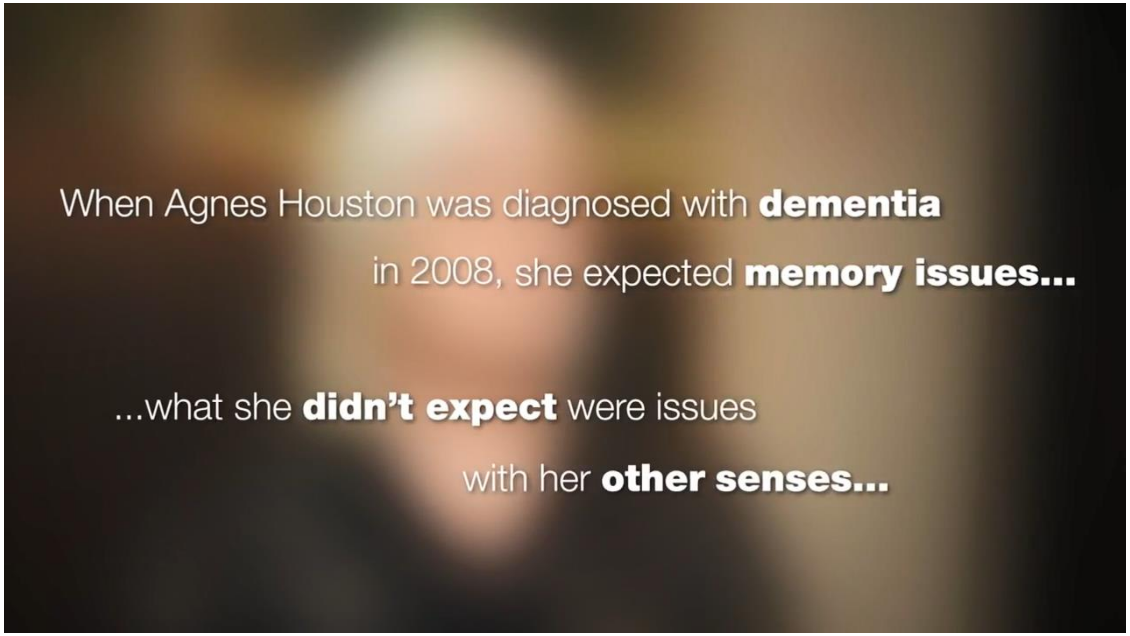
- **Dementia Capable Environments**

Homework Review

Sensory Impairment

Video:
My life living with dementia.

www.youtube.com/watch?v=q_sWiwI3yP0



When Agnes Houston was diagnosed with **dementia** in 2008, she expected **memory issues...**

...what she **didn't expect** were issues with her **other senses...**

Sensory impairments can also mimic dementia

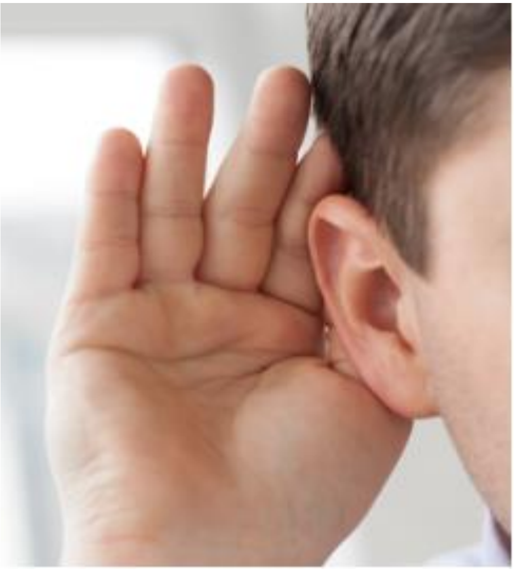
Seven Senses: responsible for our interaction with the external world.

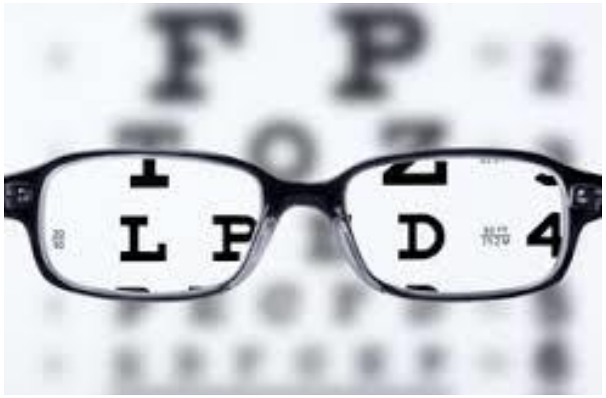
1. Auditory (hearing)
2. Visual (sight)
3. Olfactory (smell)
4. Gustatory (taste)
5. Tactile (touch)

---

1. Proprioceptor (position) – the sensory feedback that informs us where the parts of our body are and how they are moving. Integrates input from the 5 senses.
2. Vestibular (balance) - related to and dependent on the proprioceptive system. The vestibular system is what gives us balance, allows us to stand and move through space without falling over.

Auditory - Hearing

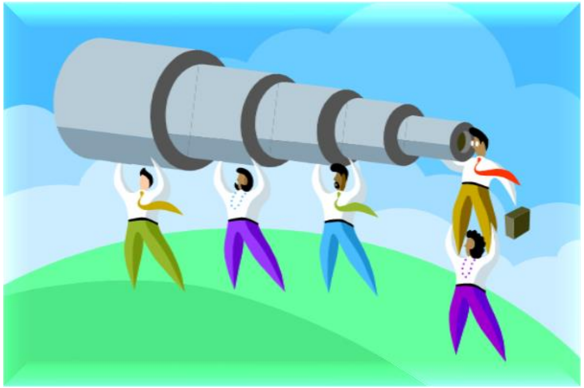




Hearing and Vision

Get hearing and vision tested if you suspect the person is having a sensory problem.

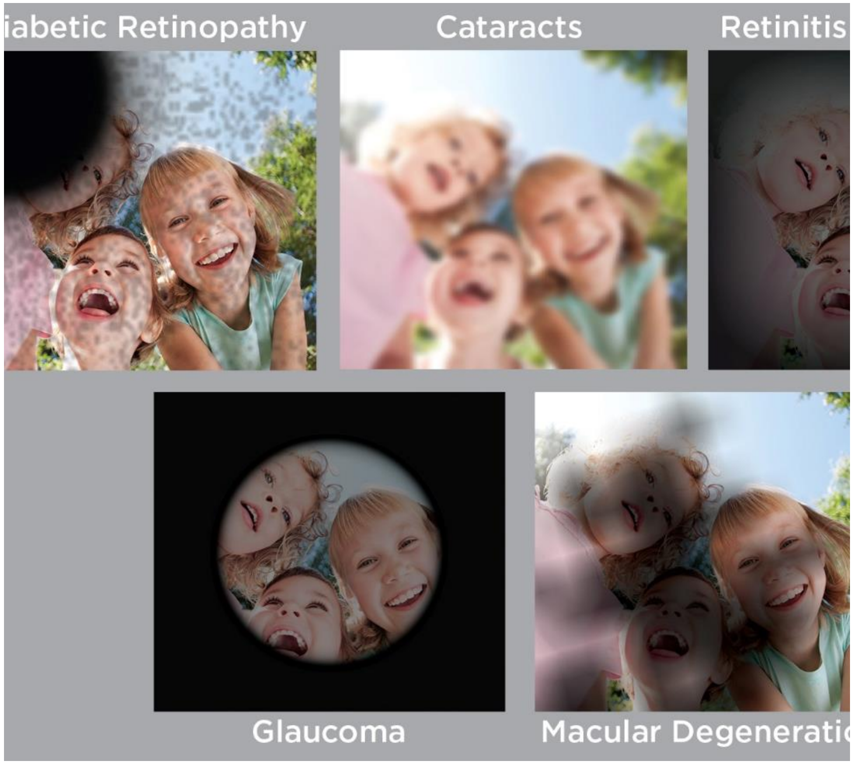
- Often mistaken for symptoms of balance and movement problems, non-responsiveness, and social withdrawal.
- It is important to accurately determine sensory functional capabilities.



Vision Changes

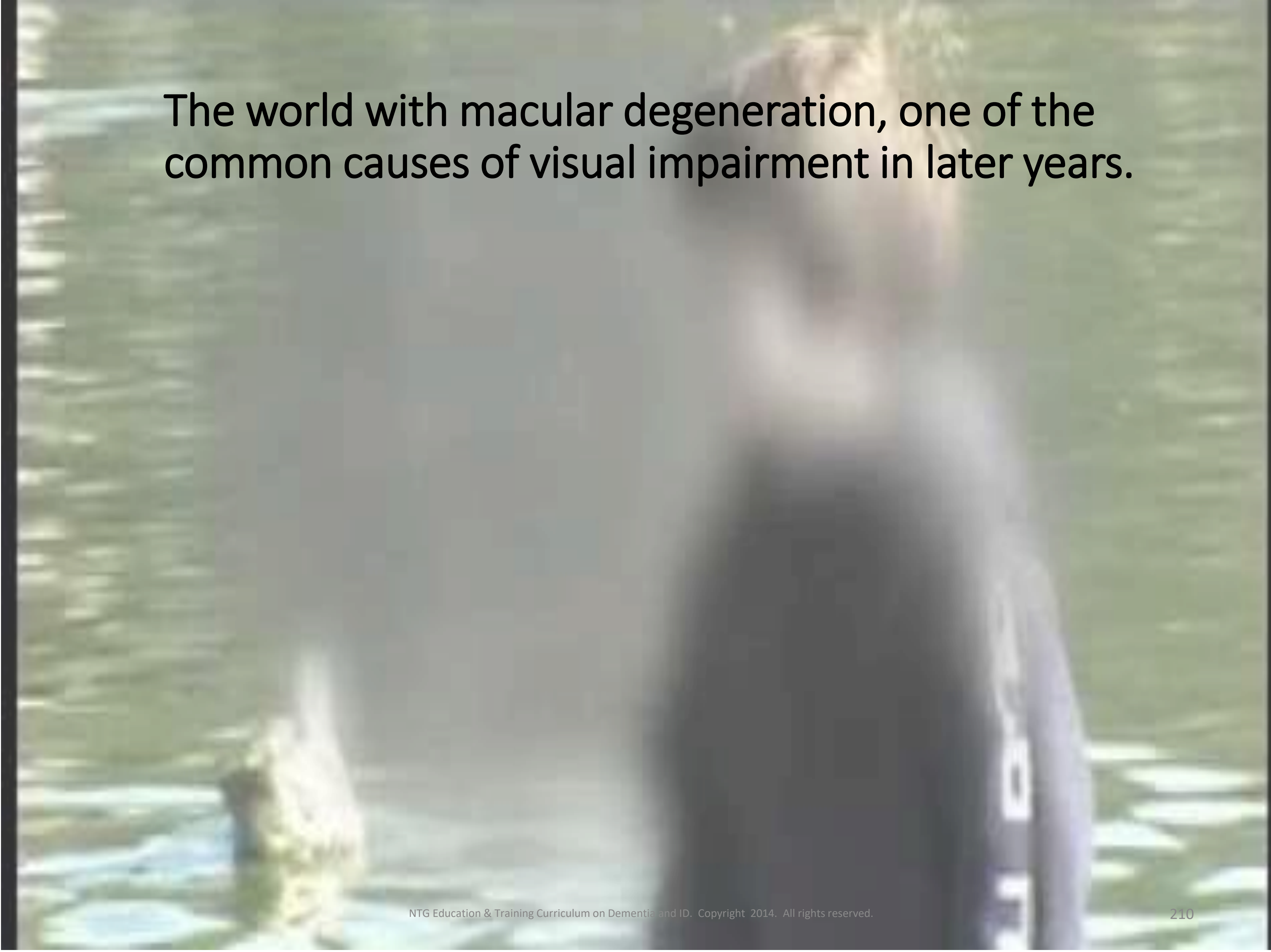
The following may all be affected by AD

- Depth perception
- Color contrasts
- Acuity
- Motion versus stationary objects
- Object identification
- Delayed recall to visual stimulation
- Figure-ground differentiation
- Size and shape
- Visual memory



How the world may appear with visual impairment

The world can appear different and frightening



The world with macular degeneration, one of the common causes of visual impairment in later years.

Visual contrasts? Cueing?

Person’s History

- Which object is the most familiar to you?
- To someone whose memory is back to a farmhouse in 1940?

Compare to what is familiar

Regression back in time and memory

Smell and Taste

- Medications
- Reductions in sensory receptors
- Confusion in reception of information
- Removal from smells and taste
- Need for smaller portions, meals
- Reduction in other senses

Tactile/Touch

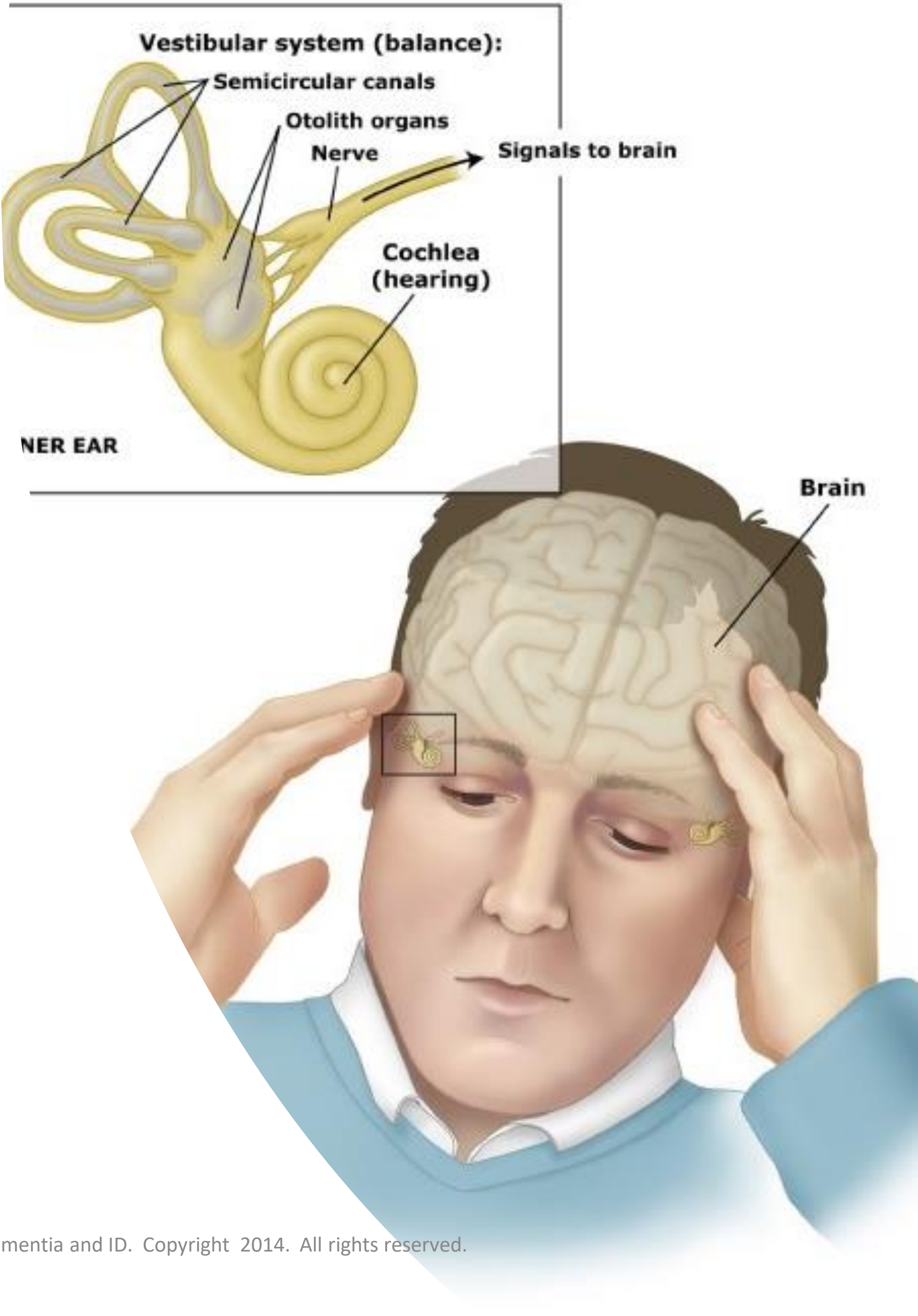
- Importance of touch/being touched
- Avoidance wearing certain clothing
- Touching every object, person
- Need for movement
- Sense of different textures can be important to enhance experience
- Taste and texture
- ADLs and tactile

Proprioception

- Proprioception system integrates the input from the five senses to create meaning of the environment and your place in it.
- Awareness of the position of one's bod y.
- Individual with AD literally "*lost in space and time*."
- Think of AD as a problem of *location in space*.
- Can not perform functions of daily living if can not locate in space.
    - Ex. Could you solve a complex math word problem while free falling on a roller coaster?

Vestibular

- Inner ear and brain
- Controls balance
- Located in the part of the brain that is damaged first in AD
- We develop a “cognitive map” for movement using landmarks that may now be forgotten or misinterpreted
- Location and directional movement is disrupted if visual stimuli are removed (such as in the dark).
    - Can be restored but not easily within AD even within familiar surroundings
    - Connecting of movement to other events and locations (episodic memory) likely impaired.



Color contrasts, cue for wayfinding?

Day Program Example – Lost in space and time?

Are there reasons other than dementia that may cause someone to be unable to find his or her bedroom?

- Would you have trouble finding your bedroom?
- Can you suggest adaptations or modifications that might make it easier to navigate?

The world with ADRD

Degrees of being lost in space.

Always compare to the person’s capacity for wayfinding earlier in life.

Abstract versus concrete wayfinding

Dementia-capable Environments

National Task Group
on Intellectual Disabilities
and Dementia Practices

Balancing Challenge, Needs, and Ease of Use

- Aging increases the difficulty in balancing the environment to the needs of the user. Adults with ID have often been challenged by incompatible environments over a lifetime.
- Dementia exacerbates the challenge, especially as the individual enters later stages of the disease.
- Need a "balance" of challenge and ease of use that *continually changes* as the adult progresses further into the disease.

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.

The 7 Senses, ID, and Dementia

7 senses work together to help individual function and respond "appropriately" to the environment.

Need to be able to discriminate, modulate, and integrate the senses.

Likelihood of preferred sense(s) for learning, taking in information from the environment.

Adults with ID may already have been compromised.

Dementia affects the ability to process, interpret, and respond to sensory information in the environment.

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.

Location & Movement: Suggestions

- Assume the environment is always new to the individual (remapping all the time).
- Keeping the landmarks the same as much as possible.
- Gentle touch to motivate movement.
- Modeling (imitating) to indicate appropriate behavior and movement.

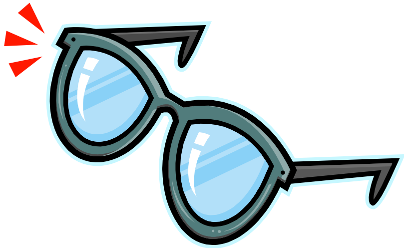
Wandering

- Assume the environment is always new to the individual (remapping all the time).
- Keeping the landmarks the same as much as possible.

Wandering: What can you do?

- Promote as exercise.
- Do not prevent the movement.
- Create safe wandering spaces with opportunities for sitting, drinking water and juices, snacks.
- Disguise doors, locks, knobs of doors, use signaling devices when door is opened,
- Add meaningful activity within the wandering as much as possible:
  - Music
  - Dance
  - Rhythm

Aging & Vision



- Likely the sense most relied upon for sensory information for functioning and movement.
- Visual impairments increase with age.
- Glare sensitivity increases.
- Yellowing of lenses results in colors appearing different.
- Loss of elasticity results in lack of acuity for figure ground detection.
- Appears to be the sense most affected by dementia.

Dementia & Vision

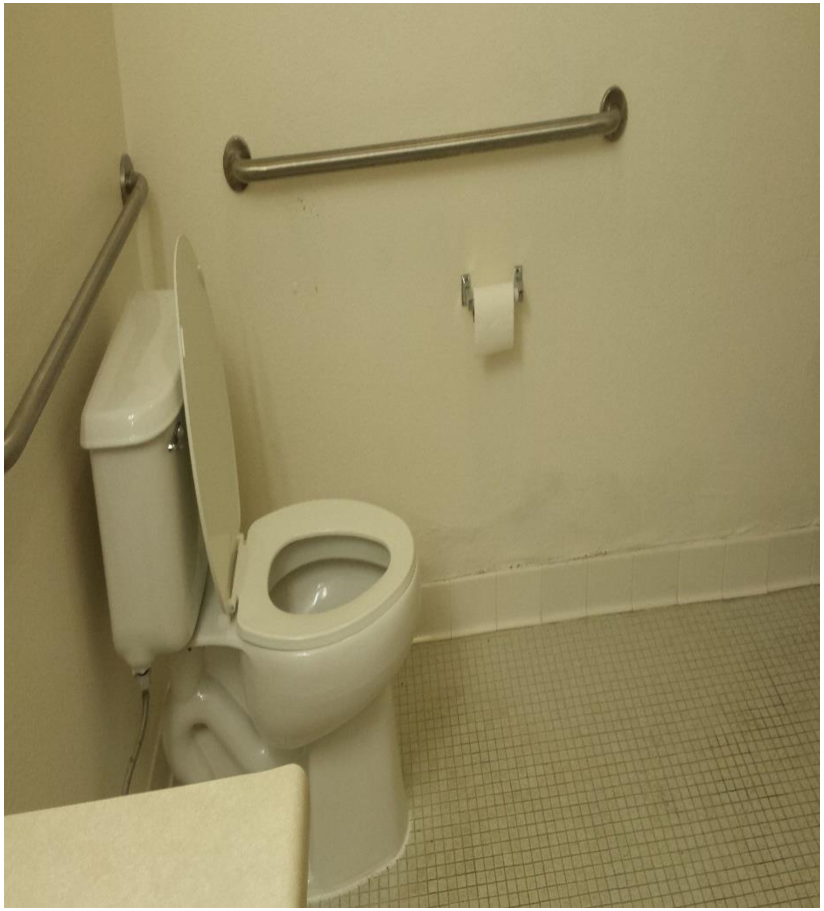
Factors that may be affected by AD:

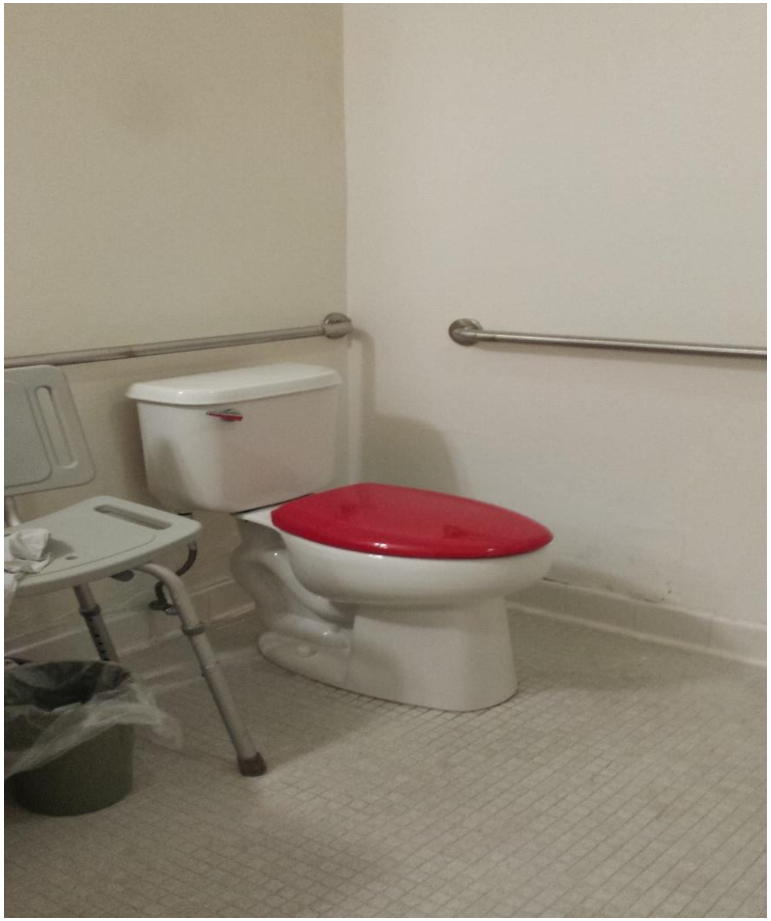
- Visual field reduced about 3 feet from the floor
- Depth perception
- Color contrasts
- Acuity
- Motion versus stationary objects
- Object identification
- Delayed recall to visual stimulation
- Figure-ground differentiation
- Size and shape
- Visual memory

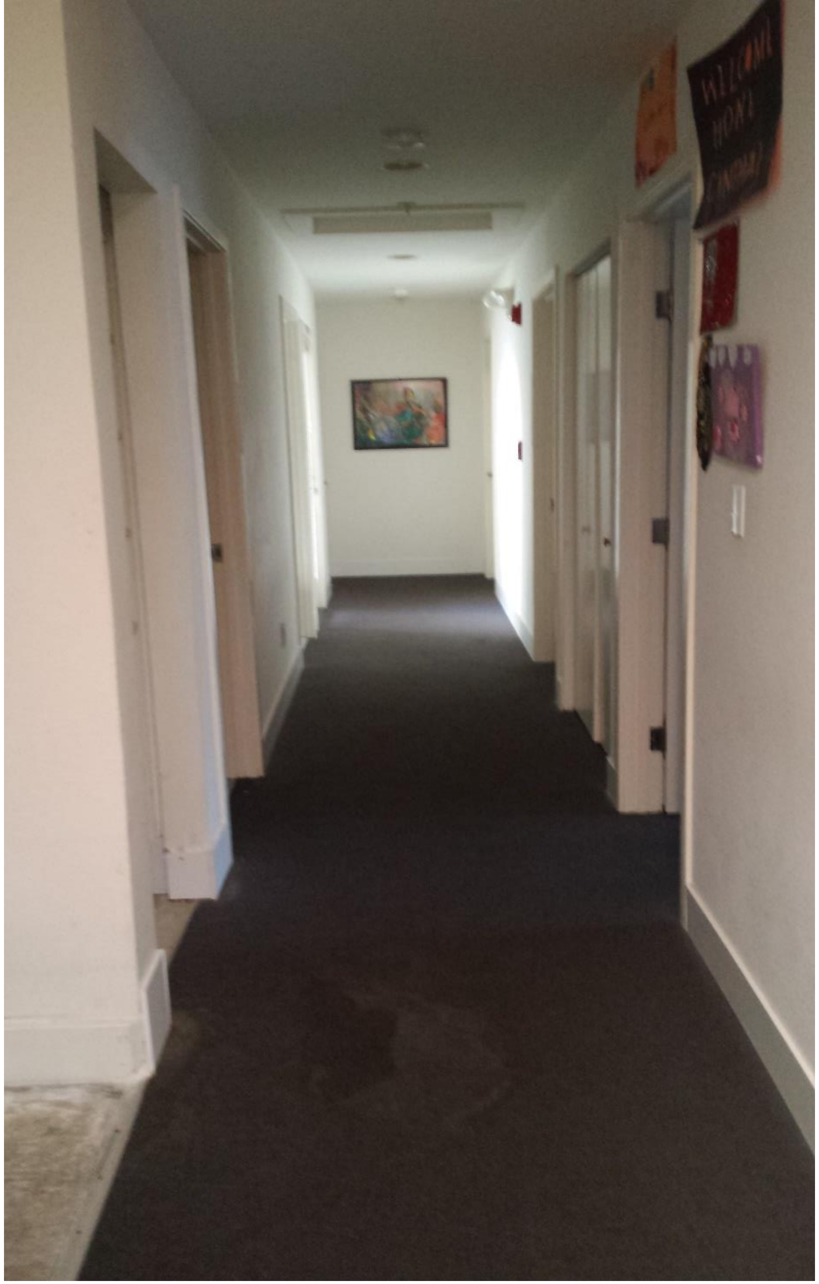
Example of Program or Senior Activity Center

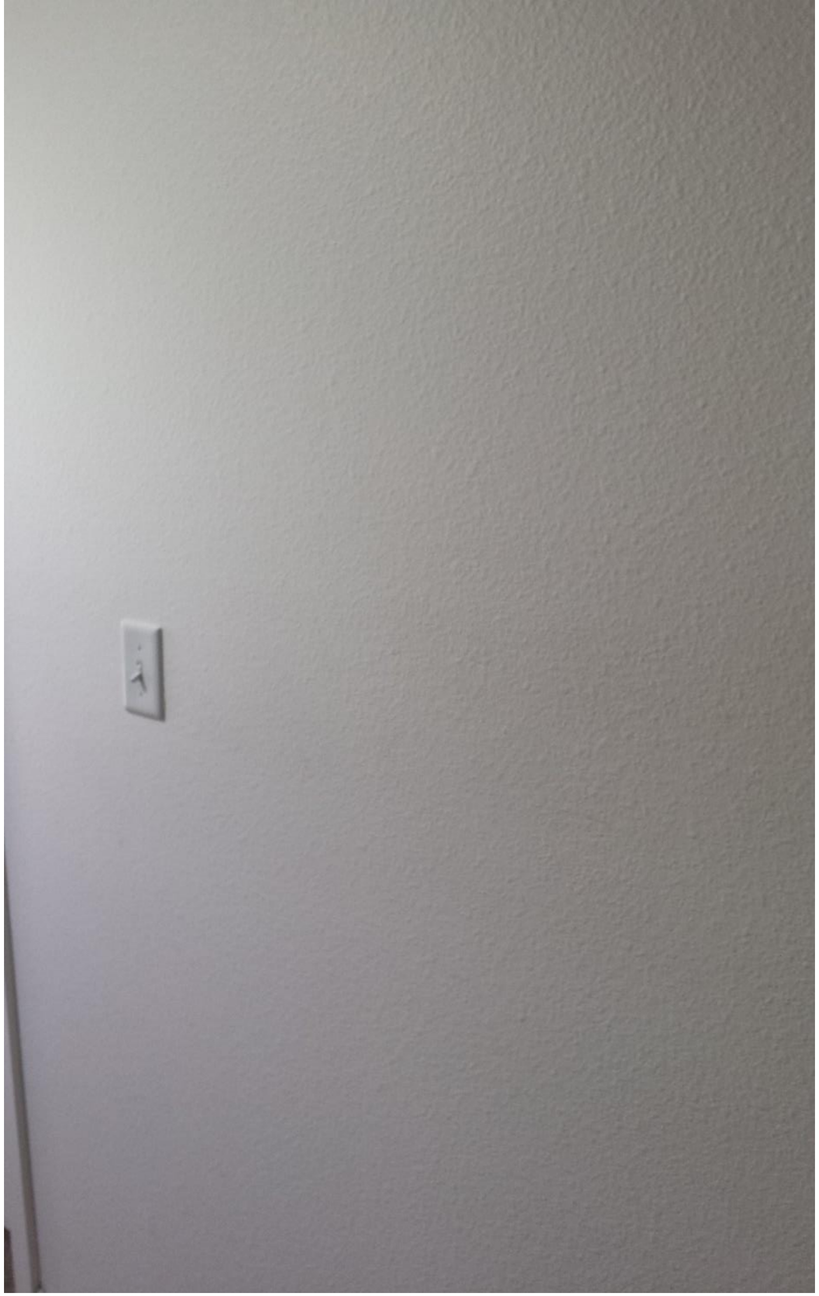
Example of a Residence for Adults with ID

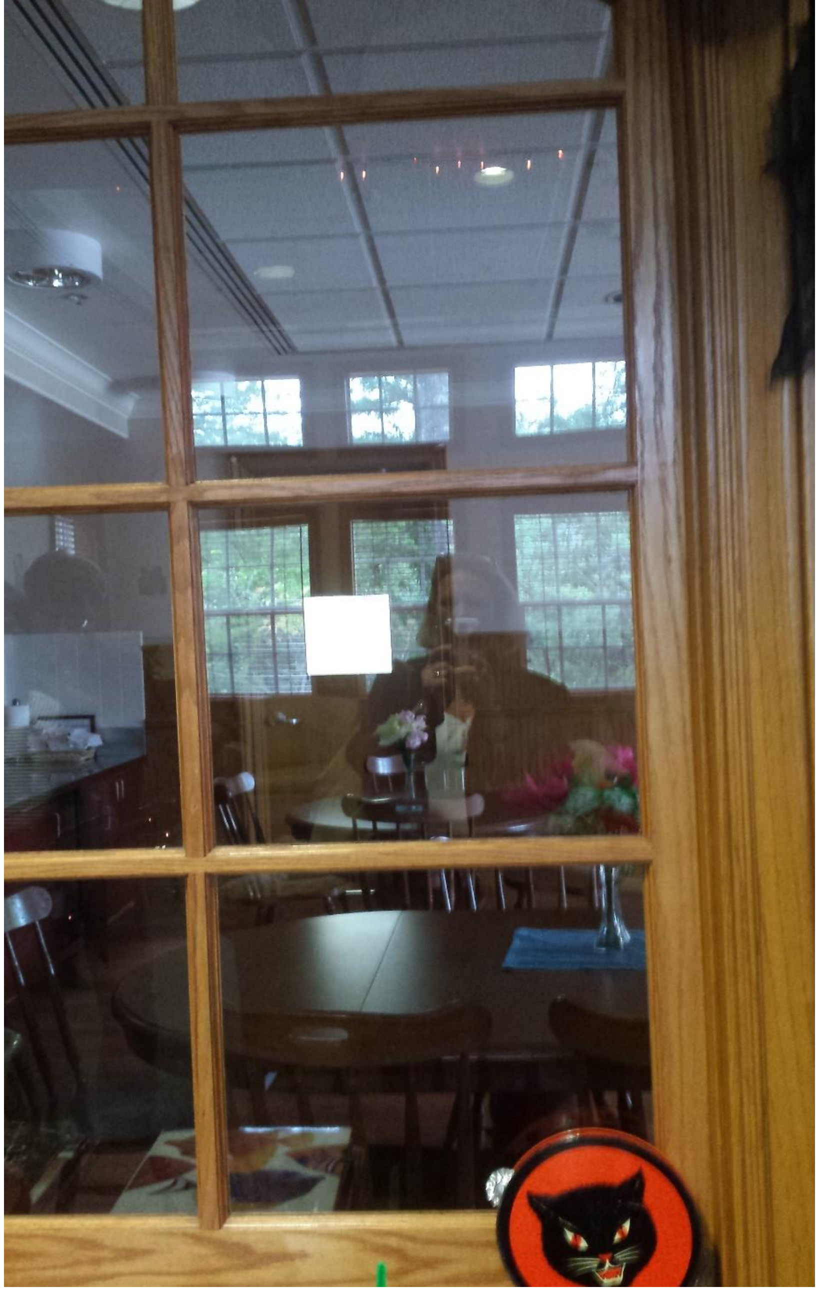
Lack of color contrasts, significant shadowing, and glare increase likelihood of difficulty functioning for the adult with ID and dementia.











Suggestions for Modifications

Reduce visual clutter.

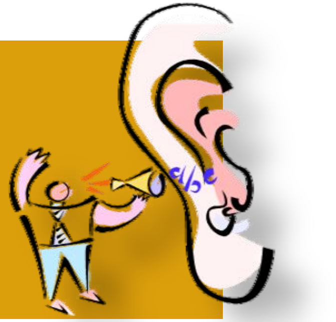
Organize visual clutter into specific appropriate places.

Clearly identified walking paths.

Reduce glare.

- Use matted and low gloss surfaces.
- Floors with texture and not shiny surfaces.
- No-gloss waxes and cleaning products.

Hearing Challenges



- Hair cells in the ear receive the auditory stimuli, transmitted to the neurons of the brain, etc.
- Increased incidence of hearing loss with dementia.
  - One study reported 83% of people with early to mid-stage dementia.
- Continual noise pollution in our environments.
- Impairment in reception and initial response to stimuli.
- Impairment in comprehension (underlying cause?).

Suggestions for Hearing Impairment

Reduce background noises (fans, radios, TVs, appliances).

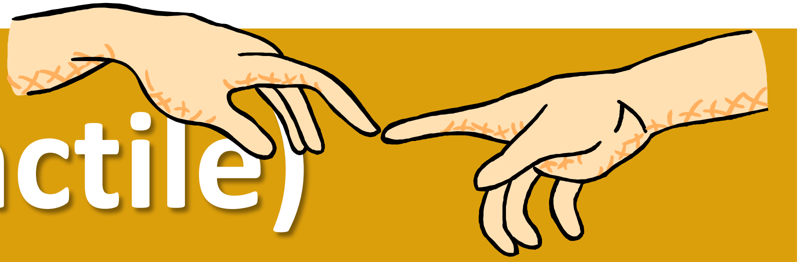
Add soft materials such as carpeting whenever possible.

Visual and/or physical cueing along with auditory information.

Staff awareness:

- Simple, short, one direction or piece of information at a time.
- Speak at eye level after gaining eye contact.
- Wait longer for the response than in the past.

Touch (Tactile)



- First developed, last lost.
- Differing degrees of sensitivity.
- Environments can have too much tactile information or not enough to meet each person's needs:
  - The need may be reduced or heightened due to disease.
  - Touch may be the main sense remaining to use for way-finding and interpreting the meaning of objects in the environment.
  - Too much or too little can result in tactile defensiveness and behavioral responses.
  - Dementia may increase touch defensiveness…especially in adults who have been defensive over the lifespan.

Touch (Tactile) Defensiveness

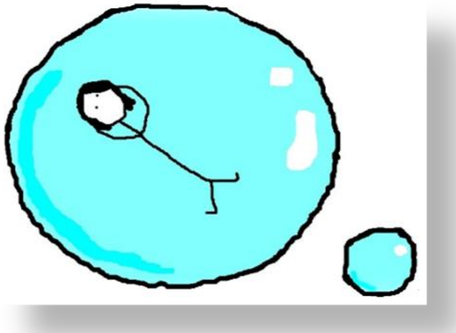
Characterized by the following behaviors:

- Avoidance of touch, hugs.
- Avoidance of textures, preference for certain clothing (refusing to wear anything else).
- Avoidance of activities or places where there are many people and possibilities of touch.
- Avoidance of baths, daily living tasks, hair care, etc.
- Avoidance of dental care.
- Responding with aggression to light touch.
- Increased stress when close to people.
- Pulling away or withdrawal.

Tactile Defensiveness

Characterized by:

- Increased need for personal space (rocking)
- Distractibility
- Increased levels of activity
- May be a result of poor tactile discrimination:
  - Not knowing how many times touched, degree of touch, or being able to recognize the shapes of objects.
- Likely increases within AD



Suggestions for Reducing Touch (Tactile) Defensiveness

Definite marking of territory and personal space.

Chairs with arms.

Clearly marked personal space in bedroom.

Areas in program and residence to get away from others, noise and visual pollution.

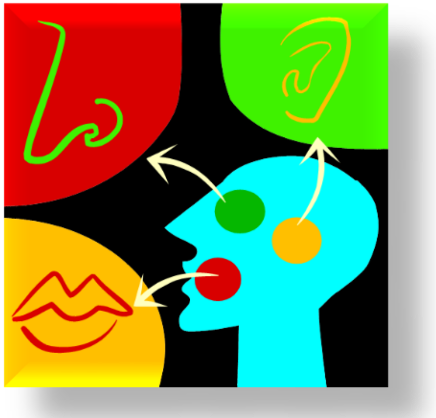
Placemats at the table.

Pay attention to materials and objects (including foods) that appear to irritate the individual and remove them from the environment.

If a person likes a particular outfit let them wear it! Buy two or three of the same or wash when sleeping.

Smell and Taste

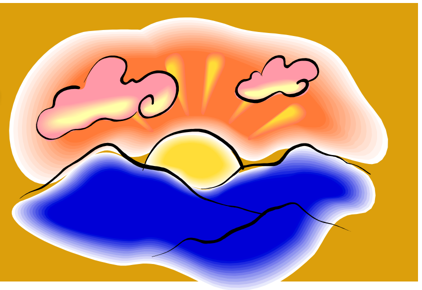
- Differing degrees of sensitivity:
  - What may be pleasant to you may be irritating or obnoxious to another.
  - Be aware of the smells in the environment & eliminate when possible or remove the person who is irritated by the smells
- Can be the cause for refusal to eat, participate in activities, and/or discomfort.
- Change with onset of dementia.
- Too much or too little.
- Can be the underlying cause for refusing eat or “inappropriate behaviors.”
- Medications - taste, smell.



Dementia, Environment, & Safety

- Remove obstacles in pathways to prevent falls.
- Create an environment supportive for the caregiver as well as the adult with ID and dementia.
- Lock or disguise hazardous objects, areas.
- Disguise doors for safe wandering.

‘Sundowning’



- Sundowning – An increase in confusion and agitation that traditionally occurs in late afternoon
- Response to change of shift, transition times, fatigue, lack of light.
- Increase full-spectrum lighting especially at 3 – 6 PM. (Ex. Full-spectrum light bulbs, daylight, light box.)
- Reduce stimuli and confusion.
- Close curtains to reduce shadows and reflections.
- Try to increase supports during transition times.

Summary of Environment & Dementia

Modifications can be made to the environment to help enhance functioning and reduce barriers to quality of life.

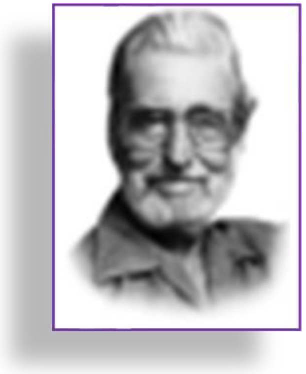
Behavior should be considered in the context of the environment:

- Change the environment, not the person.
- Reduce environmental challenges and triggers for dangerous or disrupting behaviors.
- Make sure it is disrupting to the person & peers, not just to you.

Supporting Derek

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***

Thanks to the NTG volunteers who made this training possible.

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