

MIND & MEMORY MATTERS: EARLY DETECTION & DIAGNOSIS OF DEMENTIA FOR PERSONS WITH INTELLECTUAL/DEVELOPMENTAL DISABILITIES

WI Board for People with Developmental Disabilities

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“MIND & MEMORY MATTERS” PROJECT

- Alzheimer’s Disease Initiative – Specialized Supportive Services Grant (Administration for Community Living)
 - Greater WI Agency on Aging Resources (GWAAR)
 - Alzheimer’s Association – Greater WI Chapter
 - Wisconsin Alzheimer’s Institute (WAI)
 - UW-Oshkosh Center for Career Development and Training
 - WI Board for People with Developmental Disabilities(BPDD)
- Partnership between WBPDD and WI Department of Health Services (DHS) to inform families and care providers on the prevalence of Alzheimer’s/dementia in the Intellectual/Developmental Disabilities community
- Provide outreach, screening, training, and support for professionals, families and individuals with I/DD
- Overall outcome is to increase the quality of life for people with dementia and their caregivers

HEALTHY AGING AND I/DD

Health Disparities and Challenges

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. Post polio syndrome
- Prolonged usage of medications adding to chronic conditions in older age (adverse drug reactions & polypharmacy)
 - Ex. Thorazine

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Factors Impacting Healthy Aging (cont.)

- 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

Challenges to Healthy Aging in Adults with I/DD

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 I/DD
 - IDEA: Video can provide a visual of the person over their lifespan.

Diagnostic Overshadowing

The tendency for clinicians to attribute symptoms or a change in behaviors of a person with I/DD to their underlying cognitive deficits and therefore under-diagnose the presence of co-occurring disease such as dementia.

Health Care Disparities for Adults with I/DD

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

Dementia and I/DD

4 Most Important Facts About Dementia

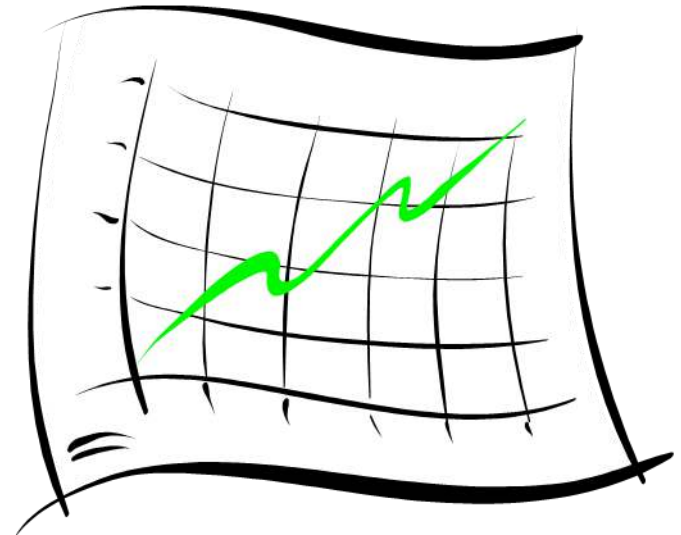
1. “A loss of cognitive (thought) function **severe enough to interfere with daily functioning.**”
2. The term “dementia” describes a group of **symptoms.**
 - a. It is **not a specific disease!**
 - b. “The doctor said my son has dementia...thank goodness he doesn’t have Alzheimer’s!”
3. The condition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

Risk of Dementia in I/DD

Most adults with I/DD are typically at no more risk than the general population.

Exception: Adults with Down syndrome are at increased risk!

- Younger (40's and '50's)
- More rapid progression.



Dementia Prevalence: I/DD vs. DS

Intellectual/Developmental 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.

Irreversible Dementias

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

Alzheimer’s disease is the most common.

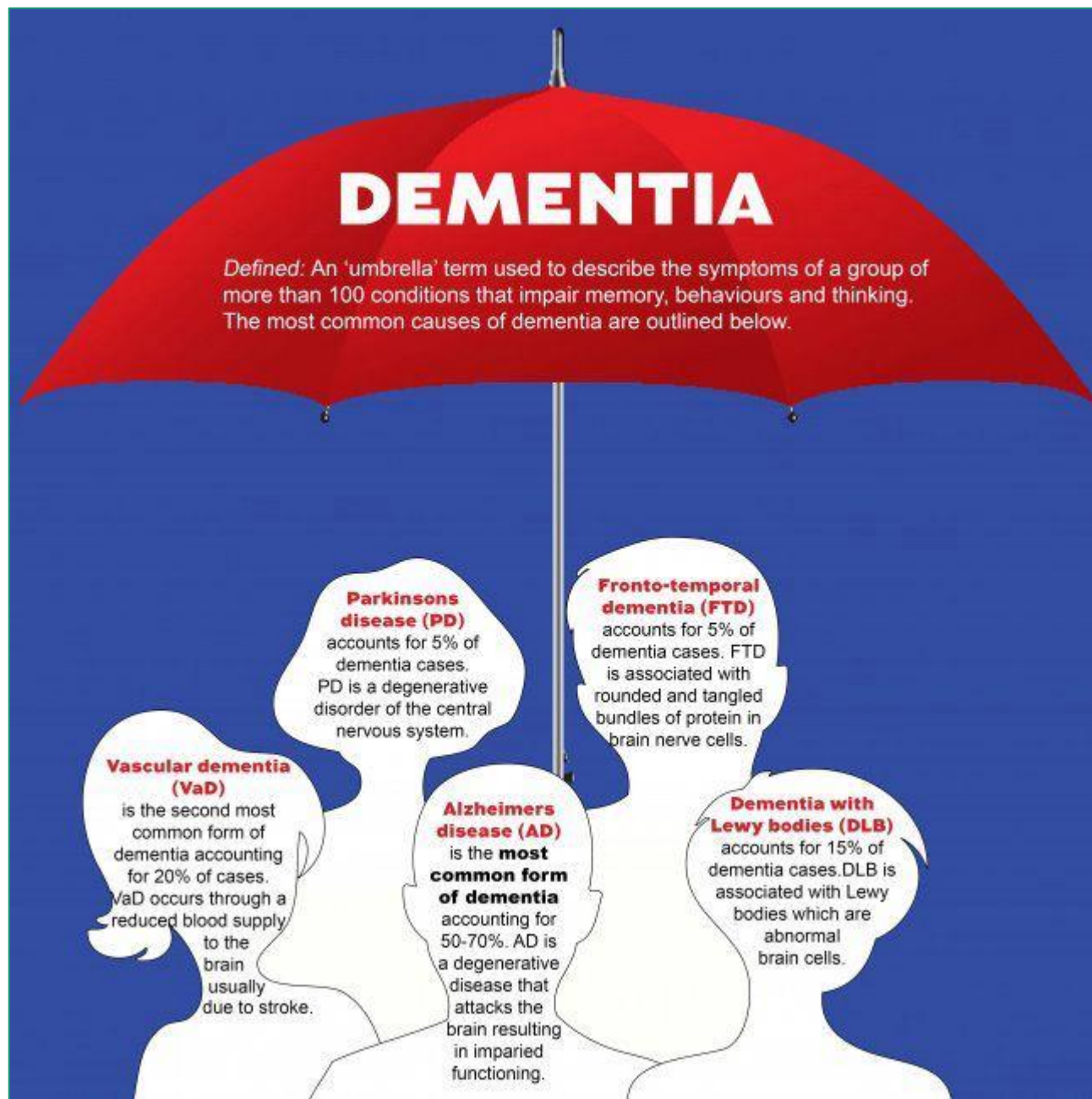


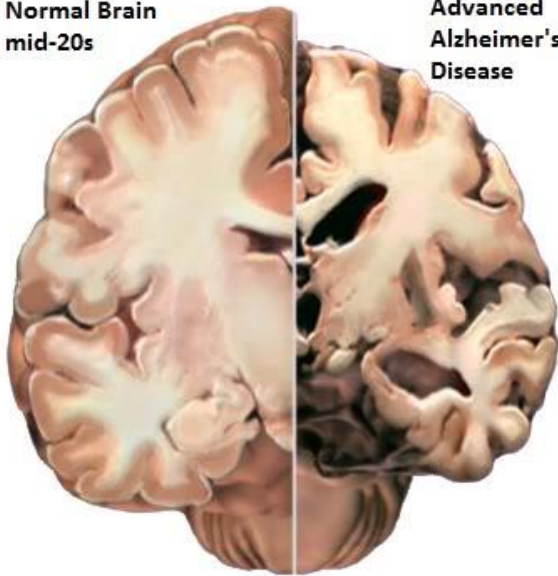
Image: Dementia Forward

Why is it Important or Useful to Know Types of Dementia?

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

Normal Brain
mid-20s

Advanced
Alzheimer's
Disease



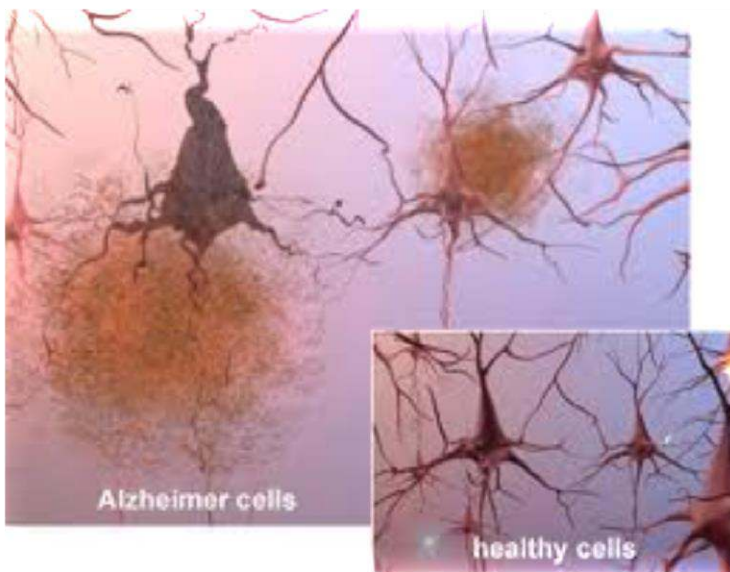
- Lewy body – visual hallucinations
- Fronto-temporal – profound personality change, disinhibition

The type of dementia may impact what medications are used.

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

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

Alzheimer's Disease



- Most common form of dementia.
- Exact cause unknown but includes some mix of genetic, environmental, and lifestyle factors.
- Gradual onset.
- Short term memory.
- Generalized brain atrophy.
 - Shrinks by 30% by time of death.
- Amyloid plaques and neurofibrillary tangles.

Alzheimer's Disease

- Damage begins 10 – 20 years before symptoms begin to show!
- 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 30-60)
- Individuals with Down syndrome develop Alzheimer's at a younger age than the general population.

Down Syndrome & Dementia

The Unique Challenges of Dementia in Adults with Down Syndrome

What is Down Syndrome (DS)?

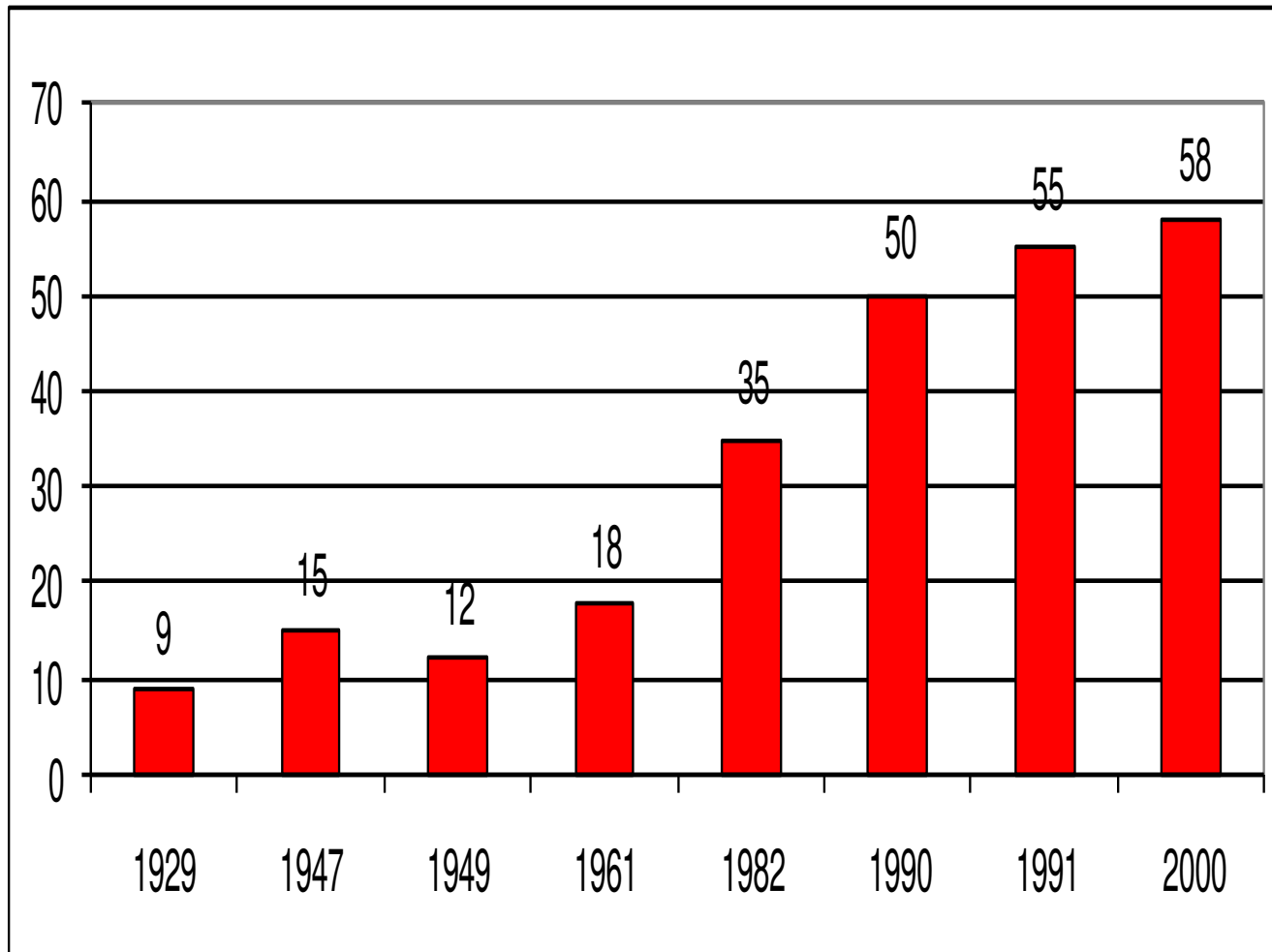
- First accurate description of a person with DS was published in 1866 by an English physician - John Langdon Down.
- DS is a developmental disability – intellectual impairment and physical abnormalities.
- DS occurs 1 in 750 live births.
- DS is caused by a genetic abnormality – an extra full or partial 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

Why a Focus on DS?

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

- Over age 40 - approximately 25% will show clinical signs of dementia.
- Over age 60 - approximately 60% will show clinical signs of dementia

Down Syndrome: Life Expectancy



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 Alzheimer's?

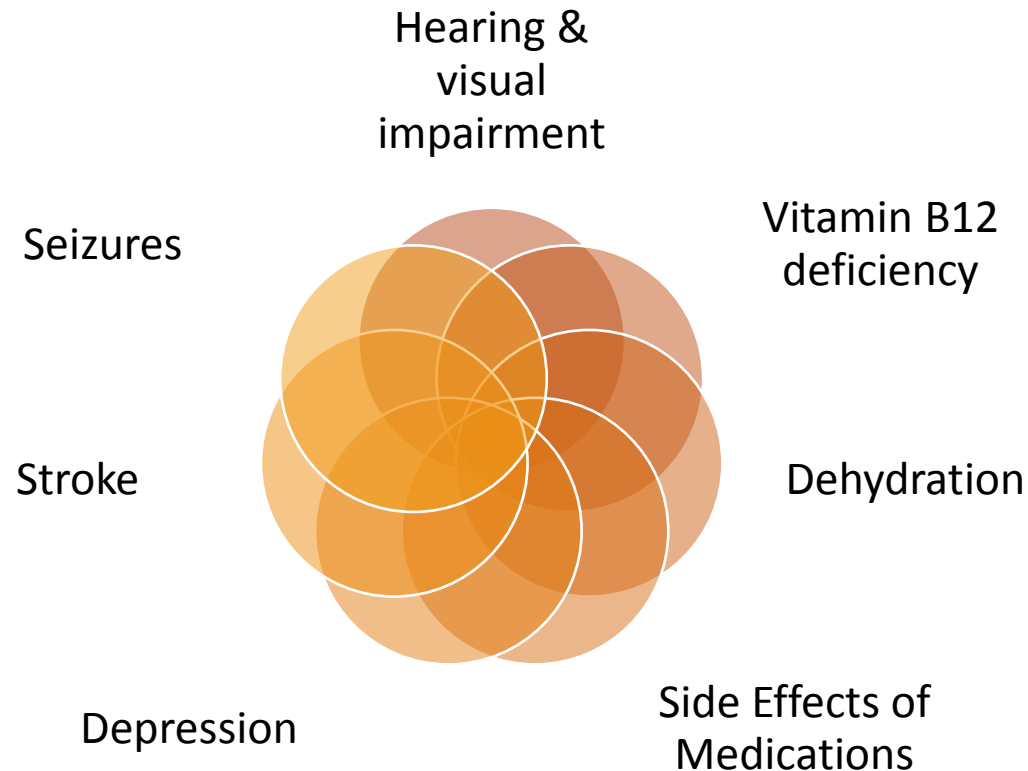
Alzheimer's often presents differently in people with Down syndrome.

- Abrupt onset of seizure activity when there had been none in the past.
- Incontinence when an individual has always been independent in toileting.
- Short-term memory loss may depend upon the previous level of memory demands and reliance on memory in everyday life.
- Sleep/wake cycle disruptions.



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

Adults with DS have Specific Risk Factors for Developing “Dementia.”



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)

Early Screening for Dementia

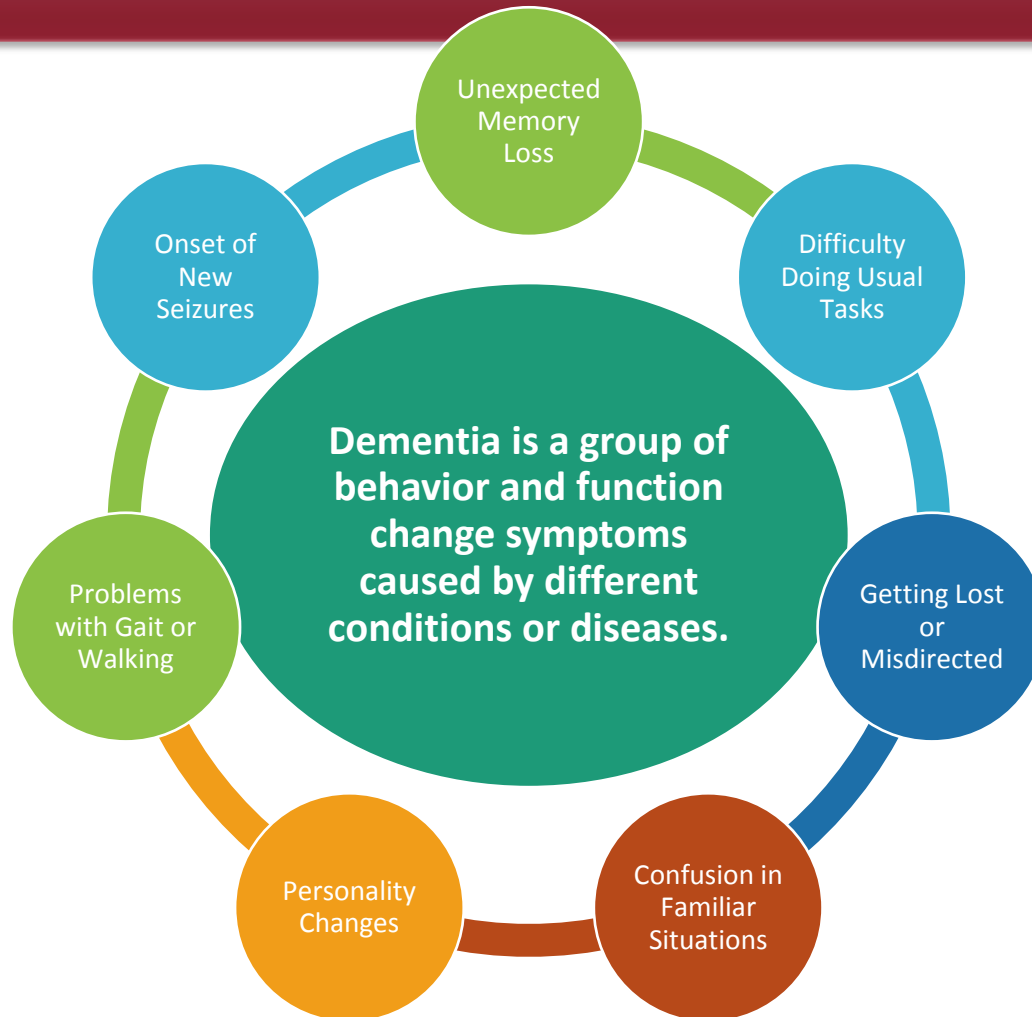
NTG-EDSD Assessment Tool

What is Early Detection/Screening?

- It is **looking for and recognizing** symptoms that if untreated may become more serious.
 - It is an important first step in managing a disease or disorder
 - Can alert to any more changes or symptoms
- Family and staff caregivers can **work together** with the person's health care provider to share information about observed changes
- Use of a **screening tool** to note changes in adaptive skills, behavior, and cognition is recommended.
 - National Task Group Early Detection Screen for Dementia (NTG-EDSD)

Warning Signs

These problems must be notable and usually occur in a cluster



What to Do When Dementia is Suspected?

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

Remember...

Early Detection is Important

- Dementia presents many **problems and challenges** for the adult affected by it and their care partners.
- When dementia can be identified early, there is potential to **proactively** address signs and delay symptoms.
- **Interventions, services or supports** may be more effective if offered prior to significant cognitive and/or functional change.
- Early detection can lead to greater opportunities to **impact quality of life and quality of care.**

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Early Detection is Important (cont.)

- Can **confirm suspicions** that behavior is changing.
- Can lead to **earlier referral** for assessment.
- Early assessments can help in **identifying potentially treatable conditions** that are causing symptoms.
- Makes **persons feel better** because what they are experiencing is being recognized and treated.
- Can help **prevent or minimize** more serious problems by initiating supportive interventions early in the disease process.

NTG Early Detection Screen for Dementia (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)

Down syndrome begin age 40 then annually.

Non-DS begin at age 50.

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



NTG of The Ohio State University
Intellectual Disability and Dementia Program

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: _____

A Screening Tool is Not a Diagnostic Instrument.

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

Who Can Complete the NTG-EDSD?



- Any caregiver, either family or staff who is familiar with the person can complete the NTG-EDSD if they:
 - Have known person for a minimum of 6 months
 - Have access to information in the person's record

How to best complete the form?

- Combine perceptions of function offered by several staff or family members.
- Use best judgment when responding to questions asking for impressions (e.g., health, function).
- Be truthful – don't 'hide' problems to make a good impression

NTG-EDSD: 4 Key Sections

Demographics

Ratings of health, mental health and life stressors

Review of multiple domains including

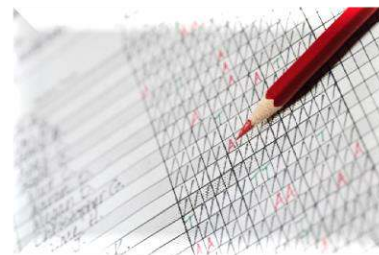
- Activities of Daily Living
- Language & Communication
- Sleep – Wake Patterns
- Ambulation
- Memory
- Behavior & Affect

Chronic Health Conditions

Why is All This Information Needed?

Can help with the physician's visit or for an assessment by a clinician.

- Collects basic information about the adult so it is all in one place.
- Focuses on behaviors that are usually associated with cognitive decline or functional changes.
- Looks at other diseases or conditions that may be present and may impact the adult's functioning.



I've completed the EDSD... now what?

- **Review** the form and see if there are any changes noted that are potentially of concern.
- **Talk it over** with the individual's key workers to ensure agreement with the findings.
- **Discuss** findings with the team and supervisor.
- If there are concerns, **make an appointment** to have the person further assessed.
 - Collate all of the information into useful packet
 - Assemble a list of medications being taken
 - Bring any digital video evidence of function or functional problems

From Screening to Diagnosis

Screening

Administrative [NTG-EDSD]
Clinical (DSDS, DLD, AADS)

Assessment

Dementia Assessment Scale
Neuro-psych evaluation
CT - MRI

Diagnosis

Possible
Probable
Definitive

Diagnosing Dementia

The Differential Diagnosis

The Importance of Differential Diagnosis

1. Rule out treatable conditions.
2. Receive appropriate treatment and support services.
3. Maintain the highest possible quality of life and functioning.



Conditions Common to Aging That Can Mimic Dementia

Dehydration,
Malnutrition

Metabolic
Disorders

Vitamin &
Mineral
Deficiencies

Sensory
Impairments

Common Conditions to Rule Out through Differential Diagnosis

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

The Three D's

Dementia

Gradual over
months to
years

Delirium

Sudden
onset, hours
to days

Depression

Recent
unexplained
change in
mood that
lasts for over
2 weeks

Health Care Advocacy

What it is and Why it's Important

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

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 is **Dementia** Health Care Advocacy Needed?

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



Caregiving Needs

Dementia Capable care in I/DD

Caring for Someone with Dementia Requires a Shift in Thinking

Developmental perspective

Focus is on encouraging autonomy
and life goal achievement

Maintaining function

Focus is on enabling residual skills to be maximized
and minimize impact of diminishing abilities

Behavior is Communication



Common “Behaviors”

Wandering

Repetitive questions

Rummaging, hoarding

Verbal outbursts – yelling, excessive vocalizations, cursing

Physical – hitting, spitting, kicking

Paranoia

Hallucinations

Sleep-wake disorders

Sundowning

Resistance to personal care

Inappropriate sexual expression

General Tips

- Do not try to reason or argue.
- Stay calm.
- Make sure you have their attention.
- Short sentences with yes/no answers.
- Loud voice can be interpreted as angry.
- Allow time.
- Respond to emotion.
- Distract and redirect.
- Step away and try again in a few minutes.

Communication: 4 Key Strategies

1) Difficult behaviors cannot be changed with words

Technique: Change your approach to the person, reaction to the behavior, the environment. Individuals with dementia have impairments in short term memory as well as an inability to learn new information. They cannot be told to do, or not do something and be expected to remember

2) Don't say "No" and never argue

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

Communication: 4 Key Strategies

3) It's their reality and you must enter it

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

4) Reduce fear by acknowledging underlying emotions

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

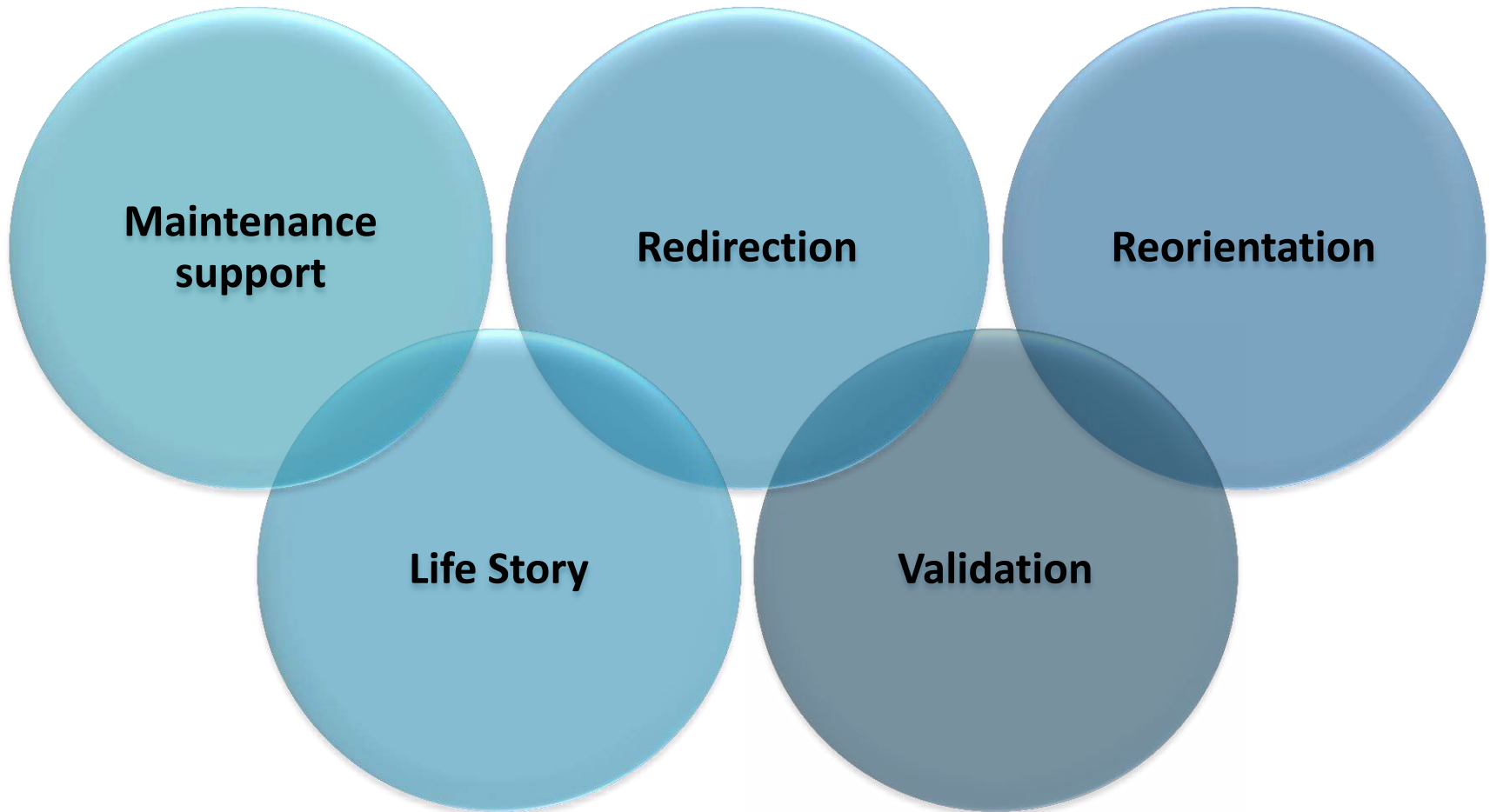
“Amygdala” – Fight or Flight – Responsible for managing basic emotions such as fear and anger. Alzheimer's disease can severely damage – the result is emotional instability (paranoia, temper outbursts, anxiety, etc.)

Dementia-Capable Environments

Dementia alters visual perception – can't shut out other stimuli

- Adults with I/DD may already have been compromised
- “lost in space” – help with cues like placemats on the table
- Bathrooms often white on white – need contrasting colors
- Keep landmarks the same – arrows to the bathroom
- Colors may appear differently, glare sensitivity, black & white tiles or “busy” carpet
- Visual field about 3' from floor
- Food – one food at a time – don't load plate with all and use contrasting colors and easy to use utensils

Key Concepts in Dementia Care



Key Concept in Dementia Care

Maintenance support

- Generally accepted as the **best practice** in dementia care.
- **Proactive** approach
- Five **'domains'** that create and maintain positive emotions.
 - A domain is an opportunity to bring about a positive emotion or, at least, not to cause a negative one.
 - Focus is on supporting remaining **abilities**.
- Respects needs and emphasizes **meaningful activity**.
- Can **reduce or eliminate difficult behaviors** at all stages.
- Appropriate for **all settings**.

5 Domains of Maintenance Support

Physical

- Reducing potential for fear and disorientation by modifying/adapting environment
 - Ex. Reduce clutter, increase lighting, limit choices.

Social

- Use of structured, failure-free activities that avoid frustration.
 - Ex. Reminiscence, music, gardening

Communication

- Increased use of body language, gestures, cueing, signs to compensate for decreased verbal skills.
 - Never say “no” or argue, use redirection, enter their reality, respond to the emotion.

Functional

- Excess disability arises due to the person’s emotional reaction to disease.
 - Avoid open ended questions, “chunking” – a series of short, simple commands

Behavioral

- Behavior is a form of communication. To change a behavior we must change our approach.
 - Analyze the behavior to find underlying trigger: pain, frustration, environment, confusion.

Key Concept in Dementia Care: 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 they can no longer tell their own story, it can still be used to inform caregiving and plan activities.
- Scrapbooks, videos, interests, hobbies, personal likes/dislikes/routines.



Key Concept in Dementia Care:

Validation Approach

- An approach that **focuses on empathy and understanding**.
- Based on the general principle of ***validation***...the acceptance of the reality and personal truth of another's experience no matter how confused.
- All **behavior has meaning** and is an attempt to communicate.
- Can **reduce stress, agitation, and need for medication** to manage behavioral challenges.
- Forcing a person with dementia to accept aspects of reality that he or she cannot comprehend is cruel.
- Emotions have more validity than the logic that leads to them.

Key Concept in Dementia Care: ~~Re~~orientation

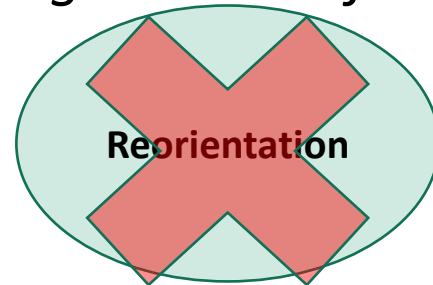
Do not correct the person or try to reorient them

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.”*

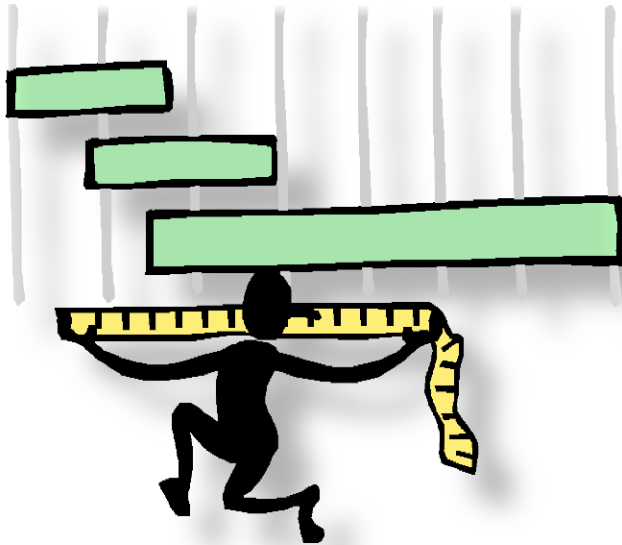


Key Concept in Dementia Care:

REDIRECTION

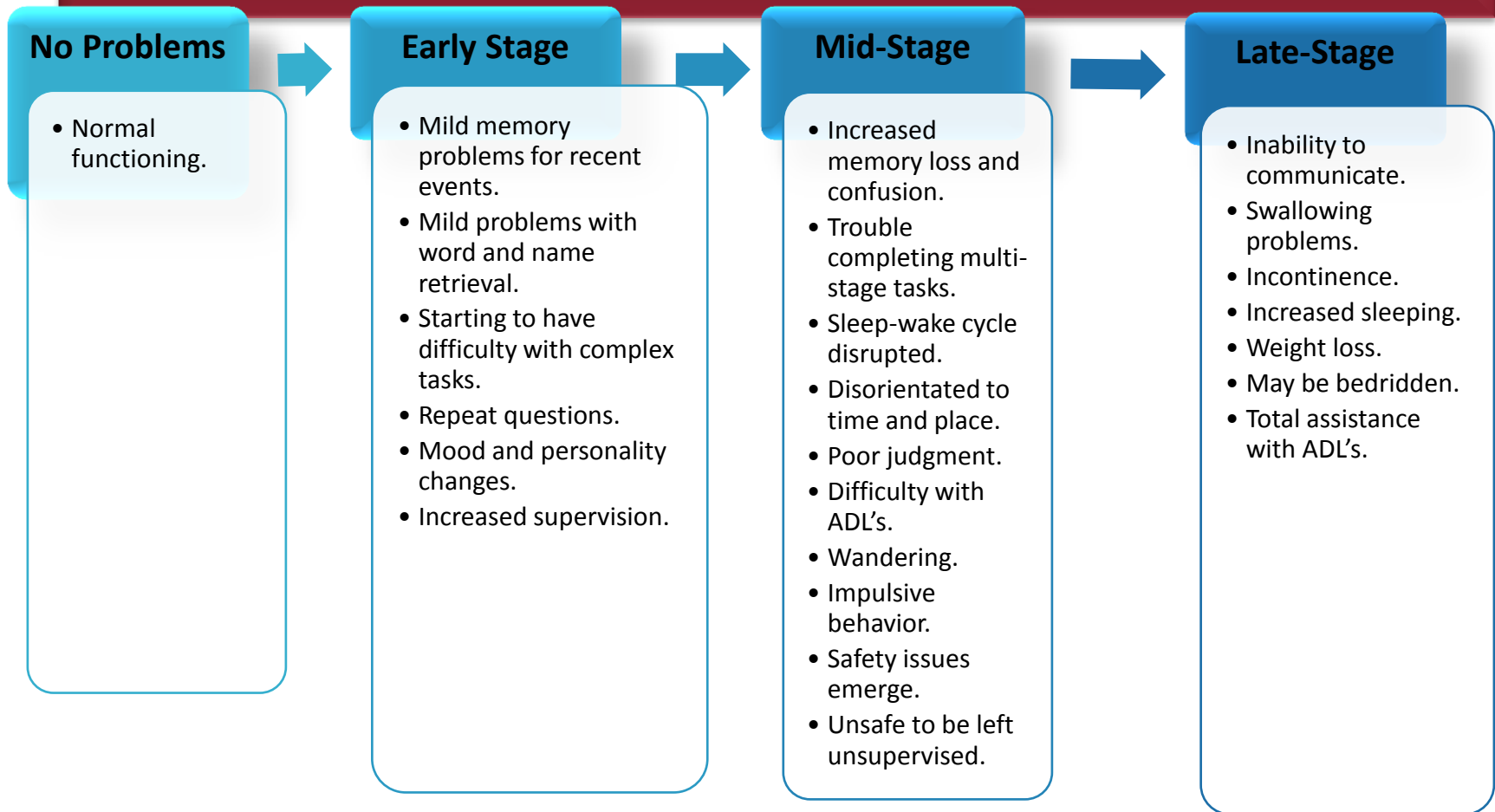
- By redirecting an individual with dementia, you may be able to avoid or delay outbursts and inappropriate behaviors.
 - Conversations and actions of a person with dementia can be redirected with gentle distraction or by suggesting a desired activity.
 - Providing food, drink, or rest can be a redirection.
- Always offer suggestions for new activities or conversation topics in a reassuring tone.
- Never focus your redirection on reprimand or by saying “no” or “don’t do that”.
- The most important thing to remember is that each person is unique.
- Activities and conversations that successfully redirect one person may not work with someone else.

Stages of Dementia



- A “yardstick” or estimate.
- A general measure of the progress of a person's cognitive decline.
- Used to determine appropriate supports and accommodations based on the individual's needs and remaining abilities.
- The NTG uses the *staging model* that is in generally accepted practice among generic dementia services.

How Dementia Progresses



Stage Based Care Considerations

Early Stage

- Screen with NTG-EDSD
- Observation & reporting of functional changes to and team.
- Support functioning and maintain quality of life

Mid-Stage

- Modify/adapt environment to support functioning and safety
- Increase staff supervision and supports
- Maintain routine and structure as much as possible

Late Stage

- Specialized re-training of staff including mobility, eating, and comfort care
- Increased use of adaptive equipment and procedures
- Grief support – family, staff, friends

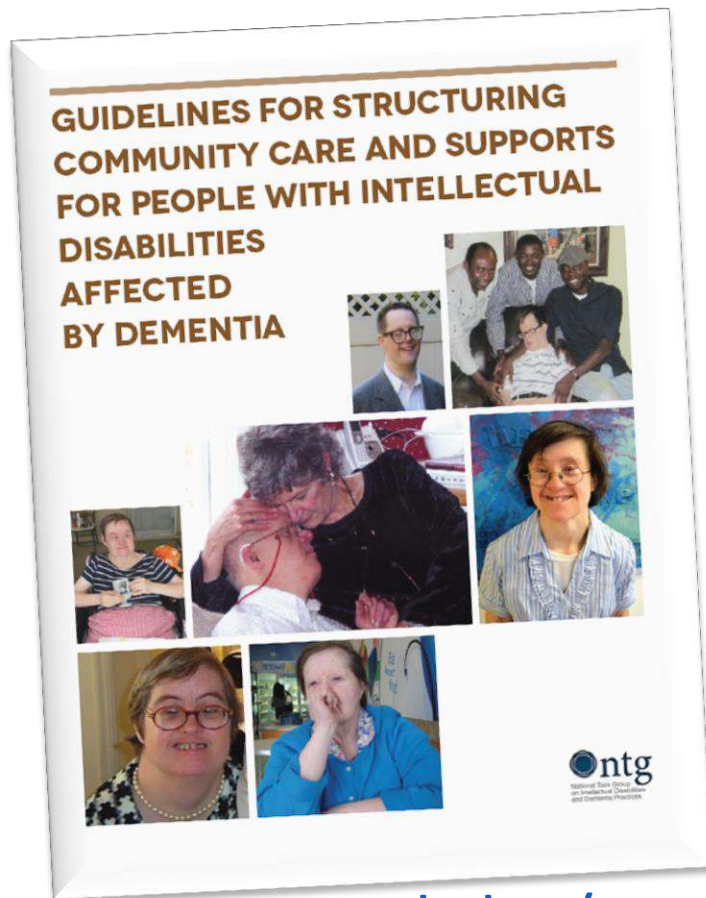
Promoting Quality of Life

- Stage-based support strategies help maintain independence, function, and community participation for as long as is possible and reflect genuine community living.



- A goal of care is to provide and maintain a quality care environment that recognizes the affected adult's dignity and personhood.

For Guidance...

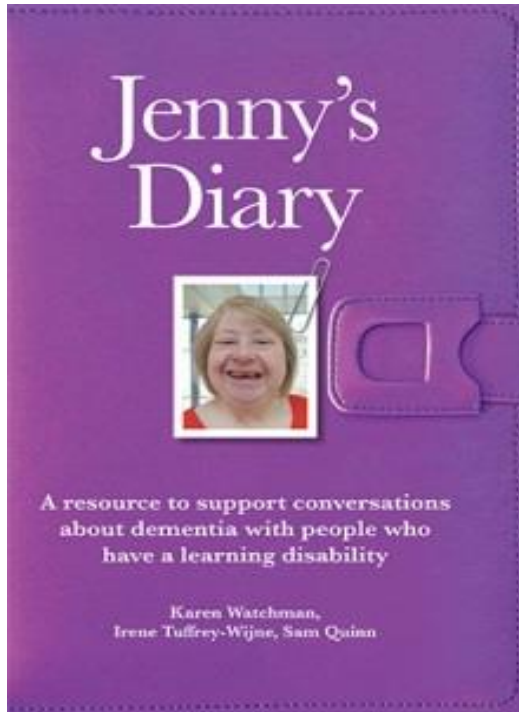


www.aadmd.org/ntg

- This NTG document provides a guide to what actions should be undertaken within the *staging model* generally accepted for practice among generic dementia services.
- The staging model flows from a pre-diagnosis stage when early recognition of symptoms associated with cognitive decline are recognized through to early, mid, and late stages of dementia, and characterizes the expected changes in behavior and function.
- The NTG document also provides information on nonpharmacological options for providing community care for persons affected by dementia as well as comments on abuse, financial, managing choice and liability, medication and nutritional issues.

For Guidance...

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

www.uws.ac.uk/jennysdiary

Take-Away Points

- Understanding the effects of dementia upon how a person functions can help with a range of support and caregiving tasks.
- Generally dementias progress in predictable patterns, with individual variations, and understanding those processes can help with caregiving.
- There are proven care techniques that can help with dementia management and make caregiving easier and help with enabling a quality care environment.

Take-Away Points

- Maintain the ESSENCE of the person – be present
- At 40 look at them as age 60 (accelerated aging)
- Structure & routine is important
- Document success and what works
- Dementia is different in every individual
- Protect the person from physical injury
- Maintain independence as long as possible
- Focus on what they can still do
- Provide physical and mental activities the person can do
- Support person's dignity and self-esteem at all times

Research Studies

Important part of finding a cure

Waisman Center Research

- The Waisman Center at the University of Wisconsin-Madison and the University of Pittsburgh Medical Center are seeking adults (ages 30 and above) with Down syndrome to participate in a research study involving an MRI and a PET scan.
- The study will consist of two visits which can be completed during a single, two-day stay in Madison. The first visit will take at least 4 hours and includes describing the study, reviewing the procedures of the MRI and PET scan via video and pictures. The second visit will take around 4 hours and includes an MRI which will take approximately 30 minutes, and a PET scan which will take approximately 1 hour. In addition, a blood sample will be drawn.
- Participants will be compensated for their time and expenses. Funds are available for participants and caregivers to stay overnight. This will allow the two study visits to be completed over two consecutive days.
- For the **Madison** site please call Renee Makuch at the Waisman Center, University of Wisconsin-Madison (608-262-4717 or toll-free at 1-877-558-7595) if you would like additional information.
- <http://www.waisman.wisc.edu/amyloid/>

Wisconsin Registry for Alzheimer's Prevention (WRAP)

- The main goal of WRAP is to understand the factors (biological, medical, environmental, and lifestyle choices) that increase a person's risk of developing Alzheimer's disease. This is a first step in developing interventions that may protect against developing Alzheimer's disease.
- **WRAP** is an observational study that is tracking the characteristics and habits of two important groups of volunteers:
 - people who have one or both parents with Alzheimer's disease (the family history group), and;
 - people whose parents lived to old age with no signs of Alzheimer's disease or other serious memory problems (the control group).
- **Participation in WRAP includes** an initial study visit and follow-up visits every 2 to 4 years. At each visit, study volunteers are asked to:
 - Complete questionnaires about their background, medical history, and lifestyle habits such as exercise or diet.
 - Have height, weight and vital signs such as blood pressure measured.
 - Complete cognitive tests to check memory, attention and other cognitive skills.
 - Give a blood sample for laboratory testing.
 - Provide stored blood samples for use in future analyses, including genetic analyses.
- Participants in WRAP are eligible to participate in research studies at the Wisconsin Alzheimer's Disease Research Center.

Helpful Resources

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www.MindandMemory.org

NTG Tool & Guidelines :

www.aadmd.org/ntg

National Down Syndrome Society

www.ndss.org

The image displays two primary resources. On the left is a booklet titled "GUIDELINES FOR STRUCTURING COMMUNITY CARE AND SUPPORTS FOR PEOPLE WITH INTELLECTUAL DISABILITIES AFFECTED BY DEMENTIA". The booklet cover features several photographs of individuals and a group, and the logo for the National Down Syndrome Society (NDSS). On the right is a form titled "NTG-EDSD" (v.1/2013.2). The form includes instructions for use, a section for personal information (Date, Last, Age), and a section for current living arrangements with checkboxes for various options such as "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", and "Lives in other".