National Task Group Early Detection Screen for Dementia (NTG-EDSD)

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Chair, Screening NTG/AADMD

Why develop an Administrative Tool?

- Need to capture observation of change early enough in process to provide a window for intervention
- Need tool that can be used to communicate with health care provider
- Tool for interagency and integrated health care planning

Need for an administrative tool

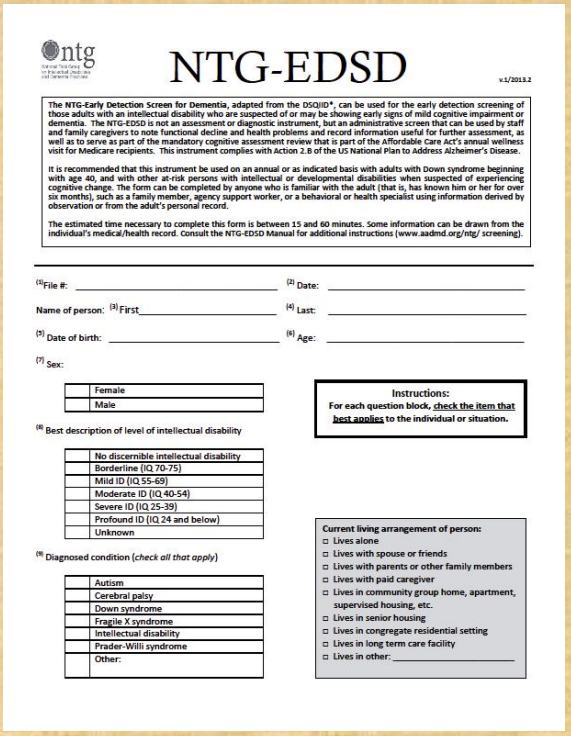
- Clinicians report that individuals are not brought to attention until well advanced in the dementing process
- Need for an administrative tool that will help link individuals who exhibit change to relevant health care options
- Cognitive and functional status are not usually included in annual health screenings
- For those eligible, the **NTG-EDSD** could be used as part of the Annual Wellness Visit

What is the Value of Early Recognition?

- Early recognition provides a larger window to intervene: we may **slow the progression** of symptoms; early treatment can help maintain a person's current level of functioning.
- An early differential diagnosis can also help to **identify reversible conditions** that may mimic dementia such as depression, medication side effects, substance abuse, vitamin deficiencies, dehydration, bladder infections or thyroid problems.
- Accurate and timely assessment can avoid the trauma of a diagnosis of dementia where it does not exist. It also prevents unnecessary and possibly harmful treatment resulting from misdiagnosis

NTG -EDSD

- Early Detection Screen for Dementia
  - an instrument adapted from the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (Deb et al., 2007) and the Dementia Screening Tool (adapted by Philadelphia Coordinated Health Care Group from the DSQIID, 2010)
- Down Syndrome begin age 40 then annually, non-DS begin when changes are noted
- Piloted in 8 sites during the Fall of 2012



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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*)

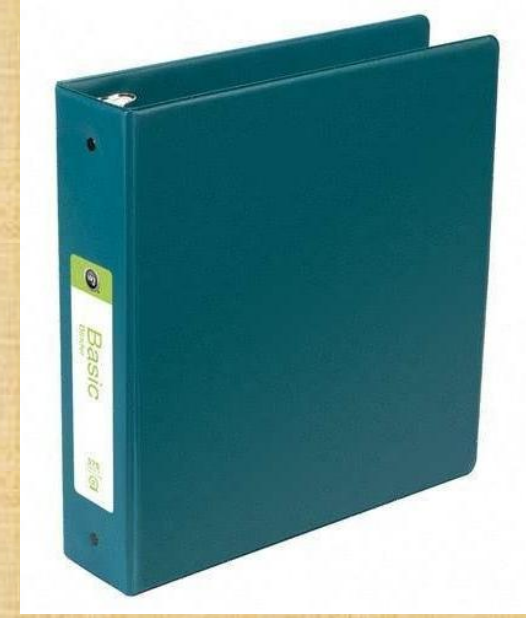
	Autism
	Cerebral palsy
	Down syndrome
	Fragile X syndrome
	Intellectual disability
	Prader-Willi syndrome
	Other:

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: _____

http://aadmd.org/ntg/screening

Role of Staff

- Staff are raters for the **NTG-EDSD**
- Staff need to have worked with the individual for at least 6 months in order to serve as a rater on this instrument
- Staff are more likely to be aware of subtle changes in behavior and functioning that may signal important information for health care providers



What complicates early recognition and diagnosis of dementia?

- Lack of standardized assessments for persons with IDD that can reliably be used to confirm/disconfirm ***significant*** changes in cognition and adaptive functioning
- Debate about what constitutes ***significant change*** among persons with pre-existing memory and other cognitive impairments
- Diagnostic overshadowing…everything is attributed to IDD

Advanced Planning

- Most dementias are progressive and deteriorative and result in increasing incapacity and eventual death
- The individual who is diagnosed with dementia will likely need increased personal care supports
- The individual may have accompanying medical problems that need attention
- The individual has a higher likelihood of delirium which may require emergency medical care
- Many individuals with dementia manifest the behavioral and psychological symptoms of dementia (BPSD) which will involve management of difficult behaviors

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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.

https://aadmd.org/ntg

http://aadmd.org/sites/default/files/NTGcommunitycareguidelines-Final.pdf

http://aadmd.org/ntg/thinker

http://aadmd.org/sites/default/files/Bishop-document-web.pdf

http://aadmd.org/sites/default/files/NTG-EDSD-Final.pdf

Policies and Procedures that Support Dementia Capable Caregiving

- The NTG recommends that agencies establish policies and practices which include the training of staff as health advocates
- The NTG also recommends that agencies develop a process for cooperation and collaboration with local health providers
- Organizations from both the disability and healthcare systems need to communicate, understand the resources and constraints of each system and identify points of collaboration around the assessment, health maintenance and active treatment

Health Advocacy

- 1. promoting health literacy among families and staff
- 2. training family and professional caregivers on the signs of decline
- 3. providing guidelines to family and professional caregivers on what to report and to whom regarding observed decline in functioning
- 4. Having discussions with health care professionals
- 5. Obtaining assessment and guidance about next steps
- 6. Keeping the health care professional and all members of the individual's valued system in communication with one another, updated, and engaged in developing and delivery specific services

Dementia Capable Care: One Clinician's Perspective

- Person-centered Pragmatism:
  - On-going assessment to determine the individual's needs
  - Realistic assessment of resources and "will" within the person's setting
  - Training toward competency using available resources
  - You use what you have, problem solve work-arounds and advocate for what you do not have but the person needs

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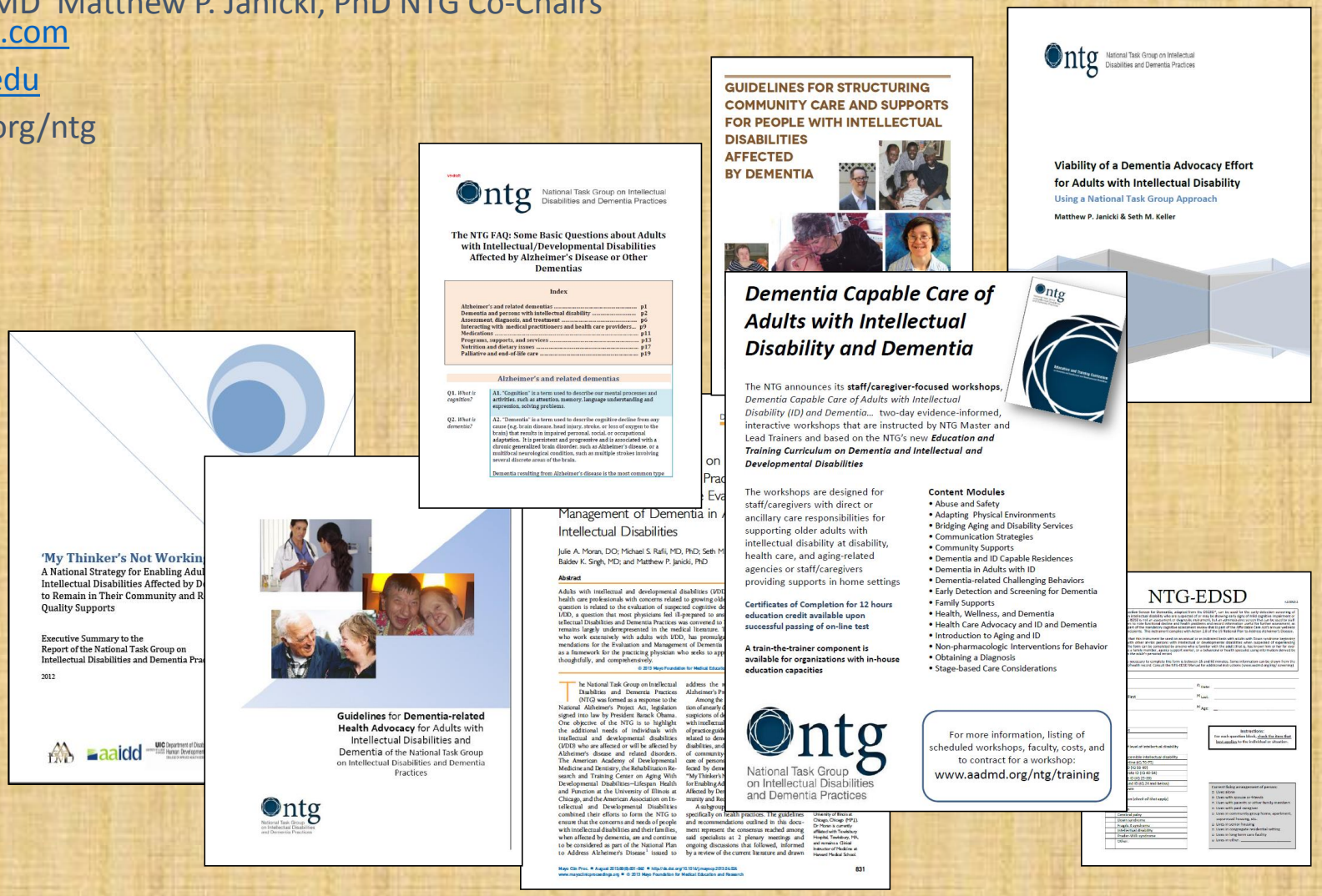


Utilizing findings from EDSD

- Has the individual displayed new symptoms in at least 2 domains on the EDSD?
- Alternatively, is the individual rated as having gotten worse for symptoms already noted in 2 areas?
- Has delirium been ruled out?
- Has depression been ruled out?
- What is the healthcare provider suggesting with regard to medication, monitoring, non-pharmacological interventions?

Additional Resources

- http://www.cddh.monash.org/research/depression/
- http://www.knowledge.scot.nhs.uk/improvingcareforolderpeople/think-delirium.aspx
- http://consultgerirn.org/uploads/File/trythis/try_this_13.pdf

Brain changes occur before signs of dementia

Brain changes are likely to precede functional signs of probable Alzheimer's dementia by more than a decade

- If dementia can be identified earlier, there is the potential to proactively address signs and symptoms.
- Interventions, services or supports may be more effective if offered prior to significant cognitive and/or functional change.
- Greater opportunity to impact quality of life and quality of care

Early Identification

- Early identification of signs and symptoms of cognitive and functional decline associated with dementia is an important first step in managing the course of the disease and providing quality care
- Family and professional caregivers should work with the consumer's health care provider to share information about observed changes
- NTG promotes the use of its screening tool the **National Task Group Early Detection Screen for Dementia (NTG-EDSD)** to substantiate changes in adaptive skills, behavior and cognition

What are we asking you to observe?

- Changes from characteristic, baseline behavior in the following areas

❖cognition (memory, attention, problem solving)

❖behavior (social and control of impulses)

❖emotion (mood, emotional regulation)

❖function (Activities of Daily Living)

Additional Comments

- The **NTG-EDSD** is an evolving instrument. Since it is a “work in progress,” we appreciate your comments and questions which can help guide further development of the tool
- There is no “score” that is currently obtained on the basis of the rating. Currently DSM-5 and DM-ID criteria for dementia will be used to determine if there has been “significant change” to warrant recommendation for further evaluation or if other recommendations are indicated to address issues that affect cognitive and adaptive functioning that may not be related to dementia

The 4 D's of differential diagnosis

- **Disability**

To what extent are observed changes attributable to aging with disability?

- **Delirium**

To what extent might changes in medical status be the source of sudden onset cognitive, behavioral or adaptive status changes?

- **Depression**

To what extent is significant depression driving a change in cognition or function?

- **Dementia**

To what extent might a significant change from baseline that affects at least two domains of function be an indication of neurocognitive disorder?

What might alert you to *delirium* as a cause of status change?

- Recent medical problems or acute psychosocial stressors
- ***Sudden onset*** changes in cognitive, behavioral or functional status
- ***Fluctuating course*** of attention, agitation throughout the day
- Note well: even if delirium is not the prime cause of status changes, it can be an overlay on existing deficits that further decreases the person's functioning and complicates care

What might alert you to *dementia* as the source of status change?

- Dementia is not a clinical diagnosis, it is a clinical description of observed change in functioning
- Dementia does not indicate etiology of decline, it denotes significant changes in cognition, function and/or behavior that interfere with the individual's independence and pursuit of daily routine and relationships
- Dementia describes the effects of neurocognitive disorder such as probable Alzheimer's disease, cerebrovascular dementia, frontal lobe dementia, etc.

Why is it important to know about intellectual level in planning care?

- Dementia is a description of a clinical phenomenon of significant decline from baseline in at least two areas of adaptive skills
- Adaptive skills and intellectual functioning are closely allied
- To the extent that we know the person's intellectual functioning at baseline (highest level of pre-morbid functioning), we are more likely to be able to recognize decline
- In most adults intellectual functioning does not significantly change by virtue of age unless there is some other process (neurocognitive disorder, health status change, etc.) driving such change

What is the value of knowing etiology of developmental disorder?

- We currently know the most about DS and dementia because of the connection between Trisomy 21 and the deposition of beta amyloid associated with Alzheimer's disease
- We know less about the connection (if there is a connection) between other forms of developmental disorder and neurocognitive decline
- Collecting data on the relationship between type of developmental disorder and observed changes may increase our knowledge base in this area
- For example, there have been reports of a connection between decline with cognitive aging and Praeder-Willi Syndrome…

Baselining cognitive, behavioral and adaptive skills

- How can we establish baseline in cognition, behavior and functioning for a heterogeneous population of adults with disabilities?
- How do we recognize significant departure from baseline among individuals who already experience significant challenges in adaptive functioning?
- How do we measure decline among individuals who are severely or profoundly intellectually disabled?
- We currently do not have any standard tools to measure change in a limited linguistic/non-verbal population and must rely on observation

How does one establish baseline?

- Obtain direct measures, rating scales and collateral information regarding the person's typical and characteristic functioning
- Adult functioning tends to be fairly stable unless there are problems that result in departure from baseline characteristic
- Share with healthcare provider observations of changes in sleep

Treat Psychiatric Symptoms

- Screen for and treat:
  - ➢Mental Illness or specific psychiatric symptoms
    - ☑Depression
    - ☑Psychosis
    - ☑Delusions
    - ☑Hallucinations
  - ➢All of which respond better to pharmacological interventions

Adapted from Desai A., Grossberg G. Recognition and management of behavioral disturbances in dementia. Primary Care Companion, Journal of Clinical Psychiatry 2001;3(3) 93-109.

Antipsychotic Medication

- Drug therapy for behavioral disorders aims to decrease behavioral disinhibition by changing the balance of neurotransmitters
- The most common class of drugs for behavioral disorders is antipsychotic medication which has severe side effects including increased mortality rates

Schneider LS, Dagerman K, Insel PS. Efficacy and adverse effects of atypical antipsychotics for dementia: meta analysis of randomized, placebo-controlled trials. Am J Geriat Psychiatry. 2006;14:191–210.

Huybrechts K, Gerhard T, Crystal S, Olfson M, Avorn J, Levin R, et al. Differential risk of death in older residents in nursing homes prescribed specific antipsychotic drugs: population based cohort study. BMJ. 2012;344:977–89.

APA Choosing Wisely Campaign

1. Don’t prescribe antipsychotic medications to patients for any indication without appropriate initial evaluation and appropriate ongoing monitoring.
2. Don’t routinely prescribe two or more antipsychotic medications concurrently.
3. **Don’t use antipsychotics as first choice to treat behavioral and psychological symptoms of dementia.**
4. Don’t routinely prescribe antipsychotic medications as a first-line intervention for insomnia in adults.
5. Don’t routinely prescribe an antipsychotic medication to treat behavioral and emotional symptoms of childhood mental disorders in the absence of approved or evidence supported indications.

Sensory impairment

- Attend to changes in vision and hearing
- Loss of sensory acuity may increase confusion and agitation
- Consider the use of assistive devices
- Consider modifications in the environment to enhance information about surroundings
- The inability to process information about the environment through our senses can either increase agitation or present as increased lethargy and disengagement

Psychosocial stressors

- Significant losses
- Significant changes
- When situations exceed the person's ability to adaptive or effectively respond
- The individual who is overtaxed by stressors may appear agitated, confused, or overwhelmed to the point of being less functional

Seizure Activity

- Individuals with a history of seizure disorder may experience breakthrough seizures even after long periods of seizure inactivity
- Individuals may experience new onset seizures who never previously had seizures

Mild Cognitive Impairment

Changes in ADLs

Language and Communication

Sleep-Wake Pattern

Gait and Balance

Memory

Differential Diagnosis: Depression

- Individuals who are significantly depressed may present with signs and symptoms that mimic dementia
- For the general population we have traditionally referred to the confusion between “depression” and “dementia” as **Pseudodementia**
- Individuals who are significantly depressed have difficulty with initiated activity, have difficulty with attention, concentration and memory
- However, the individual with depression can be treated both pharmacologically and non-pharmacologically

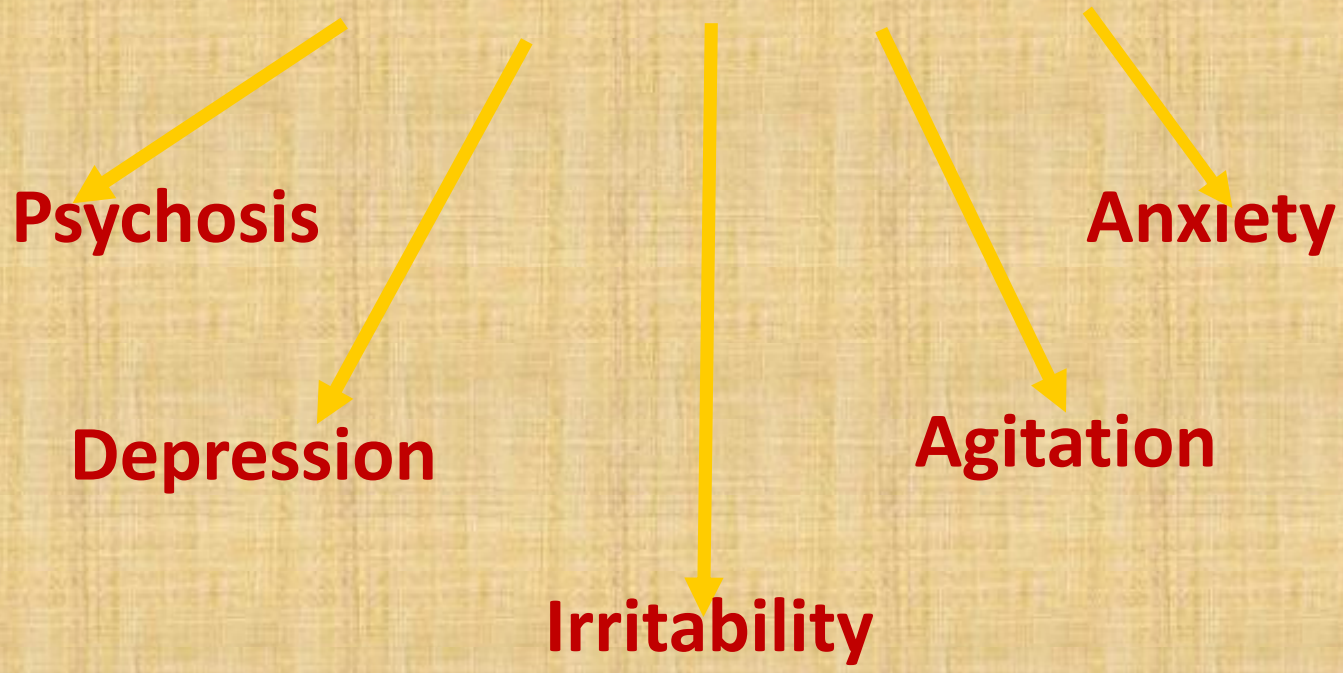
Behavior and Psychological Symptoms of Dementia

Behavioral and Psychological Symptoms of Dementia (BPSD)

A range of psychological reactions, psychiatric symptoms and behaviors resulting from the presence of dementia

Lawlor BA. Behavioral and psychological symptoms in dementia: the role of atypical antipsychotics. J Clin Psychiatry. 2004;65(Suppl 11):5-10.

Symptom of BPSD



Behavioral Symptoms of Dementia

Physical

- Social Inappropriateness
- Hitting
- Pushing
- Scratching
- Kicking and Biting
- Throwing Things
- Wandering / Pacing
- Hoarding

Verbal

- Screaming
- Cursing
- Temper Outburst
- Complaining or Whining
- Repetitive Sentences
- Verbal Sexual Advances
- Constant request for attention

Cohen-Mansfield, J., & Billig, N. (1986). Agitated behaviors in the elderly I. A conceptual review. Journal of the American Geriatrics Society, 34, 711-721.

Psychological Symptoms of Dementia

- Psychiatric symptoms can include anxiety, depression, hallucinations or delusions.
- Hallucinations are perceptions without stimuli and are more commonly auditory or visual.
- Delusions are fixed, false perceptions or beliefs with little if any basis in reality and are not the result of religious or cultural norms.

Theoretical Frameworks

Unmet Needs Model

Some dementia patients may exhibit inappropriate behaviors as a result of their basic needs being overlooked. These behaviors might be misinterpreted by caregivers as acting-out behaviors:

- Fatigue due to poor sleep
- Vision loss or lack of proper eyeglasses
- Hearing loss or lack of working hearing aid
- Dehydration
- Need to urinate
- Hunger / Thirst
- Pain / Discomfort
- Loneliness / Boredom

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Theoretical Frameworks

Unmet Needs Model

- Behavioral disturbances occur due to an inability of the individual to verbalize their needs
- Behaviors are seen as an attempt to communicate physical or emotional distress
- Behavior viewed in this way is seen as a symptom of unmet needs

Cohen-Mansfield J. Theoretical frameworks for behavioral problems in dementia. Alzheimer's Care Quarterly. 2000;1:8–21.

Behaviors are Forms of Communication

What is a person trying to communicate through behavior?

- A person with dementia may be unable to communicate well and must find other methods to get their needs met
- Usually their needs, thoughts and feelings are expressed through their behavior
- Making sense of behavior is critical to meeting the person's needs

Know the Person: The Key to Understanding Behaviors

- Understanding the person behind the illness makes recognizing their particular presentation and their “problem behaviors” much easier to treat.
- Life story
- Cultural background
- Past habits & usual behavior
- Likes and Dislikes
- Preferred activities
- Remaining abilities

Management of Behavioral Disturbances

- Assess for Danger to Self, Others or Property
- Treat Medical Conditions
- Treat Psychiatric Symptoms
- Modify the Environment
- Create a Behavior Monitor Log
- Develop and Implement the Person Centered Care Plan
- Encourage Activities
- Interdisciplinary Behavioral Team
- Provide Ongoing Training of Staff

Differential Diagnosis: Delirium

Chronic Illness and Dementia Care

- Within NTG-EDSD include a listing of chronic illnesses from the University of Illinois at Chicago
- Looking for the co-occurrence of chronic illness and neurocognitive disorder
- Has been suggested that cardiovascular issues, diabetes are among highly co-prevalent conditions for dementia of the Alzheimer's type
- Effective treatment of chronic medical conditions can increase Quality of Life for the person who does have a neurocognitive disorder

How to use observations captured by NTG-EDSD

- Discuss areas of change with member of the IDT
- Bring information to the health care provider
- Track changes in key areas of functioning
- Utilize information for advanced planning
- May influence staffing, residential, programmatic decisions

Implications for personal assistance

- Neurocognitive disorders are progressive and deterioriative
- As an individual moves through stages of dementia regardless of etiology of the change, the person will need increased personal assistance and supervision

Implications for medical care

- Continue to address chronic health issues
- Keep track of changes
- Share information with healthcare provider

Pain management and Dementia

- Pain is associated with increased depression and confusion
- Pain actively interferes with functioning
- Pain is poorly addressed

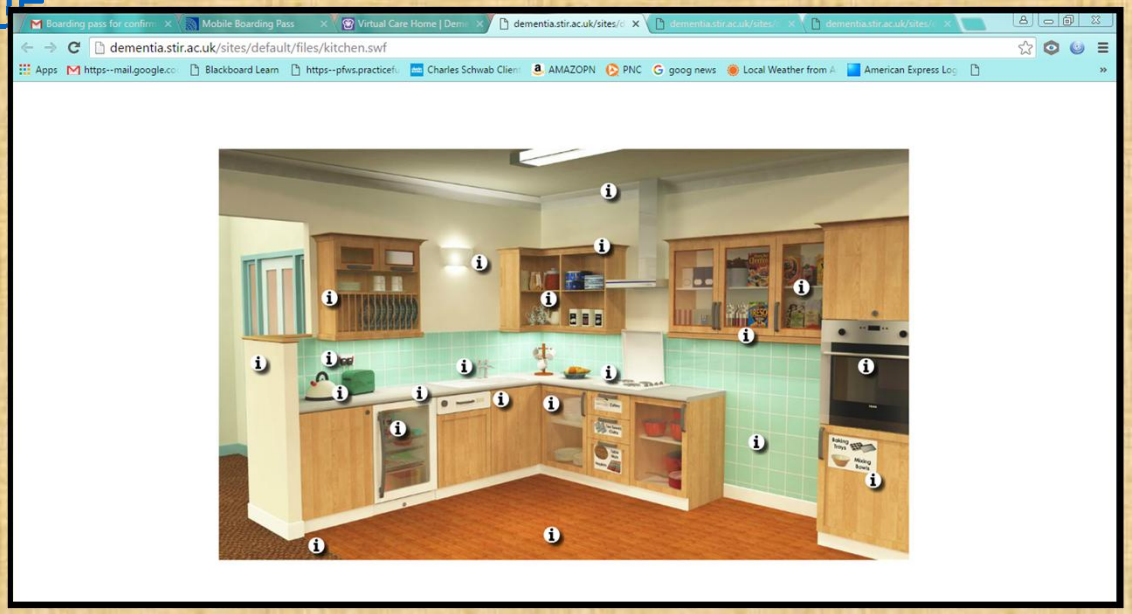
✓Consider use of the Pain AD scale

✓Consider non-pharmacological approaches to pain such as music and medical massage

Environmental considerations

Environment

- http://dementia.stir.ac.uk/design/virtual-environments/virtual-care-home



Programmatic considerations

Social considerations

Key Elements of Dementia Capable Care

1. Commitment by families and dedicated staff to obtaining skills needed to provide **dementia care focus**
2. Careful **assessment** and developed of a **detailed plan** with attention to the unique needs of the person with dementia
3. Recognize the individual with **respect and dignity**; base day-to-day care on the unique capabilities, physical health, behavioral status and personal preferences of the dementia care service recipient
4. Provide **activities** based on preferred lifestyle with opportunities to obtain pleasure and a sense of usefulness
5. Adequate and **on-going training** of family and professional caregivers
6. Environments that support **independence** while promoting **safety**

Advanced Planning

Case Presentation #1

Case Presentation #2

Case Presentation #3

What ways can we design supports and services?

Additional Comments

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Summary

- Establish baseline
- Have staff who are familiar with the individual or family complete the **NTG-EDSD** in order to capture information about change
- Share information with the consumer's health care provider
- If the individual has had a rapid change in mental status consider that there is a medical condition and this is acute confusion and not dementia
- If the individual appears to be depressed, have person evaluated for medication and psychosocial approaches to depression management

Any Questions?

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Chair, Group S

National Task Group on Intellectual Disabilities and Dementia Practices