

Safety Assessment in Dementia Care: Using Functional Change to Guide the Way

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Learning Objectives

1. Describe how safety issues change as dementia evolves from mild stage to severe stage.
2. Identify unique safety issues that develop as a result of dementia.
3. List resources available for clinicians and patients to identify and assist in safety issues for a person living with dementia.

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Disclosures

- Consulting work with NewAmsterdam pharmaceutical
- Volunteer member of the Medical & Science Advisory Board for the WI Alzheimer's Association and the Alzheimer's Foundation of America

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NIA-AA 2011 Criteria - Dementia

Presence of cognitive symptom that:

- Detected through a combination of
 - (1) history-taking from patient **and** a knowledgeable informant
 - (2) objective cognitive assessment*
- Decline from previous levels of functioning
- Not explained by delirium or major psychiatric disorder
- Interferes with ability to function in usual activities

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The difference between MCI and dementia is function

Mild Cognitive Impairment	Dementia
Concern regarding change in cognition (mild)	Cognitive loss (mild to severe)
Impairment in 1+ cognitive domains (usually memory)	Impairment in 2+ cognitive domains (usually includes memory)
Preservation of functional independence	Functionally impaired
Do <u>not</u> meet criteria for dementia	Meet criteria for dementia

Albert MS et al. Alzheimer's & Dementia 2011;7:270-279.

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What causes dementia & symptoms?


- Underlying diseases & brain pathology
 - Alzheimer's, Lewy bodies, Alpha-synuclein, TDP-43, vascular disease
- Synaptic dysfunction & neuronal atrophy
 - Absence of communication
 - Neurotransmitter deficit
 - Acetylcholine, norepinephrine, serotonin, dopamine, etc

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Stages of Dementia



- No two cases of dementia are the same
- May have symptoms from several stages at one time
- 3 stage model & 7 stage model
- Typical course duration is 8-10 years from diagnosis



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3 Stage Model

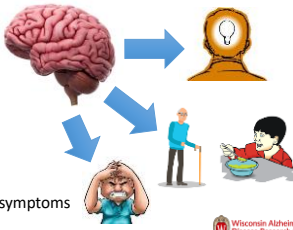

- Often used for dementia due to Alzheimer's disease
- Mild dementia
 - Early stage
- Moderate dementia
 - Middle stage
- Severe dementia
 - Late stage

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Dementia affects the whole person


- Cognitive symptoms
 - Memory
 - Language
 - Visuospatial
 - Executive function
 - Attention
- Daily function
 - IADLs
 - BADLs
- Behavioral and psychological symptoms

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Daily Function



Instrumental Activities of Daily Living <ul style="list-style-type: none"> • Making and keeping appointments • Managing medications • Managing finances • Driving • Meal preparation and cooking • Household chores • Use of technology • Maintaining hobbies 	Basic Activities of Daily Living <ul style="list-style-type: none"> • Dressing • Bathing • Toileting • Transferring • Walking • Eating
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Mild Stage Dementia



- Cognition
 - Forgetting recent events
 - Misplacing items
 - Word finding
 - Trouble remembering names
 - Trouble planning or organizing
- Function
 - Independent in ADLs, 1 or more impairments in IADLs
- Psychological function and behavior
 - Mood or personality changes
 - Irritable, apathy

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Moderate Stage Dementia




- Cognition
 - Forgetful of events & conversation, confusing personal history
 - Difficulty expressing thoughts
 - Cannot multi-task or complete simple tasks
 - Disoriented to time, place, date
- Function
 - Impairment in basic ADLs
 - Urinary and stool incontinence = moderately-severe dementia
- Psychological function and behavior
 - Sleep pattern disruption
 - Irritable, moody, focused on self
 - Withdrawn, wandering at times

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Severe Stage Dementia

- Cognition**
 - Appears to not understand surroundings
 - Cannot recognize family or self
 - Minimal to no speech
- Function**
 - Bedridden requiring 24 hour assistance
 - Physical impairments: coordination, walk, sit up, transfer, swallowing, smile
- Psychological function and behavior**
 - May have delusions, paranoia, hallucinations
 - May be minimally responsive to others

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FAST Scale



Stage	Stage Name	Characteristic	Expected Unassisted ADL Duration (months)	Minimal Age (years)	MMSE Score
1	Normal Aging	No deficits whatsoever	—	Adult	28-30
2	Preclinical Mild Cognitive Impairment	Subjective functional deficit	—	—	28-29
3	Mild Cognitive Impairment	Objective functional deficit interferes with a person's most complex tasks	84	12+	24-28
4	Mild Dementia	ADLs become affected, such as not paying, cooking, cleaning, shopping	24	8-12	18-20
5	Moderate Dementia	Needs help selecting proper attire	18	5-7	15
6a	Moderately Severe Dementia	Needs help putting on clothes	4.8	5	9
6b	Moderately Severe Dementia	Needs help bathing	4.8	4	8
6c	Moderately Severe Dementia	Needs help walking	4.8	4	5
6d	Moderately Severe Dementia	Urinary incontinence	3.6	3-4	3
6e	Moderately Severe Dementia	Facial incontinence	3.6	2-3	1
7a	Severe Dementia	Speaks 5-6 words during day	12	1.25	0
7b	Severe Dementia	Speaks only 1 word clearly	18	1	0
7c	Severe Dementia	Can no longer walk	12	1	0
7d	Severe Dementia	Can no longer sit up	12	0.5-0.8	0
7e	Severe Dementia	Can no longer smile	18	0.2-0.4	0
7f	Severe Dementia	Can no longer hold up head	36+	0-0.5	0

<http://www.wisc.edu/PresLifeYourHealth/PresLifeScaleFast/>

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Safety issues in mild stage dementia


- Instrumental ADLs**
 - Medication management
 - Financial management
 - Appointments
 - Driving
 - Cooking
 - Chores
 - Use of technology
 - Hobbies
- Basic ADLs**
 - Bathing
 - Dressing & hygiene
 - Transferring & Staircases
 - Walking
 - Eating

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Safety issues in mild stage dementia


- Instrumental ADLs**
 - Medication management
 - Overdose, underdose, not taking
 - Financial management
 - Missing payments, overpaying, tax issues, rent/mortgage/insurance issues
 - Appointments
 - Missing appointments
 - Driving
 - Accidents, violations, getting lost
 - Cooking
 - Burning items, fires, not eating
 - Chores
 - Machinery (outside yard work), laundry pods



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Key safety issues in mild stage dementia

- Medication mistakes
- Financial mistakes and scams
- Driving accidents
- Using dangerous equipment
- Kitchen safety
- Mood
- Not being able to respond appropriately to a situation



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Safety issues in mild stage dementia

- Instrumental ADLs**
 - Medication management
 - Supervise, Pharmacy wrapped pillbox
 - Financial management
 - Autopay services, bank assistance, financial POA
 - Appointments
 - Digital calendar, whiteboard
 - Driving
 - OT assessment, restrictions, stopping, DMV
 - Cooking
 - Locks over stove knobs, disconnect, meal delivery services
 - Chores
 - Hire lawn service, lock up toxic substances

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Safety issues in moderate stage dementia


- Instrumental ADLs
 - Medication management
 - Help required
 - Financial management
 - Help required
 - Appointments
 - Help required
 - Driving
 - Not driving anymore
 - Cooking
 - Help required
 - Chores
 - Not using dangerous machinery or substances



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Safety issues in moderate stage dementia

- Basic ADLs
 - Dressing
 - Inappropriate attire for weather
 - Bathing & hygiene
 - Infections, dental issues
 - Toileting
 - Incontinence & Constipation
 - Transferring & Standing & Walking
 - Wandering
 - Falling, physical injuries
 - Being unable to access food or water
 - Eating
 - Weight loss
 - Aspiration
- Basic ADLs
 - Dressing
 - Find manageable clothes
 - Bathing & hygiene
 - Determine minimum, patience, help from others
 - Toileting
 - Scheduled voiding, adult depends
 - Signs on bathroom, routine
 - Transferring & Standing & Walking
 - GPS trackers, locks
 - Assistive devices: bars, lift chairs
 - OT home safety evaluation
 - Lifeline
 - Home health aides
 - Eating
 - Speech Therapy
 - Goals of care discussion



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Key safety issues in moderate stage dementia


- General home safety, emergency preparedness
- Falls
- Wandering
- Kitchen safety
- Power tools, firearms



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Safety issues in severe stage dementia


- Instrumental ADLs
 - Medication management
 - Financial management
 - Appointments
 - Driving
 - Cooking
 - Chores
- Basic ADLs
 - Dressing
 - Bathing & hygiene
 - Toileting
 - Transferring & Standing & Walking
 - Eating



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Safety issues in severe stage dementia


- Infections
- Pressure ulcers
- Aspiration
- Falls/rolling off bed
- Comfort focused care
 - Eating/drinking to comfort
 - Treating pain appropriately



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Unique safety issues in dementia

- Sexually inappropriate
 - Business cards to hand out
 - Limit crowded places
- Wandering
 - Locks or tracking device (Tile)
- Guns
 - Locks or remove
- Financial scams
 - Remove credit cards
- Abuse or neglect
 - Physical exam for bruises
 - Caregiver won't allow exam alone
 - Lab tests
- Driving (insight)



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Driving should stop by moderate stage

- ~30% of older adults with dementia are current drivers
- Drivers with dementia are 2-2.5 times more likely to be involved in an accident
- Diagnosis of dementia alone should not prompt recommendation to retire from dementia
- Prepare for cessation, develop alternatives
 - Conversation starts in mild stage, even MCI
- Family as an ally
- Utilize resources, including OT



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Unique safety issues in dementia

- Checklist
 - Vary by stage, location
- Proactive instead of reactive
 - Empower caregiver
 - Maintain independence of person with dementia
- Tool that can be used in clinic & community
- Home Safety Inventory for Older Adults with Dementia
- Alzheimer's Association Safety Checklist
- AARP Home Safety checklist
- Dementia Home Safety Checklist
- Alzheimer's Foundation of America



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Reasons to taper off anti-dementia meds

- Lack of effect
 - Very tricky since effect is "less decline" and cannot compare
- Inability to tolerate
- Refusal of medication
- No longer eating
- Hospice care
- Financial hardship

Burns et al. Lancet Neurol. 2009. Sun et al. Euro J Neurol. 2008.
Amuah et al. Pharmacoepidemiol Drug Saf. 2010. Mansour et al. Am J of Geriatr Pharmacotherp. 2011.

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Tapering off "dementia medications"

- Risks vs Benefits
 - Risks: more cognitive decline, worsened function, withdrawal symptoms
 - Benefits: less medication burden, less side effects
 - No evidence tapering will hasten death
- Personalized assessment
 - Current status of cognition, function, behaviors
 - Is current state acceptable and worth prolonging
 - Is worsening of status lead to suffering or noticeable to person with dementia

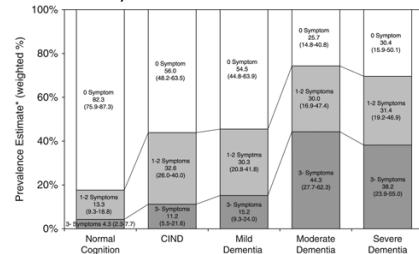
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Behaviors in dementia & Safety

- Noncognitive neuropsychiatric symptoms (NPS)
 - Occur in all types of dementia
 - Affect 98% of people with dementia at some point
 - Causes 30% of cost of caring in the community
- Depression, psychosis, agitation, aggression, apathy, sleep disturbances, and disinhibition
 - Psychosis: hallucinations, delusions, paranoia
 - Agitation: excessive verbal or motor behavior
 - Aggression: verbal or physical acts directed toward someone

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Natural history of BPSD




Okura et al. JAGS 2010; 58: 330-7.

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BPSD & the care partners


- Educating family is critical
- How family responds to behaviors can determine course
- Ask questions to help explain
 - Redirect or reframe if possible
 - Do not try to correct
- Go down the rabbit hole with them
 - Try to understand what needs are not being met
 - Fear, anxiety, sense of safety, missing
- Teepa Snow videos can be helpful
- Aggression/violence require intervention



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Non-pharmacological interventions

- Have a team
 - Family, friends, medical professionals
- Routines and familiarity
- Simplify the environment
- Simplify tasks
- Education and training on current risks and future ones




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Medications

- Side effects can impact safety
 - Sedation, mortality
- Reassess routinely and deprescribe
- “Given where we are and your stated priorities, is this necessary?”

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Finding the balance



Treatment		Palliation
Autonomy		Safety
Longevity		Quality
	Dignity Choice	

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Dementia Matters explores Alzheimer’s disease research and caregiver topics for a general audience



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- Online at adrc.wisc.edu/dementia-matters
- On the radio at 102.9 WMUU in Madison, Fridays at 4:00 p.m.



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