

A Road Map to Behavioral Management Physician Edition



Behavioral and psychological symptoms of dementia (BPSD) are one of the most stressful concerns facing caregivers and family members. Primary care physicians are on the frontlines supporting caregivers with direction and guidance. Behavioral issues usually occur in the home or settings outside of a clinic or physician's office. Providing resources, support and services in real time to caregivers and family members can be difficult. Understanding behaviors requires good communications with the patient and family, often after new behaviors arise. This booklet is a guide to practical advice and resources for physicians to support their patients and families.

Why discuss behavioral and psychological symptoms with caregivers and families after a diagnosis?

It is critical to begin to address behavior management with patients and family members early in the disease management process. Caregivers need information on how to obtain education and the support they need before behaviors arise. The need to help caregivers manage behaviors begins prior to diagnosis.

Behaviors such as forgetting information, people, recent events, repetitive statements and questions, confusion, depression, apathy, poor self-care, anxiety, anger, aggression, sleep disturbances and wandering are expected behaviors and may be exhibited by someone with Alzheimer's disease. Each patient exhibits behaviors differently and at different times during their disease progression and symptoms may worsen over time.

Some behaviors may have devastating effects if untreated and can contribute to more rapid disease progression such as earlier nursing home placement, accelerated functional decline, higher health care utilization and costs, and worsening quality of life. Planning for the management of these issues should be addressed early in the course of Alzheimer's disease management.



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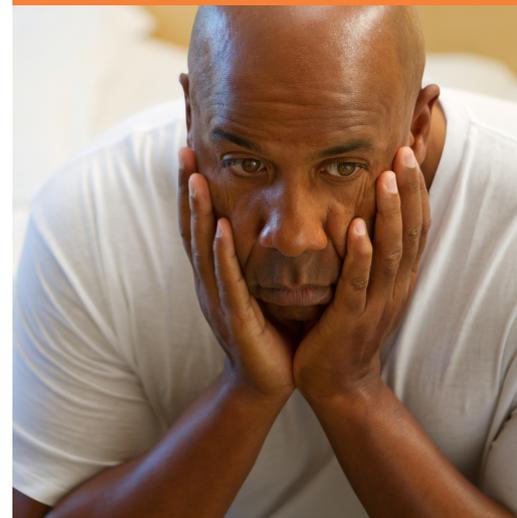


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Aging & Memory Loss Road Map Series for Physicians

I. Dementia Diagnosis Process

II. Behavioral Management



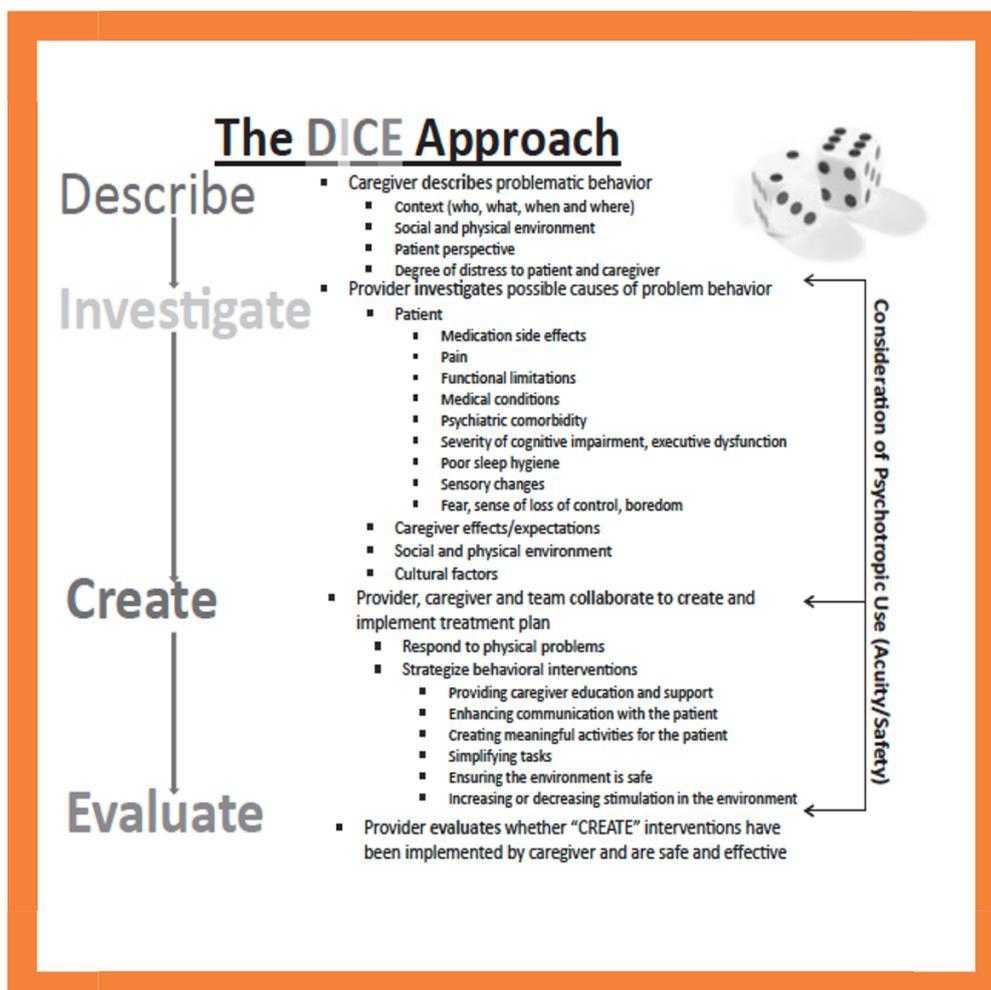
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How to assess for Neuropsychiatric symptoms (NPS) a.k.a. behavioral and psychological symptoms of dementia (BPSD)?

It is difficult for physicians to anticipate behaviors, however on-going screening and early advice on treatment options for behaviors is optimal for long-term care management. Communication is key in preventing the frequency of symptoms, targeting a source or symptom trigger and reducing symptom effects. In order to do this, it is necessary for physicians to work closely with the patient, caregiver and family members to help them accurately describe and communicate how the patient is progressing and identify symptoms early, as they develop. There are several resources for patients and families to help recognize and manage symptoms at home. Encouraging early caregiver and family education, having a communication plan in place and encouraging an open dialogue during and in-between clinic visits is key to understanding how to provide the support that is needed to effectively manage patients.

Managing NPS in Dementia



DICE stands for Describe, Investigate, Create, and Evaluate. It is an adaptation of the reasoning process used by dementia behavior specialists as well as in numerous research trials involving training family caregivers to spot behavioral triggers and to use behavioral management skills.

To obtain a copy of the guide: <https://services.publishing.umich.edu/publications/dice/>

Discuss basic information about what can cause behaviors with caregiver/family members

Behavioral/Environmental Recommendations: Compensatory strategies for NPS

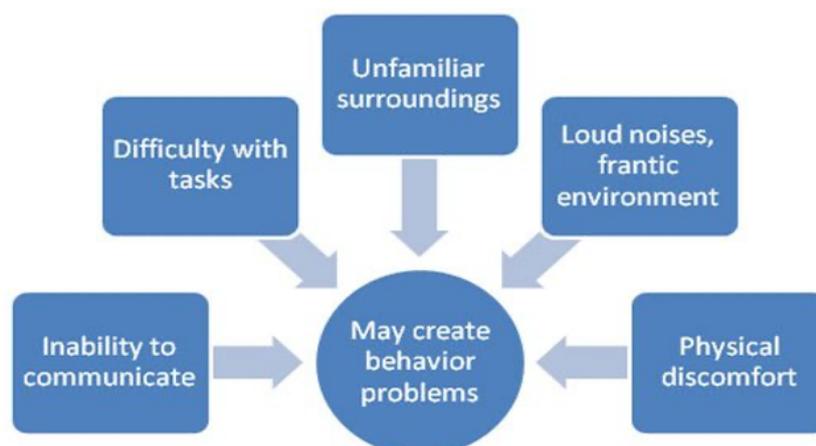
- **CARE T.I.P.S. (Try Including Practical Strategies):** Education about symptom(s), why it happens, and strategies to approach and deal with symptoms
- **Identify and avoid situational triggers**
- **For caregivers:**
 - Remember that disease symptom \neq volitional behavior
 - Recognition of “absorbing emotions” and importance of predictability
 - It is not critical to “always be right”
 - Do not attempt to logically reason with a person who lacks insight or has a fixed false belief
- For apathy/social withdrawal, nudge/prompt (provide external motivation) if the end result is positive
- **Value of routine:** regular habits with respect to sleep, eating, sunlight; physical activity; comfort; pleasant sensory stimulation; pets; etc.

Resources: social work, support groups, Alzheimer’s Association

Educating Caregivers about possible contributing factors to behaviors:

- Are basic needs causing discomfort for the patient (hunger, thirst, bathroom break (constipation), fatigue, stress, fear)?
- What is the patient’s body language saying (pain, discomfort, boredom)?
- How are others reacting to behaviors and could this be causing the patient distress (anger, disapproval, fear)?
- What are the current surroundings the patient is in (unfamiliar, disoriented, over-stimulating, language barriers, new people)?

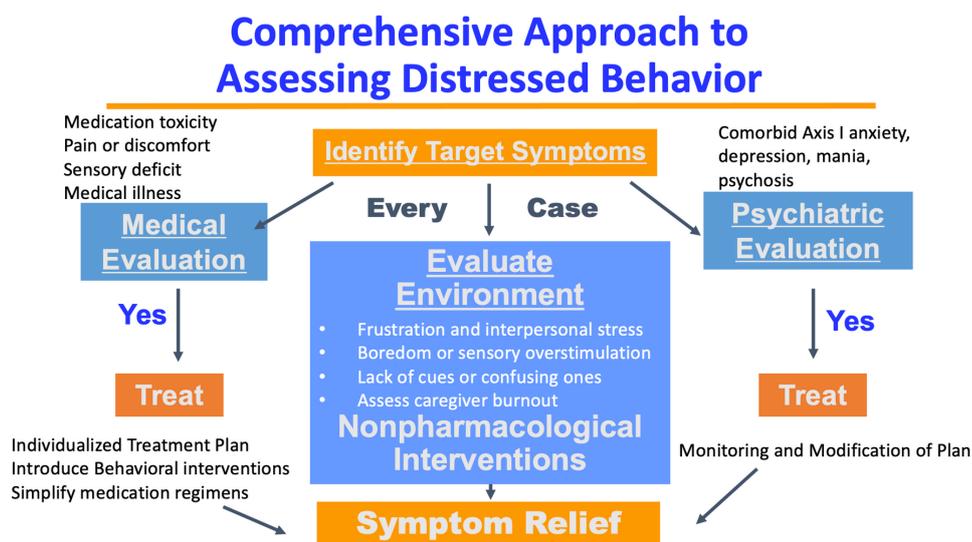
Common Causes of Problem Behavior



Helpful NPS Management Resources for caregivers and family members

- The DICE approach website at www.diceapproach.com has a caregiving training program that offers education on how to recognize behaviors, understand how they are being triggered and to respond. Understanding what is happening improves communication with patients and providers so the optimal approach to support and treatment is provided.
- The Savvy Caregiver Training is designed to train family and professional caregivers in the basic knowledge, skills, and attitudes needed to handle the challenges of caring for a family member with Alzheimer's disease. To learn more about this program, visit: <https://www.mass.gov/news/training-for-families-caring-for-individuals-living-with-dementia>
- NIA Alzheimer's and related Dementias Education and Referral (ADEAR) Center offers information and free print publications about Alzheimer's disease and related dementias for families, caregivers, and health professionals. www.nia.nih.gov/alzheimers
- The Alzheimer's Association provides education and resources for family facing Alzheimer's disease. www.alz.org
- The AARP provides Family Caregiving Information and Resources <https://www.aarp.org/caregiving/answers/info-2017/caregiver-workshops-and-training/>

How to assess and manage Neuropsychiatric symptoms (NPS) a.k.a. behavioral and psychological symptoms of dementia (BPSD)?



As dementia progresses patients can experience vulnerability in their environment. Behavioral symptoms may result from several factors and can co-occur while fluctuating in frequency and severity. One major challenge for caregivers is coping with troubling behaviors and personality changes. The first step to resolving a behavior is to understand what's triggering the discomfort. Sometimes simple instructions and changes at home, can ease stress, better manage symptoms, and significantly improve well-being.

Behavioral Interventions

- Behavioral Analysis: Identify triggers and response
- Assure Safely/Adequate Supervision
- Treatment should not exceed patients capacity to learn/remember
- Behavioral interventions can include:
 - Caregiver education
 - Prosthetic (habilitation) environment
 - Activity/exercise
 - Reminiscence therapies
 - Music therapy
 - Aromatherapy/massage
 - Bright light therapy
 - Pet therapy
- **Reducing restless nights**- If sleep-wake cycle is interrupted patients can experience disorientation, confusion at dusk (called sundowning), fear of darkness and general wakefulness. Make sure to increase activity during the day, interrupt napping, avoid caffeine and sugar. Ensure a calm, quiet comfortable sleep environment. Ensure easy access to bathroom or a commode at the bedside. Use a nightlight, allow pets to sleep in room, offer comfort items. Bright light exposure during the day may help.
- **Reduce cause for concern**- put away items that will be difficult to replace if lost -purses and documents in a safe place, have back-up glasses and keep them in the same place, encourage one spot for dentures, hearing aids, canes or adaptive equipment- mark the area well for placement reminders. Have mail delivered to a PO box and keep paperwork in an area not easily accessed.
- **Provide protection from harm**- keep unsafe substances locked up such as cleaning products, alcohol, firearms, power tools, sharp knives and medication. Block electric outlets, reduce water heater temperatures and put child proof handles on faucets. Consider hiding stove knobs, unplugging microwaves and putting away any sharp objects or items that could be harmful if misused such as a blender or beater.
- **Plan for wandering**- Monitor for restlessness and encourage an activity, install child safety-devices in home to lock doors and windows. Educate your neighbors and local authorities including fire and police about a family members dementia diagnosis. Encourage use of an ID band or digital GPS tracking device. Keep a recent photo on hand in the event wandering occurs.



A patient with dementia may respond to facial expression, tone of voice, and body language. Encourage the use of eye contact, a smile or touch to help convey a message and avoid disagreements. Agitation and aggression often happen for a reason and identifying contributing factors is important in preventing behaviors. Instruct caregivers to look for early signs of agitation or aggression and to contact you right away to avoid worsening behaviors.



Caregiver Support:

- Potential impact of caregiving on health
- Importance of caregiver well-being
- Elements of well-being
- Sustainability of care arrangements

Caregiver Resources:

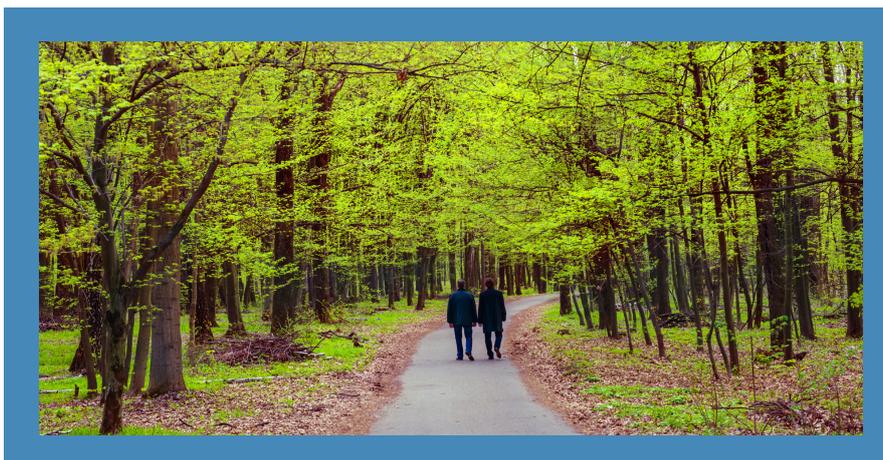
Social work, support groups, Alzheimer's Association, family/friends, respite care, dementia care consultants, day programs, home care agencies, palliative care, hospice

Caregiver Education: Diagnosis, Staging, Prognosis

- Difference between syndrome and disease
- Brain-basis of symptoms
- Pros/Cons of symptomatic medications
- Distinction between MCI, mild, moderate and severe dementia
- Predicting and monitoring progression
- Behavioral and environmental recommendations
- Safety considerations
- Advance care planning
- Caregiver support

Assess Caregiver Burnout

- Ensure caregivers are not going it alone - what is their back up?
- Encourage the building of a care team at home
- Encourage taking a break from caregiving
- Encourage caregivers to get away from the home and have fun
- Discuss caregiver feelings of loss and grief
- Give permission to find relief from caregiving
- Discuss strategies to deal with stigma around Alzheimer's/related dementias



Provide Caregiver Resources

- Massachusetts General Hospital: Dementia Care Collaborative - Monthly Conversations with Caregivers series and Caregiver Support Groups. (617) 724-0406
<https://dementiacarecollaborative.org>
- Brigham and Women's Hospital: Center for Brain/Mind Medicine (CBBM) - Social workers see patients receiving care at CBMM. If in Mass General Brigham network, you can make a referral to social work through Epic. Caregiver Dementia Skills and Wellness group educates about dementia-related behavior and coping. <https://www.brighamandwomens.org/neurology/cognitive-and-behavioral-neurology/center-for-brain-mind-medicine>
- Services outside of Mass General Brigham:
 - Alzheimer's Association - support groups, programs, education: www.alz.org/MANH, 24-hour national helpline 800-272-3900
 - Alzheimer's Family Support Group of Cape Cod - support groups, counseling and assistance: www.alzheimerscapecod.org, (508) 896-5170
 - Family Caregiver Support Program - www.mass.gov/location-details/family-caregiver-support-specialist-location
 - Massachusetts Memory Cafes: www.memorycafedirectory.com
 - Massachusetts Council on Aging (MCOA) <https://mcoaonline.com/>
 - Program of All Inclusive Care for the Elderly (PACE) www.mass.gov/program-of-all-inclusive-care-for-the-elderly-pace



Tips to help caregivers and families support someone with dementia

- **Have a regular routine**- coffee/breakfast at the same time, in same room, car ride, routine walks with dog. Whatever is comfortable and works best should be encouraged/maintained.
- **Provide a comfortable space**- acquire a comfortable chair, position it in a soothing space, place items that provide distraction in the general area, provide a cozy blanket, pillow and familiar items near by. Have a space or draw where rummaging is allowed and encouraged when items are lost or misplaced.
- **Ensure relaxed interactions**-remain calm, flexible, agreeable, use re-direction and avoid confrontations, be reassuring.
- **Create a calm environment**- turn off TV, avoid loud noise, avoid poor lighting and surfaces that reflect or may cause shadows. If repair or maintenance work is being done in the home or outside provide reminders in advance and during the scheduled work time. Consider an outing during a time of significant interruption.
- **Develop an activity list**- plan exercise, music therapy, a time during the day to sit and recall past events, home activities- folding clothes, watering plants, daily diversions- like a car ride, visits with a pet, family members, grandchildren and old friends.
- **Dealing with aggression**- avoid topics that cause anger, redirect conversations that may escalate, talk calmly and offer encouraging words for concerns being expressed. Suspicion and paranoia- monitor what is on TV/radio, avoid external contributions to paranoia from outside sources. Violent programs can contribute to paranoia. If hallucinations occur, do not argue about what is real and what is not. Reassure that you're there to provide support and try to move to a new location in the home, reduce fear, provide reassurance and distractions.
- **Reducing restless nights**- If sleep-wake cycle is interrupted patients can experience disorientation, confusion at dusk (called sundowning), fear of darkness and general wakefulness. Increase activity during the day, interrupt napping, avoid caffeine/sugar. Keep a calm, quiet comfortable sleep environment. Ensure easy access to bathroom or commode at the bedside. Use a nightlight, allow pets to sleep in room, offer comfort items. Bright light exposure during the day may help.



- **Reduce cause for concern**- put away items that will be difficult to replace if lost -purses/ documents in a safe place, have back-up glasses and keep in the same place, encourage one spot for dentures, hearing aids, canes or adaptive equipment- mark the area well for placement reminders. Have mail delivered to a PO box and keep paperwork in an area not easily accessed.
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What's a clinician to do?

- Caution colleagues about over-reacting – alternative pharmacological choices (e.g. benzodiazepines) not great evidence-base for efficacy and concern regarding tolerability
- Thorough assessment of etiology of NPS is vital
- Always employ non-pharmacological strategies, which must be studied in well-designed clinical trials with and without pharmacotherapy
- When using antipsychotics: a careful informed consent with HCP/guardian required
- Target agitation associated with psychotic symptoms
- Continuously weigh risks and benefits

Summary

- Distressed behaviors are clues to the diagnosis
- Conduct behavioral analysis to determine etiology and differential diagnosis
- Unless urgent, the complete assessment (not just the symptoms) determines the working diagnosis
- Use non-pharmacologic interventions in every case
- The working diagnosis determines management approach and medication class used; consider full range of medications
- Consider side effects and tolerability in all medication choices
- Document rational decision-making, consideration of risks and benefits
- Treatment goals to enhance quality of life of patient and caregiver

Pharmacological Approaches to NPS:

Basic Principles

- Pursue etiology of behavioral disturbance
- Identify target symptoms
- Employ behavioral approaches ALWAYS along with pharmacological interventions
- Start low and go slow
- Choose pharmacotherapy by identifying key psychiatric syndromes in patient's presentation:
 - Depression
 - Apathy
 - Anxiety
 - Agitation
 - Psychosis
 - Mania
 - Spontaneous Disinhibition

Pursue etiology of behavioral disturbance

Example: psychosis

- Impaired connection to reality or auditory or visual hallucinations or delusions
- Psychosis is a symptom, not a final diagnosis
- Psychosis is a result of well-defined illnesses
- Differential diagnosis includes dementia (all types), delirium, chronic psychotic disorders (schizophrenia, bipolar disorder, others), psychotic depression
- Impaired memory from dementia can be easily mistaken for psychosis (i.e., not all delusions are "psychotic")
 - Theft
 - House is not home
 - Mother is waiting
 - They need to go to work
 - Caregiver is an impostor
 - Mate is unfaithful
- The working diagnosis indicates duration of treatment



Pharmacological approaches to the treatment of NPS in dementia:

Antipsychotics

Conventional agents

- Limited efficacy, substantial toxicity
- Associated with a risk of falls
- Cardiac toxicity (ex: thioridazine)
- Associated with extrapyramidal symptoms
 - Parkinsonism (bradykinesia, rigidity, tremor)
 - Avoid in patients with dementia with Lewy bodies
 - Akathisia
 - Tardive dyskinesia: 28% after 1 year, 50% after 2 years, 63% after 3 years

Atypical agents

- Risperidone: 0.5-2.0 mg/day
- Olanzapine: 2.5-10 mg/day
- Quetiapine: 25-200 mg/day
- Aripiprazole: 5-10 mg/day
- Pimavensarin (FDA review is ongoing)
- Clozapine, Ziprasidone, Paliperidone, Asenapine, Iloperidone, Lurasidone: insufficient data about dosing
- Brexpiprazole: study ongoing

Cautions in atypical agents

- Avoid in patients with dementia with Lewy bodies
- Tardive dyskinesia incidence (Woerner 2011):
 - Risperidone: 5.3% after 1 year (1 mg/day); 7.2% after 2 years
 - Olanzapine: 6.7% after 1 year (mean dose 4.3 mg/day); 11% after 2 years

CATIE-AD study

A double-blind placebo-controlled trial of participants with AD dementia and psychosis, aggression or agitation over 36 weeks in 421 participants (including Assisted Living Facility residents), 42 sites Randomized to:

- Olanzapine (mean dose 5.5 mg/day)
- Risperidone (mean dose 1.0 mg/day)
- Quetiapine (mean dose 56.5 mg/day)
- Placebo

Conclusion: "Adverse effects offset advantages of atypical antipsychotic drugs for the treatment of psychosis, aggression or agitation in patients with AD"

Mood Stabilizing Anticonvulsants

- Anticonvulsant mood stabilizers used empirically for agitation and labile mood
Efficacy data equivocal
 - Valproate: need to watch CBC, LFT's, and ammonia
 - Lamotrigine: better tolerated but need to titrate slowly to avoid rash
 - Gabapentin: can be sedating
 - Carbamazepine: need to watch out for hyponatremia

Antidepressants

- Use primarily SSRI's, empirically for depression, anxiety, and irritability
Efficacy data equivocal for SSRI's (TCA's better but anticholinergic)
- Most widely used: citalopram, escitalopram, and sertraline
 - Need to watch QTc at high doses
 - Can cause apathy
 - Avoid paroxetine (anticholinergic)
 - Citalopram 10-20 mg daily was useful in agitation/ paranoia (CitAD study- in JAMA)
 - Mirtazapine (if appetite or sleep disturbance is a problem as well as mood)

Stimulants

- Apathy in Dementia Methylphenidate Trial (ADMET), 6 weeks RCT 60 AD dementia participants (29 methylphenidate 20 mg/day vs. 31 placebo)
Significant improvement in 2 out of 3 outcome measures (CGI-C and NPI Apathy item), (Rosenberg 2013).
- ADMET II Trial underway

Benzodiazepines

- Minimal efficacy data
 - Sedating
 - Further inhibit learning and memory (temporarily)
 - Falls and fracture
 - Paradoxical disinhibition
 - Dependence/tolerance
 - Short-term/emergency use may be appropriate

Cholinesterase Inhibitors/Memantine

- Donepezil, Rivastigmine, Galantamine
 - Effects important in some individuals, modest at group level, most notable benefit in dementia with Lewy bodies:
 - Decrease psychosis (visual hallucinations)
 - Decrease apathy
 - Decrease agitation but occasionally increase
 - Possibly decrease anxiety and depression
 - Donepezil not effective in reducing Cohen-Mansfield Agitation Inventory (CMAI) in 12-week RCT in AD dementia participants, who had not responded to a psychosocial intervention

Novel Strategies

- Electroconvulsive Therapy (ECT)
- Cannabinoids (CB1 receptor agonist)
- Transcranial magnetic stimulation (TMS)
- Prazosin
- Dextromethorphan/quinidine (for PBA)
- Ketamine

Assessment Tools

- Cohen-Mansfield Agitation Inventory (CMAI)) www.bcbpsd.ca/docs/part-1/Cohen%20Mansfield%20Inventory%202013.pdf
- Neuropsychiatry Inventory (NPI) http://download.lww.com/wolterskluwer_vitalstream_com/permalink/cont/a/cont_21_3_2015_02_26_kaufert_2015-10_sdc2.pdf

Clinical Support

- MGH Memory Disorders Division: <https://www.massgeneral.org/neurology/treatments-and-services/memory-disorders-division>
- MGH Multicultural Assessment and Research Center: Email: yquiroz@mgh.harvard.edu
- BWH Center for Brain/Mind Medicine: <https://madrc.websiteemt.com/bwh-center-for-brain-mind-medicine/>
- BWH Rapid Diagnostic Clinic: www.madrc.org/wp-content/uploads/2016/09/RDC-Clinician-Info.pdf
- McLean Memory Diagnostic & Assessment Clinic: www.mcleanhospital.org/treatment/geriatric-outpatient

Research Participation is Critical to Finding a Cure

The Massachusetts Alzheimer's Disease Research Center (MADRC), the Center for Alzheimer Research and Treatment (CART) at Brigham and Women's Hospital, and Geriatric Psychiatry Research Program at McLean's Hospital offer a variety of research opportunities ranging from observational studies to clinical trials. Several studies are underway to look at the management of NPS. Visit MADRC.org, BWHCART.org and geriatricpsychiatryresearch.org for additional information and resources.

Take away points:

- Distressed behaviors are clues to the diagnosis
- Conduct behavioral analysis to determine etiology and differential diagnosis
- Unless urgent, the complete assessment (not just the symptoms) determines the working diagnosis
- Use non-pharmacologic interventions in every case
- The working diagnosis determines management approach and medication class used; consider full range of medications
- Consider side effects and tolerability in all medication choices
- Document rational decision-making, consideration of risks and benefits
- Treatment goals to enhance quality of life of patient and caregiver

Additional Resources:

Massachusetts Alzheimer's Disease Resource Center - WWW.MADRC.ORG
Center for Alzheimer Research & Treatment - WWW.BWHCART.ORG
Alzheimer's Association - WWW.ALZ.ORG
Alzheimer's Foundation of America - WWW.ALZFDN.ORG
NIA: Alzheimer's Disease Education & Referral Center - WWW.NIA.NIH.GOV

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A graphic with a red border. On the left, it lists social media handles for Facebook (@MassADRC), Twitter (@ADRCMass), and YouTube (ADRCMASS) next to their respective icons. Below these is the logo for the Massachusetts Alzheimer's Disease Research Center. On the right, a smartphone displays the website MADRC.ORG with a 'Join a Study' button and a 'Learn More' button. A stethoscope is connected to the phone, and a pair of headphones is at the bottom.