

**Behavioral and Psychological Symptoms of Dementia (BPSD) - Agitation
Associated with Dementia (AAD) Rx without Antipsychotics**

A practical rough and tumble guide for family and professional care partners for prevention and treatment of BPSD and AAD without antipsychotics

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One Day Mindfulness Millionaire: A light-hearted primer for the uninitiated.

Abhilash Desai and Faith Galliano Desai

Book available at store.bookbaby.com

2-4-25

Each of us literally chooses, by his way of attending to things, what sort of a universe he shall appear to himself to inhabit.

- William James

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Introduction

Individuals with dementia experience agitation frequently, and it is an expression of emotional distress caused by one or more factors that need to be looked for and addressed (e.g., pain, boredom). Agitation manifests as verbal aggression (e.g., yelling), physical aggression (e.g., hitting), physical hyperactivity (e.g., exit seeking, pacing). It is often accompanied by anxiety, depression and occasionally psychotic symptoms (delusions, hallucinations).

Behavioral and psychological symptoms of dementia (BPSD) involve anxiety, depression, insomnia, delusions and hallucinations besides agitation.

BPSD and Agitation in persons with dementia are often treated with antipsychotics.

Antipsychotics are high risk medications that are often used inappropriately / unnecessarily and often cause more harm than good.

Risks of antipsychotics in persons with dementia include but not limited to:

- **Black box warnings (strokes and death)**
- Dysphagia
- Aspiration pneumonia
- Falls and injury (e.g., hip fracture, traumatic brain injury)
- Day time sedation
- Tiredness and fatigue
- Increased visits to emergency department
- Akathisia (motor restlessness)
- Insomnia (with certain antipsychotics like aripiprazole)
- Dysphoria, irritability, apathy

Our hope with this eBook is to provide education and guidance on all the things we can do to reduce agitation and improve experience of positive emotions in persons with dementia so that they can live the best life possible. This can be done without the use of antipsychotics in 99% of cases (our opinion, not based on any research study).

AAD: Agitation associated with Alzheimer's Dementia and Related Disorders

- Excessive motor activity (e.g., pacing, aimless wandering)
- Verbal aggression (e.g., cursing, swearing, use of obscenity, profanity)
- Physical aggression (e.g., hitting, pinching, kicking, banging, throwing)

Frequency: rarely (less than once a week), sometimes (once per week), often (several times a week), very often (daily, once or more times)

Severity: mild (little distress to the patient), moderate (more disturbing but redirectable), severe (very disturbing and difficult to redirect)

Diagnosis of AAD (Sano et al. Agitation in cognitive disorders: Progress in the International Psychogeriatric Association consensus clinical and research definition. International Psychogeriatrics 2023.)

- Diagnosis of dementia
- Clinical diagnosis of Dementia due to probable Alzheimer's Disease
- "Agitation" that meets the International Psychogeriatric Association (IPA) proposed definition

Criteria:

Criteria A: Dementia

Criteria B: at least one of the following three: excessive motor activity, verbal aggression, physical aggression for two weeks

Criteria C: causes distress and or impairment in relationships and or ADL

Criteria D: not due to other comorbidities (Comorbidities include the following: Delirium, Suboptimal care conditions, Medication adverse effects)

Other terms used in place of AAD:

Behavioral and Psychological Symptoms of Dementia (BPSD)

Neuropsychiatric symptoms (NPS) of Dementia

Dementia with behavioral disturbances (old ICD diagnostic category)

AAD / BPSD / NPS are often:

- More challenging and distressing symptoms than cognitive symptoms and functional challenges
- Common cause of caregiver burden, ED visits, hospitalizations, premature institutionalization
- Their management with psychiatric medications involves navigating many ethical challenges (Beck et al. Ethical issues in psychopharmacology. Focus 2021.)

Prevention of AAD / BPSD / NPS: Four Key Domains

- 1) Ten Dementia Friendly Frameworks
- 2) High quality medical care
- 3) Comprehensive Bio-Psychosocial-Spiritual Wellness Care Plan (includes SPPEICE [strengths-based personalized psychosocial environmental initiatives and creative engagement] and PERMA positive psychology science based daily activities [Positive emotions, Engagement, Relationships, Meaning, Accomplishment])
- 4) Caregiver STEPS (support, training, empowerment, praise, support)

High quality medical care:

- Comprehensive geriatric assessment by a geriatrician and their team (especially pharmacists, social workers, chaplains and whenever possible, occupational therapists).
- 4Ms of Age-Friendly Care (what Matters, Medications, Mentation, Mobility)
- Rational de-prescribing
- Goal concordant care

Key Resources for Prevention and Treatment

My book: Psychiatric consultation in long-term care. A guide for healthcare professionals. Cambridge University Press 2017; 2nd Edition. Written with my co-author Dr. George Grossberg, a nationally and internationally renowned expert in prevention, diagnosis and treatment of Alzheimer's disease and related dementias.

- Chapter 3: Neurocognitive disorders / Dementias
- Chapter 12: Psychiatric aspects of Rational De-prescribing
- Chapter 13: Comprehensive Psychosocial Spiritual Wellness Care Plan for Persons with Dementia

Key Resource for Expert Assessment

- Saint Alphonsus Geriatrics Clinic and Memory Center. They take self-referrals and provide telemedicine visits. 208-302-5400. Website: <https://www.saintalphonsus.org/specialty/memory-center/resources>

Ten Dementia Friendly Frameworks

1. Evidence-based care
2. Ethical care (Do no harm, Do good, Autonomy, Distributive justice)
3. ABCD of Dignity Conserving Care – as created and described by Dr. Harvey Chochinov (a Canadian psychiatrist)
 - a. Attitude (of respect, even reverence)
 - b. Behavior (that matches your attitude)
 - c. Compassion (love is all effort to improve happiness, compassion is the other side of the same coin – all effort to relieve suffering)
 - d. Dialogue (talking to each other about creative and routine ways to make this happen)
4. Biopsychosocial spiritual approach (agitation is expression of unmet biopsychosocial spiritual needs)
5. 4M's of Age-Friendly Health Systems
6. Trauma-informed care
7. DIEBA – Diversity, Equity, Inclusion, Belonging, Anti-Dementiaism
8. Need Driven Dementia Compromised Behaviors (behaviors have meaning, it is a way of communicating distress due to unmet needs)
9. Progressively Lowered Stress Threshold (as dementia progresses, stress threshold gets lowered)
10. LOSILDA – loneliness, social isolation, living daily alone (human touch and connection is like oxygen)

Resources:

1. <https://dignityincare.ca/en/the-abcds-of-dignity-in-care.html>
2. <https://www.ihl.org/networks/initiatives/age-friendly-health-systems>

CMS Directive: Age-Friendly Hospital Measure (AFHM)

CMS directive effective 2025; Hospitals will be paid less if they don't track AFHMs
Age 65 and above

Five domains based on 4Ms of Age Friendly Hospital Systems. Each worth one point. Total of five points. There are no partial credits for each domain. It is either zero points or one. Additional details and specifics will be released soon.

1. Eliciting patient health care goals
2. Responsible medication management
3. Frailty screening and intervention
4. Social vulnerability
5. Age-friendly care leadership

Attestation Statements

#1: eliciting patient health care goals

these are reviewed and documented, and updated before major procedures and significant change in clinical status

- Health goals
- Treatment goals
- Living wills
- Identification of health care proxy - Advanced Care planning

#2: responsible medication management

- Medications reviewed for identifying potentially inappropriate medications (PIMs), upon admission, before major procedures, upon significant changes in clinical status
- Once identified, PIMs should be considered for discontinuation and or dose adjustment

#3 frailty screening and intervention

- Using validated instruments, screening for risks regarding cognition, mobility and malnutrition
- Positive screens result in management plans including but not limited to delirium prevention, encouraging early mobility, and implementing nutritional plans as appropriate
- Plans included in discharge instructions and communicated to post discharge facilities
- Data collected on rate of falls, decubitus ulcers, and 30-day readmission
- Protocols to reduce ED delirium risk by reducing length of ED stay by targeting percentage of older adults out of ED within eight hours of arrival or 3 hours of decision to admit

#4 social vulnerability

- screening for geriatric specific social vulnerability including social isolation, economic insecurity, limited access to healthcare, caregiver stress, and elder abuse: upon

admission and prior to discharge

- Positive screens addressed through intervention strategies (e.g., appropriate referrals and resources)

#5 age-friendly care leadership

- hospital designates a point person (champion) and or inter professional committee to ensure AFHMs are prioritized and staff educated

- compiles quality data stratified by demographics and social factors to drive Improvement



Source: Health Quality Innovation Network

<https://hqin.org/wp-content/uploads/2024/07/Quick-Start-Guide-Proposed-Age-Friendly-Hospital-Measure.pdf>

ICD 11 Codes: Behavioral and Psychological Symptoms of Dementia (BPSD)

6D86.0 – Psychotic symptoms in dementia

6D86.1 – Mood symptoms in dementia

6D86.2 – Anxiety symptoms in dementia

6D86.3 – Apathy in dementia

6D86.4 – Agitation or Aggression in dementia

6D86.5 – Disinhibition in dementia

6D86.6 – Wandering in dementia

F02.A11 – Mild dementia due to Alzheimer’s disease with agitation

F02.B11 – Moderate dementia due to AD with agitation

F02.C11 – Severe dementia due to AD with agitation

Basics of Agitation Associated with Dementia (AAD) Management for PCPs

1. STAR approach: Safety, Team input, Action plan, Response to treatment
 - a. Safety: assess if the person is in delirium or a similar condition posing imminent danger to self and or others. If so, they may need ASAP assessment or emergency department assessment.
 - b. Team input: just input from one family member is not enough, especially if the person with dementia appears calm during the visit.
 - c. Action plan: Biopsychosocial spiritual care plan based on the strengths and interests of the person with dementia.
 - d. Response to treatment using objective measures (behavioral tracking data) and modification of action plan based on response or lack of response.
2. MMSE (acronym – not the cognitive test 😊)
 - a. Medical causes – pain, constipation, dehydration, skin infections, dental problems, metabolic-endocrine-nutritional problems.
 - i. OT referral
 - ii. PT referral
 - iii. Community health worker
 - iv. Memory center referral
 - b. Medication induced – de-prescribing
 - c. Social factors – family / staff directed interventions (e.g., powerful tools for caregivers, DICE training), adult day programs.
 - d. Environmental – Occupational therapy, environmental modifications
3. Biopsychosocial spiritual wellness care plan
 - a. Biological: chamomile extract, lavender extract, melatonin, citalopram, escitalopram
 - b. Psychological: engagement in fun activities, communication
 - c. Social: family support and intervention
 - d. Spiritual: purpose and meaning in daily life, spiritual rituals
4. STEPS Support system training education praise support
 - a. Community resources education
 - b. Communication
 - c. DICE Approach Online Training Program: <https://diceapproach.com>
 - d. TADA approach
 - e. Don't TRAC – Test, Reason, Argue, Correct
 - f. Don't BITE – Blame, Insist on reality, Take things personally, Expect unrealistically
 - g. Individual counseling
 - h. Support groups
 - i. Respite
 - j. Bibliotherapy

Basics continued: Five-Step Approach

Step one: Medical assessment

Thorough initial assessment and workup for medical causes of psychiatric problems. Example: pain, dehydration, constipation, infection, delirium. Consider CBC, CMP, TSH, B12, D, Mag levels and for chronic insomnia, ferritin levels (iron deficiency can cause RLS and restless sleep). Address hearing and vision impairment.

Step two: Rational Deprescribing

Review medications and look for medication induced psychiatric problems. This includes medication adverse effects, toxic levels (may need blood levels), and medication withdrawal. Consider rational deprescribing of unnecessary medications, medications not in keeping with goals of care, and medications on AGS 2023 Beers list of medications potentially inappropriate in older adults. Consider checking for total anticholinergic burden of medications using the www.acbcalc.com and reduce anticholinergic burden. Consider pharmacy, geriatrician or geriatric psychiatry eConsult for review of meds and suggestions for deprescribing.

Step three: Psychosocial environmental interventions

Identify social and environmental factors causing or contributing to agitation. Examples include lack of structure, boredom, loneliness, lack of respect and inclusion in decision making. The nursing and social work team can take leadership role in addressing this. Family / staff training, education, praise and support are included here. Create an individualized, strengths-based psychosocial spiritual care plan. Create an IPAS: individualized pleasant activity schedule. Examples: continuous fun and meaningful activities programming, lavender lotion several times a day, bright light therapy, exercise therapy, soothing bedtime rituals.

Step four: Benign psychopharmacological interventions

Consider relatively benign medications first psychopharmacological interventions are needed. Anxiety: chamomile extract 350-500mg one to three times daily; lavender extract 80mg once or twice a day
Insomnia: melatonin 3mg at bedtime daily, chamomile 500mg-1500mg at bedtime daily, lavender 80mg-160mg at bedtime daily

Step five: Traditional psychopharmacological interventions

This step is fraught with ethical challenges, especially if antipsychotics, benzodiazepines and trazodone (all high risk and often cause more harm than good) are being considered. Comprehensive psychiatric assessment and traditional psychiatric medications may help in certain situations (e.g., severe depression, severe persistent aggression, suicidal ideas, distressing psychotic symptoms). This may be done by primary care providers with psychiatrist available via telemedicine for guidance. Citalopram and escitalopram may be considered.

P.S. Depending on the context, all five steps may need to be done simultaneously with different team members tackling different steps. Family members can have PCP help with these steps or seek help via telemedicine from one of the Dementia Physician Experts (page 53)

Collaborative De-escalation for Behavioral Emergencies in persons with Dementia

Guidance for first responders, family and professional caregivers.

REACH acronym – Florida State University School of Medicine Department of Geriatrics:
<https://reach.med.fsu.edu/be-prepared-for-emergent-situations-involving-persons-with-dementia/>

R – Risk perception (assess risk of the person with dementia injuring themselves or harming others)

E – Establish trust (includes keeping personal energy calm and friendly, do not challenge what they believe is true)

A – Assess immediate needs (includes providing information and handouts on community resources to family caregivers)

C – Calm environment (includes reducing distractions or stressors, turning off TV, interacting in as calm and quiet environment as is feasible)

H – Healthy partnership (collaboration with the person having dementia and their family members; this includes getting the person with dementia to an Emergency Department for assessment)

The same website has a 4-minute video for first responders.

Examples of common behavioral emergencies: suicidal behaviors, violent behaviors, physical aggression towards family members or others, severe agitation combined with high risk of falls, involvement of guns.

Five most common causes of behavioral emergencies:

- Delirium
- Psychotic symptoms
- Pain
- Medication adverse effects
- Alcohol and or cannabis intake

Namaste

AAD – PsychUsim Disease State Education Simulator

Website: <https://psychusim.org>

Simulator available for Agitation Associated with Dementia (AAD), Schizophrenia, Major Depression and Bipolar disorder

In AAD simulator: Several nodes available to click and learn more

- Cognitive impairment and screening tools
- Prevalence
- Agitation assessment (they use CMAI – Cohen Mansfield Agitation Inventory, freely available as pdf on the internet)
- Pathophysiology
- Clinical presentation and diagnosis
- Caregiver burden
- Patient burden
- Economic burden
- Treatment guidelines
- Non-pharmacological treatment
- Pharmacological treatment

My take: This is good for education purposes. You will do better getting prevention and treatment of dementia including AAD from a dementia expert team such as our Saint Alphonsus Memory Center with clinics in Boise, Eagle and Nampa and we offer telemedicine consultation.

14 Common Reversible Medical Causes of Agitation / Acute Psychosis in Persons with Dementia

1. Dehydration
2. Hyperglycemia / hypoglycemia
3. Infection (e.g., urinary tract infection, pneumonia, dental infection, cellulitis)
4. Medication adverse effects and toxicity (may need blood levels of certain medications)
(common cause I have seen in my practice: medications used for Parkinson's disease and restless leg syndrome [e.g., ropinirole, pramipexole, levodopa-carbidopa])
5. Alcohol, opioids, and cannabis withdrawal
6. Sedative hypnotic withdrawal (e.g., a benzodiazepine such as lorazepam)
7. Acute traumatic brain injury (typically after a fall – witnessed or unwitnessed)
8. Electrolyte imbalance (e.g., low sodium, high calcium)
9. Acute endocrine disorders (e.g., thyroid problems – took more than prescribed thyroid medication or not taking thyroid medication)
10. Acute cerebrovascular event / stroke
11. Substance use / intoxication (e.g., marijuana, alcohol)
12. Acute hypoxia (e.g., due to an acute respiratory condition)
13. Epilepsy / seizures
14. Multiple causes (more than one cause)

Top 10 Signs of Adverse Events from Psychotropic Medications

- recent falls and injury (including fractures, TBI)
- daytime drowsiness or sleepiness
- abnormal movements (e.g., shaking or stiffness)
- confusion or disorientation
- balance problems
- dizziness
- postural hypotension
- reduced self-care
- restlessness, and dry mouth

Clinical tip:

Routinely inquire about these adverse events during follow up and consider de-prescribing if these events have occurred and are thought to be due to psychotropic medication(s). Individuals with dementia are especially prone to adverse effects of psychotropic medications.

Even antidepressants (e.g., SSRIs) can increase risk of falls, risk of bleeding if used along with anticoagulants, and risk of low sodium especially if used along with a diuretic.

Source:

McInerney et al. *Top 10 Signs and Symptoms of Psychotropic Adverse Drug Events to Monitor in Long-Term Care Residents*. JAMDA June 2024.

**Psychotropic medications Adverse Events Screening Tool
PAEST-10**

Name of the patient:

Age:

Date:

Adverse events	Yes	No	Not sure / Don't know*
Recent falls			
Daytime drowsiness or sleepiness			
Abnormal movements (e.g., tremors, shakiness, stiffness)			
New or increased confusion or disorientation			
Balance problems			
Dizziness			
Postural hypotension			
Reduced self-care			
Restlessness			
Dry mouth			

*complete this with the physician / APP (advanced practice provider [nurse practitioner, physical assistant])

PAEST-10 Score (number of "yes"):

Clinical tip

Routinely complete this and if score is one or more, discuss with physician / APP regarding de-prescribing the suspected offending psychotropic medication(s). In general, there are more than one causes of each of these adverse events and psychotropic medication is one of the most common potentially reversible cause.

Based on:

McInerney et al. *Top 10 Signs and Symptoms of Psychotropic Adverse Drug Events to Monitor in Long-Term Care Residents*. JAMDA June 2024.

Note: This tool is made up by us. It has not been researched.

Checklist to Identify Biopsychosocial Environmental Factors causing “Behavioral” Problems

Checklists are an important tool to manage complexity. I use the acronym MMSE

M = Medical conditions

M = Medications induced (includes substances such as caffeine and illegal drugs)

S = Social factors

E = Environmental factors

Questions	Yes	No	Don't know
Was there any abrupt change in behaviors?			
Are there any active medical problems going on?			
Is the person experiencing pain?			
Is the person having constipation?			
Is the person drinking adequate fluids?			
Is the person eating too little or excessively?			
Is the person sleeping too much or too little?			
Is the person having any skin problems?			
Are there any sensory sensitivities, hearing, vision problems?			
Is the person taking medications are prescribed?			
Is the person having any adverse effects from medications*?			
Is the person taking substances that alter mood?			
Is support team creating a positive validating environment?			
Has there been a significant change in support system?			
Are there physical environmental factors causing stress?			
Does the care team know what brings the person joy**?			

*headache, stomach discomfort, drowsiness, insomnia, vivid dreams, nausea, vomiting, loss of appetite, increased appetite, tremors, agitation, mood instability, tearfulness, anxiety, dry mouth, constipation (onset correlates with when medication was started or dose increased). Adverse effects from medications includes discontinuation and withdrawal symptoms and signs.

**aka what matters to the person

Feel free to modify these questions or add questions that reflect the common MMSE factors for that particular person. I use this to help individuals with advanced dementia, ASD, and IDD.

Namaste

CALM-Checklist

Controlling Agitation with Less Medications (CALM) – Checklist for Older Adults with Dementia

To be completed by family members and or staff (nurse, social worker, certified nursing assistant) in collaboration with primary care providers prior to Psychiatry consult for management of agitation in persons with dementia.

Check if done	Intervention
_____	Mr./Ms. ___ is adequately hydrated
_____	Mr./Ms. ___ is having regular bowel movements
_____	Mr./Ms. ___ is not in pain / pain optimally controlled
_____	Mr./Ms. ___ is sleeping well regularly
_____	Mr./Ms. ___ has exposure to sunlight or BLT* at least 20 minutes a day
_____	Mr./Ms. ___ has some physical activity every 1-2 hours
_____	Team has created an Individualized Pleasant Activity Schedule (IPAS)**
_____	Mr./Ms. ___ is engaged in IPAS throughout the day
_____	Mr./Ms. ___'s MedRev*** done
_____	Mr./Ms. ___ support systems have been encouraged to be with resident
_____	Mr./Ms. ___ has access to his preferred food and activity
_____	Sensory deficits (e.g., hearing, vision) have been addressed.

*BLT: Bright Light Therapy using a bright light therapy box (<https://cet.org/product/light-therapy-lamp/>)

**IPAS: It is a list of activities that the patient in the past has found pleasant/meaningful/fun (created using information obtained from interviews with patient, his family and friends, and observation by medical team) and includes spiritual activities and interaction with a chaplain.

***MedRev: Medication Review. Best done by PCP in collaboration with facility's consultant pharmacist. There are two goals of MedRev: Rational Deprescribing and Identifying medications that may be causing psychiatric symptoms and distress. Rational deprescribing involves at least three of the following: anticholinergic load (if any) has been minimized; medications on Beers'

list have been minimized / discontinued; unnecessary medications and medications where risk is more than benefits have been discontinued through the process of *Rational Deprescribing*****.

Note: Primary interventions for prevention and treatment of agitation involve nursing and psychosocial-environmental approaches and rational deprescribing.

**** Chapter 12. Rational Deprescribing. *Psychiatric Consultation in Long-Term Care: A Guide for Healthcare Professionals*. George T. Grossberg and Abhilash K. Desai. The Cambridge University Press 2017.

The SHIELD Plan for prevention and treatment of agitation, exit seeking in persons with Dementia

SHIELD is an acronym for the following predisposing and precipitating factors of agitation and exit seeking behaviors seen in individuals with advanced dementia, especially those living in nursing homes and assisted living communities:

	Anticipate and Address	Interventions (examples)*
S	Stress (elevated stress hormones, elevated BP, HR)	Soothing music, Lavender lotion, cold compresses to eyes and face, address sources of stress (e.g., pain, constipation, dehydration) Encourage 1500 cc fluid daily or more to prevent dehydration
H	Hearing and vision deficits and other sensory sensitivities may cause frustration and agitation that may lead to increased exit seeking behaviors	Address these deficits or make accommodations
I	Insomnia causing agitation and exit-seeking behaviors	Discontinue medications and care practices that cause / worsen insomnia, sunlight – bright light therapy, avoid daytime naps, soothing bedtime rituals, melatonin
E	Exercise insufficiency: lack of adequate physical activity causing restlessness and exit seeking behaviors	Physical and occupational therapy, walking program
L	Loneliness and boredom causing exit seeking behaviors	Increase interaction with family, friends, pets, engage them in meaningful and strengths-based activities throughout the day
D	Drug-induced agitation manifesting as exit seeking	Discontinue medications that are unnecessary, that are highly anticholinergic and drugs that are causing / can cause agitation; involve PCP, pharmacist and psychiatrist in reviewing medications

*Need to personalize it (e.g., if they prefer a different aroma than lavender, switch to it)

A-Z Psychosocial Spiritual “Therapies” for prevention and treatment of AAD

Aromatherapy
Art therapy
Animal – Assisted therapy
Bright light therapy
Cognitive stimulation therapy <https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/cognitive-stimulation-therapy.php>
Clown therapy
Cooking therapy
Doll therapy
Dignity therapy as described by Canadian psychiatrist Dr. Harvey Chochinov
Exercise therapy, includes walking therapy
Feeding the squirrels therapy, includes feeding fish, feeding birds
Fun activities therapy
Garden / horticulture / plant therapy
Group activities therapy
Gratitude based therapy
Humor-based therapy
Humanitude therapy <https://humanitudesingapore.com/#>
Individualized pleasant activities schedule therapy
IN2L (It’s Never 2 Late) now called Life Loop <https://lifeloop.com>
Laughter therapy
Massage therapy, includes hand massage, scalp massage
Music therapy, includes personalized music, singing, dancing, spiritual music
Nature therapy, includes farm therapy, river and ocean therapy, sky-time therapy, stars therapy
One-to-one therapy, companionship and fun + meaningful activities done together
Pet therapy
Relaxation exercises therapy
Reminiscence therapy
Robotic pets’ therapy
Simulated presence therapy (basically audio video recordings of family members, pets)
Spiritual therapy, practices, rituals
Sun therapy
Tai Chi therapy
Tech therapy – IN2L, virtual reality, guided meditation / relaxation with high quality free apps (e.g., Healthy Minds Program, UCLA Mindful, Cleveland Clinic Wellness CCW Mindful Moments)
Timeslips therapy, creative engagement therapy <https://www.timeslips.org>
Touch therapy (includes hugs – 20 seconds or more)
Validation therapy, <https://vfvalidation.org>
Virtual reality (VR) therapy
Weighted blanket therapy
Yoga therapy, includes chair Yoga
Zen garden therapy

Sundowning / Sundowner syndrome in Persons with Dementia

Symptoms: Increased anxiety and restlessness in afternoons and evenings.

Management: Address the potential cause(s) – typically more than one cause. Create a “Do’s” and “Don’t” list that is individualized, strengths based. No meds have been found to be useful.

Potential cause	Intervention
Brain fatigue	Short afternoon nap
Elevated stress hormone causing severe anxiety	Relaxing / Calming activities <ul style="list-style-type: none"> - Lavender lotion massage three times in afternoon - Back rub / massage - Soothing music - Soothing multisensory room - Going through photo album - Favorite laughter programs on TV - Watching recording of children / grandchildren - Meaningful calming activities (e.g., folding towels) - Pets / Robotic pets
Overstimulation (excessive noise, too many people, too much movements of people)	Taking the person to a quieter place with less stimulation, reduce visits by family friends in the afternoon (can visit in the morning)
Under stimulation / boredom	Walking / other exercise program in the morning and individualized meaningful and pleasant activity schedule
Insomnia	Avoid excessive daytime napping, remove meds causing insomnia, soothing nighttime rituals (e.g., bedtime prayers) and other interventions to address insomnia effectively
Low lighting	Exposure to sunlight, bright light therapy, open blinds and curtains in the daytime, reduce shadows
Diet	Reduce / eliminate caffeine, excessive sugar with dramatic blood sugar fluctuations
Medication(s)	Request provider / consultant psychiatrist / pharmacist to review meds and suggest rational deprescribing
Medical condition(s)	Request provider to assess for potential reversible causes (e.g., pain, dehydration, infection, vitamin deficiencies, thyroid dysfunction, hypo/hyperglycemia)

Trauma-informed care in person with dementia who cannot remember traumatic event

Step 1: Try to find out as much details from collateral sources of the nature of trauma (including TBI). Keep in mind that trauma may be from past events as well as present experiences. For example: use of physical restraints in a hospital setting; holding the person to give intramuscular injection.

Step 2: Try to avoid situations that would mimic the trauma experienced.

Step 3: Monitor for the person's statements that may indicate the type of trauma they may have experienced. For example, they may say, "go away...get out of the room" when she sees a male caregiver would indicate a male may have caused the trauma.

Step 4: Monitor using observation scales for depression as depression is often caused by trauma. Cornell Scale for Depression in Dementia is one such scale.

Step 5: Educate staff that this person has experienced trauma and that their approach should be slow, gentle, closely observing for any triggers, communicating any identified triggers first-hand to other team members, documenting triggers if observed, and then minimizing the person's exposure to triggers.

Step 6: Create a psychosocial wellness care plan that includes focus on the following:

- Trust building – the caregivers reassure that they are there to help and not harm
- Identifying and avoiding triggers (e.g., avoiding male caregivers if trauma was caused by a male)
- Reducing sympathetic nervous system overdrive – calming rituals and routines, simple breathing exercises, lavender lotion three times a day, chamomile tea or extract twice a day, soothing music, calm and predictable environment are examples of achieving this. These same strategies can be employed when the person is having trauma-related symptoms (e.g., nightmares, flashbacks, panic attacks)

Step 7: Consult a clinician for possible need for psychiatric medications if symptoms are moderate to severe and not responding to psychosocial spiritual, behavioral and environmental approaches.

Note: The order of the steps can be changed to better meet the needs of the person.

Namaste

Long Buried Sorrow

What is her yelling? A sign, a signal. A symptom of moral anguish calling our souls to understand her plight. My patient had never learned to experience her feelings as there was no one in her childhood or later who accepted her fully, who understood and supported her. And now with advanced dementia long buried sorrow that could never be expressed is set free and only touch and soothing voice can do the miracle of bringing her some solace. No meds please. No meds.

Trauma-Informed Dementia Care

- Address power differences (e.g., empower the person with dementia to participate in decision making)
- Relationship building communication techniques (includes nonviolent communication [NVC], not “forcing” them)
- Understands “behaviors” as reactions that make sense when the person’s perspective, dementia and past trauma are considered.

Routine Psychosocial Spiritual / Non-Drug Interventions (NDI) Orders for AAD

1. Lavender lotion (or another scent that the person prefers) three times daily and as needed
2. Personalized music / soothing music 20 min three times daily and as needed
3. Walking (with assistance if necessary) 15 min three times daily and as needed
4. Outdoor sitting and sipping chamomile / lavender tea twice daily and as needed
5. Bright light therapy 20 min – 2 hours once a day (morning or afternoon) and as needed

Namaste

Relationship Building Communication Techniques

Relationship building communication approaches are an essential skill for all healthcare professionals. Many persons having dementia (PhD) are looking to be part of warm loving relationships when they express wish to “go home” and relationship building communication approaches are key to making PhDs feel emotionally secure. “Agitation” in PhDs is also frequently related to feelings of insecurity, loneliness, lack of feeling connected and feeling “lost” (in the interpersonal world).

There are at least six key relationship-building communication techniques that all care-partners / caregivers (family and professional) of PhDs should become familiar with and utilize in their daily interactions with the PhD.

Reflective listening: This technique involves making eye contact, adjusting body posture (e.g., leaning forward, avoiding hands folded across one’s chest), and providing nonverbal and verbal encouragement for PhD to express themselves (e.g. nodding, stating verbal continuers [e.g. “I see,” “Go on,” “Sounds like...”]). It is important to avoid expressing judgment, getting distracted, or redirecting the PhD. Repeating what the PhD has stated and seeking clarification is also important. Humanitude training may facilitate development of this skill.

Elicit storyline: Positive (e.g. joy) as well as negative emotions (e.g. anger) are embedded in stories that are unique to each PhD. A PhD’s narrative can be brought out through use of open-ended questions and continuers (e.g., “tell me more,” “what next?”) as well as Improv techniques such as “Yes and”. Understanding the PhD’s narrative is essential to seeing the PhD as a unique person.

Explore the PhD’s perspective (point of view): When another person understands our perspective, we feel heard. Specific questions can help elicit PhD’s perspective (e.g. what is your opinion? How do you feel about the care you are getting? Is anyone bothering you? How are they bothering you?).

Validate PhD’s experiences: When our experiences are validated, healing occurs. Validation can be done by genuinely felt and expressed statements such as, “I would also feel scared if I was in a strange place...I would feel sad too if my family was not with me.” Giving advice, opinion and correcting or interrupting the PhD is avoided. Gentle touch is important.

Mirroring: This technique involves mirroring PhD’s emotions such as a smile or sadness. Mirroring conveys to the person that we understand their emotional state.

Touch: Gentle touch can promote bonding through release of oxytocin (and other mechanisms) and help build trust in relationship.

Case Example: When do I go home?

Ms. G has been very upset, anxious, and tearful almost every day from the day a few weeks ago when she was admitted to a secure memory-care unit of an assisted living community. She has been repeatedly stating “when do I go home.... Did I do something to be here...just kill me...” Staff listens to Ms. G using reflective listening skills mentioned above (e.g., “sounds like you are unhappy here”). Staff then make efforts to bring out the PhD’s narrative (e.g., where would you like to go? Tell me more about your home?). Staff then try to explore Ms. G’s perspective (e.g., “what is worrying you? What would you like us to do? If you could have anything, what would you want? Why is it so terrible over here?) and validate her feelings of abandonment and loneliness. Staff also mirrors PhD’s sadness and frequently holds PhD’s hands.

Relationship building communication approaches over time will give Ms. G a sense that staff care, that they understand her perspective and this will help Ms. G slowly but surely feel less anxious and lonely. Ms. G will feel part of several loving relationships with different staff members.

Resources:

1. Abhilash Desai and George Grossberg. Chapter 13 “Psychosocial Spiritual Wellness Care plan for persons with dementia” of the book titled *Psychiatric Consultation in Long-Term Care: A guide for healthcare professionals* by Cambridge University Press, 2017.
2. Boissy et al. Communication skills training of physicians improves patient satisfaction. *Journal of General Internal Medicine* 2016; 31(7):755-761).
3. Humanitude International. <https://humanitudesingapore.com/#>

Namaste

STEPS: Support system / Staff Training Education Praise and Support

STEPS is a comprehensive approach to improving quality of care provided by family members (patient's support system) and professional caregivers (e.g., staff to our long-term care residents). It involves three components:

1. **Education and Training:** Two key areas:
 - a. Understanding and implementing SPPEICE – Strengths-based Personalized Psychosocial Environmental Initiatives and Creative Engagement*. Goals of this training: Improved wellbeing of residents using SPPEICE and Reduced use of psychotropic medications.
 - b. Mindfulness training. Goals of this training: Improved skills to provide care with mindfulness (with awareness and compassion) and Increased Joy at work (besides reduced burnout)
2. **Praise:** This includes case-based in-time praise for specific behavior of the staff that lead to specific positive outcome. Sharing success stories routinely during meetings and at other times is one of the many ways to praise staff regularly.
3. **Support:** This includes direct one-on-one support by leadership team members, one-to-one support by colleagues and group support strategies.

*SPPEICE – detailed information available in chapter 13 – *Psychosocial Spiritual Wellness Care Plan* in my book: *Psychiatric Consultation in Long-Term Care: A Guide for Healthcare Professionals* 2nd Edition. Cambridge University Press 2017.

Six essential trainings:

1. DICE – Describe Investigate Create Evaluate. www.diceapproach.com
2. Relationship building communication techniques (see page 25)
3. Mindful Care-Partnering (see page 77)
4. T.A.DA method to manage agitation in delirium training (see page 32)
5. Training by Teepa Snow, OT (Positive Approach Training)
6. TimeSlips Creative Storytelling training <https://www.timeslips.org/trainings/>

Caregiver Dementia – CD-9 screening tool

1. Do you forget that TRACing is counterproductive?
2. Do you forget that BITEing is counterproductive?
3. Do you forget that your loved one has dementia?
4. Do you repeat the same mistakes?
5. Do you forget to take time to maintain your health?
6. Do you forget what you have learned in support groups and caregiver education and training workshops?
7. Do you get confused about how to cope, what to say?
8. Do you have emotional outbursts?
9. Do you forget to give yourself a break?

TRACing = Testing, Reasoning, Arguing, Correcting

BITEing = Blaming, Insisting on reality, Taking symptoms personally, Expecting unrealistically



Resource Book: *Travelers to Unimaginable Lands*. Stories of dementia, caregiver, and the human brain. Dasha Kiper. Psychologist. Caregivers are provided education and training to minimize TRACing and BITEing in their interactions with their loved one with dementia but this book beautifully and with great compassion illustrates just how hard it is.

Scored like Patient Health Questionnaire – 9 (PHQ-9) used for depression; 0-3 points for each. Max score 27. 5-12 mild; 13-20 moderate; 20-27 severe

Rx:

normalize (most caregivers develop mild caregiver dementia)

empathize

expand / improve utilization of their support network

respite

support group

individual counseling

bibliotherapy – Dasha Kiper’s book

mindfulness skills training

creative engagement (e.g., journaling, Improv, poems, art)

other practical help

family interventions

participate in dementia friendly community programs like Memory Cafes

Caregiver Dementia 100% reversible but if not addressed, can leave serious negative effects on mental, spiritual and physical health. Reversing *caregiver dementia* is key to reducing AAD.

Note: I have made up this term *Caregiver Dementia*. No research to support this.

**Caregiver Dementia Questionnaire – 9
CDQ-9**

Name of the caregiver / care partner of the person living with dementia:
Date:

Over the past two weeks, how often:

#	Behavior	Not at all	Several days	More than half days	Nearly every day
1	Do you forget that TRACing is counterproductive?	0	1	2	3
2	Do you forget that BITEing is counterproductive?	0	1	2	3
3	Do you forget that your loved one has dementia?	0	1	2	3
4	Do you repeat the same mistakes?	0	1	2	3
5	Do you forget to take time to maintain your health?	0	1	2	3
6	Do you forget what you have learned in support groups and caregiver education and training workshops?	0	1	2	3
7	Do you get confused about how to cope, what to say?	0	1	2	3
8	Do you have emotional outbursts?	0	1	2	3
9	Do you forget to give yourself a break?	0	1	2	3

Score 0 + + +
Total score (max 27):

TRACing: Testing, Reasoning, Arguing, Correcting the person living with dementia.
BITEing: Blaming, Insisting on Reality, Taking things personally, Expecting unrealistically

Interpretation:

Mild Caregiver Dementia: 5-12
Moderate Caregiver Dementia: 13-20
Severe Caregiver Dementia: 21-27

Source: Abhilash Desai MD. Geriatric Psychiatrist. Dr.abhilashdesai@icloud.com

Note: This tool has NOT been researched / systematically studied. Dr. Desai has made up the term *Caregiver Dementia*. There is no research to support this concept.

Don't TRAC: Test Reason Argue Correct

A common cause of agitation is when family members (especially spouses and children) test their loved one with dementia, try to reason with them, argue with them or correct them.

It is important for family members to take a deep breath and go back to minimizing TRACing.

Don't:

- Test: avoid asking questions that require memory such as "what did you do today, what did you eat."
- Reason: avoid trying to reason with them and trying to use logic to get them to change their beliefs or behavior based on their perception of reality
- Argue: avoid going back and forth stating your point and perspective again and again
- Correct: avoid correcting them

We have seen agitation escalate to verbal abuse and even paranoia and physical aggression if the family caregiver continues to TRAC.

It is very difficult not to TRAC so family caregivers need lot of support and guidance in their efforts to master this important communication skill. In many situations, individual counseling is needed for family caregivers to tackle the trauma, grief, guilt, fear, and shame they are struggling to cope with.

Don't BITE: Blame, Insist on Reality, Take things personally, Expect unrealistically

A common cause of agitation is when family members (especially spouses and children) start either blaming the person with dementia or themselves about mistakes or setbacks; when family members insist on reality, take what the person with dementia says in anger, personally; and when family members have unrealistic expectations from their loved one with dementia.

It is important for family members to take a deep breath and go back to minimizing BITEing.

Don't:

- Blame: avoid blaming the person with dementia (e.g., "you make me feel bad about myself") or oneself (e.g., "see what you did, you are the reason she is unhappy").
- Insist on reality: avoid trying to insist that the loved one with dementia live in reality, especially your (family caregiver's) reality
- Take things personally: avoid believing every negative statement and accusation your loved one with dementia makes regarding you (e.g., "you are a terrible daughter for leaving me here" [meaning in the assisted living community])
- Expect unrealistically: avoid unrealistic expectations (e.g., the loved one with dementia will be reasonable or grateful for all the sacrifices you – the family caregiver – have made).

We have seen agitation escalate to verbal abuse and even paranoia and physical aggression if the family caregiver continues to BITE

It is very difficult not to BITE so family caregivers need lot of support and guidance in their efforts to master this important communication skill. In many situations, individual counseling is needed for family caregivers to tackle the trauma, grief, guilt, fear, and shame they are struggling to cope with.

T-A-DA method of managing agitation

Dr. Joseph Flaherty, geriatrician at Saint Louis University School of Medicine has a YouTube video on this. Please check it out. Although he describes this method to manage agitation in the context of delirium in the hospital setting, all the principles apply also to management of agitation in individuals with dementia.

T-A-DA is an acronym. It stands for:

T: Tolerate – increase your tolerance for negative behaviors of the loved one with dementia as often times, they are transient [like bad weather] and pass on their own).

A: Anticipate – anticipate the unmet needs and triggers so that agitation can be aborted. For example, anticipate that they will get agitated if not toileted frequently, if they don't drink adequately throughout the day, if they get constipated or are in pain. Best to see all agitation as a way of communication of unmet needs (biological needs like hunger; psychological needs like having a choice; social needs like companionship; spiritual needs like having a purpose).

DA: Don't Agitate. TRAC and BITE mentioned in earlier sections are common ways that family caregivers can worsen agitation. Other ways they can worsen agitation is by ignoring the persistent negative behaviors of the person with dementia (aka not investigating and meeting their unmet needs), and giving them psychiatric medications when the agitation is due to dehydration or pain or constipation or other biopsychosocial needs.

Mission Impossible

As we mentioned earlier, most family caregivers struggle to understand the negative emotions, statements, behaviors, verbal and physical abuse and paranoia expressed by their loved one with dementia. Family caregivers have told us that our suggestions on “Don’t TRAC” and “Don’t BITE” are “Mission Impossible” and that we are having unrealistic expectations from the family caregivers and we (my wife and I) are doing the same thing that we are telling them (the family caregivers) to stop doing. We are having unrealistic expectations from family caregivers.

We acknowledge everything that the family caregivers are saying and agree that it often is “Mission Impossible.” Both of us have been family caregivers to our elderly parents (one of them had vascular dementia) and it indeed was “Mission Impossible” at times.

With lot of support, guidance, role-playing (I take the role of the family caregiver and the family caregiver takes the role of their loved one with dementia), Improv, creative and compassionate engagement and communication, and time, we do feel that many family caregivers are able to dramatically reduce TRAC and BITE behaviors, increase T-A-DA approaches and will see amazing results in terms of not only reduction in agitation but even increase in frequency, duration and intensity of joyful and happy moments.

Mindful Caregiving / Care-partnering – Improv Workshop Handout

Mindfulness is our capacity to be in the present moment, with intention and non-judgmentally. The two key ways to be mindful while providing care to your loved one with dementia is by accepting the challenges involved in caring and engaging in creative and gentle ways.

This workshop will involve learning the two key skills of mindfulness – acceptance and creative engagement – through the use of Improv and one-minute guided meditations.

Improv is a form of theater in which much of the performance is created spontaneously, without any scripts. Improve, using a variety of techniques and strategies including comedy, has been shown to improve skills like empathy, teamwork, and creative problem solving.

During this three-day workshop, we will engage in at least two two-minute meditations, one at the beginning and one at the end of each day. The mindfulness teacher will guide you through the meditations and mind the time. There will be a brief lecture and discussion to explain mindfulness and mindful caregiving / care-partnering.

Instructions for guided meditation:

Get into a comfortable position. Gently close your eyes. Keeping eyes open and focused on something is okay. Put one hand on your belly and another on your chest and bring your attention to the movements of your hands as you breathe in and out. The mindfulness teacher will be repeating the aspirations “may you accept the challenges involved in caring; may you creatively overcome the challenges.” In between the aspirations, you will bring your attention back to the movements of your hands as you breathe in and out. As we do this meditation, your attention is likely to wander. No need to get upset. That is what our mind does. When you become aware that your attention has wandered, gently bring it back to your breathing and rejoin the meditation. Let’s begin the meditation

Improv training will involve a few interactive sessions to help you utilize Improve strategies and techniques to mindfully switch from negative TRAC to positive TRAC during caring.

Negative TRAC – Testing, Reasoning, Arguing, Correcting

Positive TRAC – Touching gently, Reassuring, Accepting and validating, Creative problem solving

One of the fundamental skills of Improv is “Yes And.” During this training, an Improv expert will teach us this fundamental skill and how it can be applied during periods of challenging behaviors experienced by your loved one with dementia in order bring them some relief.

If you are struggling, you can change the C for Creative problem solving to Compassion for self. This involves giving yourself a break and seeking emotional support for yourself as caring is hard. Self-compassion is another essential mindfulness skill and a core component of resilience.

Bright Light Therapy

Depression, insomnia and sun-downing related agitation are prevalent in persons with dementia and is typically treated with antidepressants and or sedating medications (e.g., trazodone). Bright light therapy (BLT) is a good non-pharmacological intervention that may help some residents with depression and or insomnia. It should generally be used along with other non-pharmacological interventions (e.g., behavioral activation, individualized pleasant activity schedule, exercise, music, gratitude-based interventions, dignity therapy) and / or pharmacological interventions.

If you prefer natural sunlight, try to get it early in the morning as damaging UV light is lower in the morning. Sitting next to the window for sunlight is also fine.

Usual indoor lighting is not strong enough to provide benefits.

BLT should be considered for all residents with seasonal affective disorder (especially winter depression) and may also help residents with non-seasonal Major depression and or Insomnia disorders (e.g., chronic insomnia). Research has also found it useful as an adjunct to pharmacological interventions for Bipolar depression (1).

BLT with sleep hygiene may improve sleep in individuals with dementia.

I recommend a BLT lamp (NLT bright light therapy lamp) available at the Center for Environmental Therapeutics (<https://cet.org/shop/>). It costs around \$190 (includes shipping). I have no financial relationships with the makers of this BLT box. I recommend this because it was used in research settings. Other sources of BLT lamp are also fine.

A 10,000-lux light box is recommended. Intensity needs to be individualized and is effective in the range of 2,500 – 10,000. For most cases, 10,000 lux is needed for 30 minutes daily for beneficial effects. Light boxes with larger screens are preferred over smaller screens due to less eye strain. If lower intensity is used, extend the exposure to more than 30 min.

Benefits can be seen as early as 2 days but generally take 2-4 weeks. Many patients who show improvement in the first four weeks continue to improve further over next 4 weeks (2).

The resident can begin exposure to bright light for 15 minutes initially and slowly increase (15 minutes per week) as tolerated to 60 minutes per day. The box should be above the resident's head at a 45-degree angle. One can start with exposure in the morning (6am-9am) but some residents may respond to exposure in the afternoons (noon-3pm). The resident is generally around 30-80 cm (30cm = one foot) from the screen, not looking at the screen but engaged in another activity (e.g., reading, watching TV).

Adverse effects are typically minor and transient and include eye strain, nausea and headache. Using BLT for a shorter time or lowering the intensity may be needed to reduce these problems

for some individuals. Although rarely BLT could trigger a switch to a manic / hypomanic episode, in the two studies (1,2), that did not happen. Both the studies had a small N (small sample size).

Reference:

1. Sit et al. Adjunctive bright light therapy for bipolar depression: A randomized double-blind placebo-controlled trial. *American Journal of Psychiatry* 2017; October 3rd
2. Cuomo A, et al. Effectiveness of light therapy as adjunctive treatment in Bipolar depression: a pilot study. *Journal of Affective Disorder* Jan 15. 2023.
3. Lam RW, Levitt AJ, Levitan RD, et al. Efficacy of bright light treatment, fluoxetine, and the combination in patients with nonseasonal major depressive disorder: A randomized clinical trial. *JAMA Psychiatry*. 2016;73(1):56-63.

Resource:

1. *University of Wisconsin patient handout on BLT.*
https://www.fammed.wisc.edu/files/webfm-uploads/documents/outreach/im/handout_light_therapy.pdf

Namaste

Feeding the Squirrels Therapy

Ms. Linda came to our center at the beginning of this year. In the beginning she was apprehensive about long term placement, she was frustrated at her family for leaving her and distressed about leaving her animals. Ms. Linda quickly found companionship with those around her and found she enjoyed sitting next to fellow residents, giving hugs, candy and kisses on the forehead. When COVID precautions began, Linda struggled. She became frustrated at staff reminders to social distance. After a few months Ms. Linda settled into her new way of life, visiting others from afar and waving at fellow residents as she walked through the hallway. As precautions increased due to facility exposure to COVID-19, Ms. Linda was encouraged to stay in her room to decrease her level of exposure. These increased precautions resulted in a significant increase in behaviors. Staff reported that Ms. Linda was throwing objects at the window to see if the glass would break, formulating plans to escape, threatening to kill staff if they wore the proper protective gear in her room, hallucinations of Jesus and her grandmother in her room. To help deescalate behaviors staff would visit with Ms. Linda throughout the day, taking her on walks outside, and facilitating socially distanced family visits. Staff quickly found out that Ms. Linda enjoyed feeding the squirrels in the courtyard and watching them eat from her window. Now, twice a day Ms. Linda will seek out social services or activity staff to help her feed her "babies." There has been a visible improvement in Ms. Linda's behaviors, she feels she has a purpose in life and that she is "God's helper."

Credit: Credit for this goes to a wonderful social worker, Ms. April Bench that I have the privilege to work with in a local nursing home.

Doll Therapy (DT) for Behavioral and Psychological Symptoms of Dementia (BPSD)

Landmark study:

Santagata F, et al. The Doll Therapy as the first line treatment for behavioral and psychological symptoms of dementia in nursing home residents: a randomized controlled study. BMC Geriatrics 2021; 21:545.

Intervention: 2 hours of DT twice daily (morning and afternoon) and prn for agitation / aggression / wandering. The patient's interaction with the doll was observed for 7 days. Patients with positive attitude towards the doll were entered into the study.

Results: DT is more effective than standard treatment for reducing BPSD and may be effective in reducing the incidence of delirium. DT also reduced perceived professional caregiver burden.

Dr. Milta Little (one of our national and international leaders in geriatric medicine and dementia care) stated in her discussion of this study at the annual 2022 conference of the AMDA (American Medical Directors Association [same as PALTC Post-Acute and Long-Term Care society]) that "doll therapy is based on the principles of attachment...dolls may actually be used as a translational object where people with dementia may be able to translate BPSD into a caregiving role towards what they perceive as a baby" – especially in cases where BPSD is due to unmet attachment needs. Dr. Little also highlighted the finding in the study that in 28 out of 32 instances when DT was used as needed for agitation, it was effective (with no need for as needed psychiatric medications) and in the other 4 instances, as needed medications were needed.

I agree totally with Dr. Little and would add that many patients who respond to DT may be feeling better because taking care of the doll gives them purpose and makes them feel needed. I have seen benefits with DT when used in a respectful manner (after education of staff and family that our intention is NOT to infantilize the person but to enhance positive experiences).

Doll therapy is controversial as many would see this as infantilizing the person with dementia. It is important to talk about this concern with family and team.

Resistance to Care in persons with Dementia

Individuals with advanced dementia often resist personal care, and sometimes even become aggressive. Antipsychotics are often used to reduce aggression during personal care. The following strategies are best practices to reduce distress experienced by the person with dementia during personal care and improve their comfort during such care.

If done with love, patience, training and creativity, these times of personal care can become an important bonding experience for both the person with dementia and the caregiver. Both may experience positive emotions, beauty in relationship and deeper meaning in life and living.

One key consultation: Occupational therapy to address decline in self-care skills due to agitation and identify non-pharmacological strategies to address agitation during self-care activities

The Seven Essential Strategies

1. Know the individual – really know them (read a brief personal statement that represents the individual’s unique attributes and essence). This would apply not only to professional caregivers (e.g., staff in nursing homes and assisted living communities) but also family members who are struggling to see the person behind dementia.
2. Identify and consistently use individualized effective communication strategies (read the strategies and even post the strategies on the bathroom door)
3. Involve the individual in their own care (allow them to do what they can or put their hand on yours)
4. Gently massage the individual’s hands and feet (lavender lotion can be soothing and relaxing, but any other aroma may also work)
5. Engage and distract with positive images (pictures that have been found to hook the individual in a positive way and have been identified in advance)
6. Address pain (scheduled acetaminophen if appropriate)
7. Soothing background music (preferably personalized)
8. Singing by care-partners (caregivers) during provision of care.

ABCD of Spiritual Assessment

A = Ask. Ask permission to inquire about patient's spirituality. Explain that spirituality is an important factor in wellness, resilience and healing. Involve family whenever possible.

B = Beliefs. Inquire about their spiritual beliefs so that you can better understand them.

C = Community. Inquire about the patient being part of a spiritual community.

D = Daily practice. Discuss what daily spiritual practices can be continued and new ones added to promote wellness, resilience and healing.

Common spiritual practices and rituals

- Prayers
- Meditation (Healthy Minds Program – Best app for learning to meditate and understanding mindfulness)
- Reading religious scriptures and spiritual books (including audio books)
- Attending church, mosque, temple events and events and gatherings of other spiritual communities
- Volunteering
- Yoga, Tai Chi, Qi Gong
- Spending time with nature
- Listening to spiritual / religious podcasts
- Singing religious / spiritual songs and dancing to it
- Gratitude and Awe – based practices and rituals

Suggested reading:

1. Sulmasy DP. Physicians, Spirituality, and Compassionate Patient Care. NEJM 2024.

Dignity Conserving Care / Dignity Therapy

Dignity conserving care / Dignity therapy can improve depression and anxiety in older persons and greatly enhance their functioning and quality of life. For persons with dementia, doing this with their loved one besides the person is key.

1. Tell me a little about your life history, especially the parts that are the most important / meaningful to you.
2. When did you feel most alive?
3. Are there specific things that you would want your family to know about you and particular things you would want them to remember?
4. What are the most important roles you have played?
5. Why were these roles so important to you and what did you accomplish in those roles?
6. What are the most important accomplishments and what do you feel most proud of?
7. Are there particular things that you feel still need to be said to your loved ones or things that you would want to take the time to say again?
8. What are your hopes and dreams for your loved ones?
9. What have you learned about life that you would want to pass along to others?
10. What advice or words of guidance you would wish to pass along to your (son, daughter, husband, wife, others)?
11. Are there words or perhaps instructions that you would like to offer your family to help prepare them for the future?
12. In creating this permanent record, are there other things that you would like included?

Resources:

- Dr. Harvey Chochinov. Dignity and the essence of medicine: the a, B, C, and d of dignity conserving care. BMJ 2007. Freely available on the internet.
- Dr. Shapir Rosenberg. Dignity Therapy. The American Journal of Psychiatry Resident's Journal 2018. Freely available on the internet.

SPPEICE: Strengths-based Personalized Psychosocial behavioral nutritional sensory spiritual Environmental Initiatives and Creative Engagement (aka Non-Drug Interventions) to improve psychosocial emotional cognitive spiritual wellbeing of individuals with advanced dementia.

In-depth information on SPPEICE is in chapter 13 of the book titled *Psychiatric Consultation in Long-Term Care: A guide for healthcare professionals* by Cambridge University Press, 2017.

- Relationship building staff approach (includes getting to know the resident well [using Life Story page posted outside the door or just inside the door, Life Story picture book, Life Story bin], validation, *AwareCare approach*)
- Spend time with friends and family
- Touch (includes massage)
- Exercise (includes postural exercises, walking with a song, chair Yoga)
- Music therapy
- Multisensory approaches in a multisensory room
- Individualized pleasant activity schedule with continuous activities throughout the day
- Pet / Animal assisted therapy
- Aromatherapy
- One on one
- Simulated presence therapy (e.g., video and audio recording a family event for 1-5 minutes and showing it to the resident; family may need some guidance and coaching and “multiple takes” to get the most emotionally strong and positive recording)
- Robotic pets (see Amazon video: Hasbro’s *Joy for All Pet* interactive puppy and cat; available on Amazon [around \$120])
- Fidget blankets (available on www.etsy.com cost \$15 upwards)
- Avoid / minimize intake of caffeine and chocolate
- Avoid alcohol
- Preferred food and drinks

Resources for SPPEICE:

1. AwareCare approach by Linda Clare PhD (<http://psychology.exeter.ac.uk/media/universityofexeter/schoolofpsychology/reach/documents/AwareCare.pdf>). A must for every staff working in long-term care and with persons having dementia.
2. TimeSlips (<https://www.timeslips.org>) creative storytelling. Online training course available. At least one long-term care staff should be trained in *TimeSlips*
3. Book: *Aging Together: Dementia, Friendships and Flourishing Communities*. By Susan McFadden and John T. McFadden. Johns Hopkins Press. Available on Amazon for around \$26 (search word: Aging Together). Social workers in long-term care should take a leadership role in utilizing this resource to improve spiritual wellbeing of long-term care residents.
4. Cognitive Stimulation Therapy (<http://www.cstdementia.com>). Online training course available. At least one staff member should become trained in CST.
5. *Bathing Without A Battle* DVD (<http://bathingwithoutabattle.unc.edu>). All staff should undergo free online training.
6. *Alive Inside* movie (<http://www.aliveinside.us>). All staff should watch this movie and long-term care leadership should consider this work-education time.
7. Idahoan Dave Potter's website <https://palousemindfulness.com> provides opportunity for FREE self-paced online training on Mindfulness and Meditation (eight-week Mindfulness Based Stress Reduction [MBSR] course). At least one long-term care staff should be trained in MBSR.
8. Multisensory room. Watch the video on Healing Spaces at <https://news.usc.edu/147930/healing-spaces-video-game-targets-alzheimers-dementia-patients/>
9. Educational programs by the Occupational Therapist and a celebrity in the dementia training world, Teepa Snow <http://teepasnow.com>

Strengths-based Personalized Psychosocial sensory spiritual and Environmental Approaches and Creative Engagement (SPPEICE) for Mr. MT.

When Mr. MT becomes agitated and calls out and reaches for things on the floor, provide him with things to do and the behaviors may quickly go away. Use the same activities to prevent agitation from happening in the first place. In general, give him only one activity at a time and put away the one before. This is to prevent him from getting overwhelmed or distracted. Rotate activities after 30-45 minutes or when Mr. MT loses interest.

Suggested additional activities and approaches (besides coloring and puzzles):

1. Use cookies to encourage resident to move to a different area in the common room.
2. Staff to start playing with the blocks for a few minutes and then encourage resident to try messing around with the blocks.
3. Encourage resident to play deck of playing cards with the bright circus pictures. With the recreational therapist (RT), for almost 45 minutes Mr. MT contently played various ways with the cards. He was counting them. He was putting them in piles. He was talking to them. Twice RT approached Mr. MT to help him sit up better but then without further direction left him to himself again.
4. Staff to approach Mr. MT respectfully to ask if they could show him something interesting. If he says "yes," give him a National Geographic Magazine. He may flip through it, stop and observe many pages. This activity may engage him for 15 minutes or more. Keep the cards around as he may put the magazine aside and pick up the cards again.
5. Encourage resident to stand, stretch and walk (with assistance as necessary) around for a few minutes (or more) every hour.

Create a plastic bin with the following:

- Cards of several kinds – regular playing cards, Wild Kingdom Animal Playing Cards, playing cards that have pretty scenery or interesting pictures on them.
- Several interesting magazines like National Geographic, gardening, travelling, Architectural Digest (for his engineering background). Often used magazines can come from libraries or family members and friends if the word is given that they would like them.
- Many Nuts, Bolts, Washers and Screws of various kinds in a plastic container and 2-3 disposable muffin tins for sorting. The family may purchase the hardware at Second Chances or Goodwill at relatively low cost. Have Mr. MT sort the hardware and/or match up the nuts and washers. Staff may watch Mr. MT the first time for 5 minutes to make sure he isn't trying to eat them.
- Historical picture books that have very little words but interesting pictures. Other hardback picture books of things Mr. MT used to love to do (e.g., gardening, outdoors), and other hard back books.
- Easy word searches, mazes, and easy brain builders.
- A Matching game with only give 20 matching cards at a time.

- Blocks (multicolored Jenga game)– especially wooden blocks instead of the plastic large Legos which Mr. MT might view as childish. Encourage resident to build a tower all one color or different colors. Resident can sort according to color. Staff can make a pattern and encourage resident to copy the pattern.

Note: Keep the bin in a place that is accessible to Mr. MT. The content of the bin can be modified over time so that activities that are of interest are kept, activities that Mr. MT did not find interesting can be removed and new activities may be tried.

Address Posture:

- To encourage better posture and reduce pain due to abnormal posture, the staff may push Mr. MT's wheelchair forward for him as he leans too much to move his own wheelchair. The staff may prop Mr. MT up and to the side (that is leaning) with a pillow to straighten his body so he sits almost upright. Mr. MT may also be able to handle the items on the table much better after the posture is corrected.
- Staff to transfer Mr. MT to a regular sitting chair at the table so that it doesn't slide as easily. Staff may lock the wheelchair in place if the resident wants to be at the table and not constantly roll away from the table?

Therapeutic Communication:

- Staff need to get to the eye level of the resident and make eye contact when interacting rather than standing over Mr. MT or answering from across the room.
- Staff encouraged to avoid statements such as:
 - Let go of the knob. You don't need to hold it. Let go.
 - You said you needed the restroom. That's what we are here for. Let's do it then.
 - Mr. MT, sit down, sit down. Just wait one minute and we will go.
- Staff are encouraged to make statements such as:
 - thank you for letting me help you
 - Please sit down for a moment
 - Mr. MT, I see your frustrated. I'm sorry. I'd like to help. Please let go of the knob;
 - Mr. MT, please let go of the knob. That's great, thank you!

**Strengths-based Personalized Psychosocial sensory spiritual and Environmental Approaches
and Creative Engagement (SPPEICE) for Mrs. B.**

Brief Personal History: Her daughter reports that Mrs. B loved sewing and crafting. She was involved in the church as a Nazarene and took her religion very serious. She enjoys Bible reading. Beaches were one of her favorite places to visit. Daughter reports she can still read.

1. Addressing spiritual needs
 - a. Mrs. B may find a large print simple devotional beneficial (www.lifeway.com an online Christian bookstore [there are also stores in Boise] may be a good place to find a large print devotional).
 - b. A subscription to a conservative Christian magazine may also be worthwhile as a way to meet Mrs. B's spiritual needs. Looking at the pictures, advertisements and perusing the articles may remind her of her days in the Nazarene Church. Magazines such as "Today's Christian Living" or "Christianity Today" may be good options.
 - c. Environmental enrichment initiatives
 - d. Consider putting a couple of large beach pictures that have scriptures on them to be place on the walls. Mrs. B spends considerable time looking around her room and seeing those might add warmth and encouragement.
 - e. Please consider removing the red bag hanging in the room since, sometimes it causes her distress.
 - f. Mrs. B may enjoy listening to music, reading her devotional or enjoying her fabric squares in the nicely lit front living area of the Orchards. People come and go and it is a bright cheery room. This might help her disposition and reduce weepiness if she has a warm drink and something to do in front of the large windows.

2. Tapping into the Magic of Music
 - a. Christian music may be particularly beneficial because of Mrs. B's church background. Suggest soft inspirational worship music and instrumental worship music. A CD player could be added to her room since she spends quite a bit of time in her room. I would also suggest some soothing beach music. If the resident enjoyed other music (oldies, jazz, etc.) an additional CD may be added.

3. Relationship Building Approaches (Social enrichment initiatives)
 - a. Regular interactions with 1-2 other resident ladies Mrs. B could chat with if they have similar interests (magazines or fabric squares) may provide socialization and comradery. Mrs. B was quick to enjoy conversation as the recreational therapist was there and seemed to enjoy conversing with her. Since Mrs. B spends a lot of time in her room, interacting with (or even being around) other pleasant ladies in a common area may be very beneficial.

4. Individualized Pleasant Activities

- a. Mrs. B loved crafts and sewing and often talks to herself about knitting. A small bin of fabric squares would bring her joy. 5-6 pieces of 5-6 different kinds of fabric cut into 4" squares may allow her to sort them, arrange them in patterns or just look at them. Suggest brightly colored prints and different textures.
- b. A lap mechanical pet may bring great comfort since Mrs. B spends much time in her room. This animal could sit on her bed or lap. Suggest the www.joyforall.com Hasbro mechanical pets because they are so life-like that most residents feel they are real. They take 4 C Batteries that only need to be replaced every 4-6 weeks depending on the extent of use. Depending on the resident's preference Hasbro offers dogs or cats.
- c. Touch: Hand massages with lavender lotion for 5 minutes four times a day and as needed. Especially if resident Mrs. B is having anxiety due to delusions or hallucinations, it can help calm her mind and body.
- d. Physical Activity: Suggest 5-10 minutes of physical activity where daughter or a caregiver plays bean bag toss or ring toss game with Mrs. B. Such bags and rings are relatively inexpensive and may be found on www.orientaltradingcompany.com or at a local toy store. Mrs. B has mentioned that one time she played a game of bean bags and liked it. For this activity the resident could have a set in her room and when her daughter visits they could play and staff can also play before or after any care-giving tasks.

Strengths-based Personalized Psychosocial sensory spiritual and Environmental Approaches and Creative Engagement (SPPEICE) for Grace.

The following is a list of ideas on how to better manage interactions with Grace. When she is “acting up” she can be difficult to work with, but here are some ways to avoid these episodes or calm her down during them. The information comes from people who have worked closely with her during her time on our unit, such as nursing staff and family.

1. **Grace loves praise.** When you need Grace to do something, or even if you would like her to calm down, she responds well if you focus on positive things she is doing. For example, if you would like her to walk a certain distance, tell her she’s doing a great job and she will walk twice as far as your initial goal.
2. **1-on-1 communication.** When Grace is “acting up,” the environment around her is key to getting her to calm down. If possible, make sure she is in a room with just her and one other person. She will respond much better if she feels that one person is talking to her at her level (and speaking loudly) than if she has 3 nurses surrounding her to calm her down.
3. **Grace loves animals.** Cats especially – at the nursing home we have heard that there are several cats and that when they are around she is much less likely to act out.
4. **She loves Bingo.** This is Grace’s favorite activity and she has played it every day for years up until recently, when she has had trouble with her cataract on her ‘good’ eye. If there is a way to have someone play with her as her partner and help her with the visual aspect of the game, this could be a great way to keep her calm or distract her during fits.
5. **Play music.** Having music playing is a good way to relax her. She enjoys all genres.
6. **Avoid CNN.** Try to avoid upsetting or serious television programs. These tend to get her worked up and anxious and appear to contribute to her paranoia.
7. **Get her walking.** She often complains that she is in her chair too long or in her bed for too long, but needs encouragement to get up and get moving. She also currently has a pressure ulcer on her coccyx and the pain could increase her agitation.
8. **During an episode, give her time alone.** When Grace acts out, sometimes it is best to let her spend time alone in her room. She needs an environment with low simulation to calm herself down.

Thank you for reading this and hopefully it helps Grace enjoy more of her time and makes her caretaker’s job easier.

Credit for this goes to an amazing medical student Matthew Colburn, MSIII at Saint Louis University many moons ago.

Sexually “Inappropriate” Behaviors in Persons with Dementia Psychosocial Environmental Approaches

Words matter: Let’s call them socially inappropriate behaviors. Masturbation and other forms of self-pleasure per se are not sexually inappropriate behavior as long as they are done in private.

Behaviors that are most problematic: Masturbation / self-pleasure in public places, touching others (typically caregivers) in private parts without their consent.

Assessment: PCP assesses the person with dementia for medications (e.g., drugs that increase dopamine [drugs used for Parkinson’s disease]), medical-psychiatric conditions (e.g., mania, psychosis) that may cause / contribute to hypersexuality and impulsive sexually “inappropriate” behaviors.

Key Bio-Psychosocial Environmental Approaches:

- Biological approaches: Many medications (e.g., ropinirole, pramipexole, levodopa) can contribute to sexual disinhibition. Please seek guidance of your PCP, pharmacist, psychiatrist, geriatric psychiatrist, geriatrician, or other experts to assess for medication induced sexually disinhibited behaviors.
- Try to understand the behavior as an unmet intimacy need and address the need directly.
- Limit the changes in the person’s life. These can make them confused and keyed up and lead to new or different sexual behavior.
- Provide physical touch. Everyone has a need for loving touch and physical contact. This need is generally unmet in individuals with dementia, especially in residents living in nursing homes. Find a way to touch them as part of your everyday routine. Hold their hand or give them a hug or back rub.
- Spend time with them. Keep them entertained: Look at photo albums, play board games, or go for a walk. These activities can prevent boredom that can lead to sexual behaviors.
- Avoid things that trigger the behavior. If it happens regularly, pay attention to what happens right before and try to avoid it.
- Allow certain behaviors in private. Masturbation and other forms of self-pleasure may be one of the few ways someone with dementia can feel pleasure or relieve sexual desires. If they do it in private and don’t hurt themselves, it’s often best to support it.
- Educate the family / staff:
 - That sexual needs, need for physical touch and sexual pleasure is normal, even in the old-old and in presence of advanced dementia. The sex drive is seen in many older adults for as long as they live.
 - Dementia often impairs frontal lobe function – the seat for socially appropriate behaviors (disinhibition) – and so the normal expression of sexual needs gets manifested in socially inappropriate ways. There is no reason for the caregiver (family / professional) to take offense or take it personally.

- Dementia often causes the person to get “stuck” in one area and it is hard for them to get out of on their own.
- It is important to stay calm, be patient and respectful and avoid using words or tone of voice that would make the person feel ashamed. The person is just looking for human connection, love, affection, freedom from boredom and or looking for excitement and fun.
- Watch body position and avoid reaching over the resident.
- Create a safe distance between you and the person with dementia (or between the person with dementia and another resident in nursing home) so that the person cannot “grab” private parts.
- Guide the person to a private area so that they can engage in self-pleasure.
- Use distraction – redirection techniques if the resident does not want to self-pleasure in private. Change the subject, turn on the television or music. Goal is to engage the person in fun and meaningful activities.
- Remove triggers.
- It may be necessary in some situations to say respectfully but firmly (slightly raised voice), “stop” or “no” to the person with dementia if they are touching you inappropriately. Then back away and re-approach after some time. It is important for all staff to be consistent in indicating that this behavior is not appropriate. If even a few staff condone such behavior, laugh and tease back, the behavior may become harder to address.
- Understand that the behaviors are not the fault of the person with dementia but also, the caregivers (family, professional) have a right to and obligation to protect themselves and other residents from inappropriate verbal and physical behaviors (which may even be traumatizing).
- Caregivers (family, professional) should not be arguing, scolding, reasoning, punishing, or shaming the person with dementia with these behaviors.
- Tracking (for nursing home residents) – behavior log (number of episodes per 8 hours): verbal towards staff, physical towards staff, verbal towards other residents, physical towards other residents
- Goals (for nursing home residents) – examples: the person with dementia will engage in at least one socially appropriate behavior to meet their sexual needs (e.g., self-pleasure in private, physical touch – hugs as often as possible); the person with dementia will have less socially inappropriate behaviors (e.g., less than one episode per 8 hours).
- Interventions (examples) for nursing home population:
 - Monitor the resident’s problematic behaviors using the behavior log (accurate logging of behaviors is an absolute essential – interventions generally help modestly, and successful interventions need not be stopped even if benefits are modest as long as there are no / minimal negative effects)
 - Assessment (as mentioned above)
 - Provide resident privacy for self-pleasure (sign outside the door stating “do not disturb”; knocking on the door twice, calling the resident’s name and asking for permission to enter)

- Promote holding hands, hugging, back rub and kissing (on the cheek or forehead) as safer and appropriate ways to meet some of the person’s intimacy and affection needs.
- Educate and train staff (especially new staff and staff new to dementia care) of appropriate person-centered communication techniques
- Distract resident with fun and meaningful activities
- Avoid triggers (e.g., boredom, loneliness)
- Staff to wear professional attires such as scrubs

Opinion and Guidance from other Experts:

- (1) Dr. Jim Wright, MD, PhD, CMD, medical director at Westminster Canterbury Richmond in Virginia has talked about “the empowerment of impermanence” in his presentation on “Intimacy and dementia in the long-term care setting” at the PALTC22 in Baltimore, MD (annual AMDA conference). He said, “to identify the personhood of someone is to say ‘I give you permission to change at every stage of life.’ Being whole person means being allowed to express preferences today that are different from those in the past....letting them make choices inconsistent with their previous choices and values (or even their advance directives), and allowing their sexual preference to change.” He shared the story of Justice Sandra Day O’Connor, whose husband had dementia, was in a LTC home, and had formed a romantic relationship with another woman. Justice O’Connor approved of the relationship because she wanted her husband to be happy, even as his dementia advanced.
- (2) Dr. Peter Jaggard, MD, CMD, medical director at Presbyterian Homes in Evanston, IL also spoke along with Dr. Wright. He recommended that nursing assessments for ISB (inappropriate sexual behaviors) should be conducted to assess for triggers, and strategies for redirection and maintaining the dignity of the person with dementia should become part of the care plan.

Resource:

Sex and Sexuality. Page 90-95. Chapter 3. Major Neurocognitive disorders. Book: *Psychiatric consultation in long-term care: A guide for healthcare professionals*. 2nd Edition. Abhilash Desai and George Grossberg. Cambridge University Press. 2017.

<https://www.uclahealth.org/dementia/sexually-inappropriate-behaviors>

Ten Best Practices: Reducing Use of Antipsychotic Medications in individuals with Dementia

Inappropriate use of antipsychotics to manage behavioral disturbances in individuals with dementia is prevalent. Antipsychotic use is associated with serious risks such as strokes, death, falls and fractures, and accelerated cognitive decline. Antipsychotics also may severely impair daytime functioning and quality of life by causing sedation, tiredness, unsteady gait and swallowing problems.

Best Practices:

1. Spend time to get facts and diagnoses correct. Use the DICE/STAR model
 - a. 78-year-old Japanese widowed male with COPD, DM, insomnia, “anxiety attacks and paranoia” at night. Etiology: hypoxia, hypoglycemia, beta-agonist inhalers, wants to reconcile with his estranged son
 - b. 70-year-old with diagnosis of “Parkinson’s disease (PD)”, Dementia, “Schizophrenia” on Carbidopa-levodopa and pramipexole, olanzapine and sertraline. PD psychosis misdiagnosed as schizophrenia or drug-induced parkinsonism misdiagnosed as PD.
 - c. Alcohol, marijuana, delirium and polypharmacy induced psychosis common
2. Geriatric Scalpel (rational deprescribing) and Medical Deintensification (includes DNH)
 - a. 80-years old Caucasian widowed female in advanced stages of dementia, erratic eating, severe agitation, visual hallucinations. Rx: reduce and discontinue insulin, discontinue donepezil and memantine, discontinue metformin, reduce anticholinergic burden of meds, palliative care
3. STEPS (Support system [family, staff]) Training Empowerment Praise and Support in relationship-building communication, environmental initiatives, creative engagement and other aspects of SPPEICE, and Snoezelen.
4. SPPEICE – strengths-based personalized psychosocial environmental initiatives and creative engagement) – includes comprehensive exercise program
5. ATMAN approach to managing pain effectively without opioids and tramadol
6. Judicious short-term non-antipsychotic psychotropic medication trial if symptoms distressing and persistent (e.g., chamomile, lavender, citalopram, escitalopram)
7. Collaborative psychiatric care using telemedicine (collaborate with PCP and pharmacist) to problem solve and make accurate assessment of underlying causes of severe agitation
8. Occupational therapist consults routinely
9. Recreational therapist and or music therapist and or art therapist consultation
10. Fulltime advanced practice nurse or physician assistant supervised by a geriatric psychiatrist rounding frequently

Alternatives to Antipsychotics for Management of Agitation in Individuals with Dementia

Before prescribing medications, please ensure the following two steps:

1. A thorough assessment-work up and treatment of reversible factors for agitation. Examples of these factors: medication adverse effects, pain, infection, dehydration, constipation, nutritional deficiencies, caregiver depression.
2. Psychosocial spiritual interventions. Examples: family/staff education on DICE* approach, caregiver respite, recreational therapist guided strengths-based personalized activity schedule involving meaningful and or fun activities throughout the day, exercise therapy / walking, music, lavender (or alternative lotion) lotion three times daily and as needed, pets, adult day program, community care program (SW Area Agency on Aging).

Medication	Clinical tips
Chamomile extract 500 mg one or two or three times daily	May help with anxiety, safer than other prescription medications
Lavender extract 80mg once or twice daily	May help anxiety, safer than other prescription medications
Cholinesterase inhibitors and memantine	Small beneficial effect for visual hallucinations and apathy in a small subset of populations (e.g., Lewy Body Dementia)
Memantine	Small reduced risk of emergent agitation (future AAD) in individuals taking memantine
Citalopram 10mg daily, may increase to 20mg after a week	May help with agitation, anxiety, irritability, physical aggression and even psychotic symptoms; takes 4-8 weeks, even longer sometimes to work; carries all the risks and benefits of SSRIs
Escitalopram 5mg daily, may increase to 10mg after a week	Has less QTc prolongation than citalopram, otherwise benefits and risks similar to citalopram
Sertraline 25mg daily, may increase to 50mg after a week	Preferred over citalopram and escitalopram if there are concerns about QTc prolongation, otherwise benefits and risks similar to citalopram and escitalopram
Suvorexant 5mg, may increase to 10mg	Approved by the FDA for insomnia Rx in AD
Mirtazapine 7.5mg at bedtime, may increase to 15mg	May be considered for treatment of insomnia due to major depression causing agitation
Trazodone 25mg at bedtime for insomnia	Risk of falls, orthostasis, tiredness in daytime
Melatonin 0.5-3mg at bedtime for insomnia	May also help REM sleep behavior disorder
Prazosin 1mg at bedtime, titrated up slowly to maximum dose of 6mg	Used if all other medications have failed; risk of falls, orthostatic hypotension

Carbamazepine 100mg at bedtime, titrated up slowly to 300-600mg daily or least effective dose	Used if all other medications have failed and agitation and aggression is severe; risk of falls, low sodium, drug-drug interactions
Dextromethorphan plus Quinidine	Approved by the FDA for pseudobulbar affect (PBA). PBA is typically seen in patients with ALS (amyotrophic lateral sclerosis – Lou Gehrig’s disease), not in Alzheimer’s dementia.
Pimavanserin	Approved by the FDA for treatment of Parkinson’s disease psychosis; no high-quality peer reviewed publications in Alzheimer’s dementia.
Cannabidiol (CBD)	Often used for treatment of pain, anxiety and insomnia but there are no high-quality peer reviewed publications to support this use in any population including individuals with dementia.
Tetrahydrocannabinol (THC, medical marijuana / cannabis)	Many states allow use of THC for many conditions including Alzheimer’s dementia but there are no high-quality peer reviewed publications of large, randomized controlled trials to support this use in individuals with dementia.

*DICE (Describe Investigate Create Evaluate) – involves training family / staff in being a detective, seeing agitation as expression of unmet need, addressing the need and evaluating response to intervention: <https://diceapproach.com>

Resources and References:

- *Psychiatric Consultation in Long-Term Care: A guide for healthcare professionals*. 2nd Edition. Cambridge University Press 2017. Abhilash Desai and George Grossberg. Chapter 13: Psychosocial spiritual wellness care plan for persons with dementia.
- Chen A et al. Harvard South Shore Algorithm for management of behavioral and psychological symptoms of dementia. *Psychiatry Res* 2021

Citalopram for Treatment of Agitation in persons with Dementia

Antipsychotics are often used for management of agitation in persons with dementia. Antipsychotics carry serious risks and have very modest benefits and should be reserved for situations when there is severe danger to self or others due to agitation and nonpharmacological interventions have not been effective and there are no reversible medical conditions that are causing the agitation.

In my opinion, citalopram can and should be used before antipsychotics in majority of the situations where antipsychotics are being given to treat agitation or psychosis in patients with dementia. Citalopram is eminently safer than antipsychotics, even at 30mg dose (the FDA guidelines suggest avoiding more than 20mg in older adults due to risk of prolonged QTc interval).

The following are the three key research studies that support my recommendation.

1. CitAD study: A 9-week randomized placebo-controlled study (published in JAMA, Feb 19, 2014) found citalopram (30mg) did significantly better than placebo in reducing agitation and caregiver distress in patients with Alzheimer's dementia.
2. Citalopram vs risperidone: A 12-week double blind controlled study did not find any statistical difference between citalopram and risperidone for the treatment of agitation or psychotic symptoms in patients with dementia. Agitation and psychotic symptoms decreased in both groups (published in American Journal of Geriatric Psychiatry 2007).
3. Citalopram vs perphenazine (an older antipsychotic) vs placebo: This was a 17-day double-blind placebo-controlled study in hospitalized patients. Citalopram did better than placebo in reducing agitation in dementia patients. Perphenazine also did better than placebo but citalopram did better than perphenazine (published in American Journal of Psychiatry 2002).

In all patients with dementia where antipsychotics are being considered to treat severe persistent agitation, I recommend we use citalopram first. The benefits do take time (compared to antipsychotics) but risks are way less. Antipsychotics carry risk of stroke, premature death, aspiration pneumonia, increased risk of falls and injury, increased risk of hospitalization, antipsychotic-induced parkinsonism, sedation, dysphagia and other serious risks.

Check EKG whenever feasible to look for prolonged QTc interval. In majority of cases, you will be able to safely start citalopram.

Start at 10mg daily for Dementia with behavioral disturbances, increase it after a week to 20mg daily and monitor for response to treatment and adverse effects. In some cases, I have increased it further to 30mg and found benefits without significant adverse effects and I have felt that benefits outweigh risks in all cases where the response has been significant.

Note: Citalopram does increase QTc but this increase has not been linked to cardiac outcomes. FDA needs to revisit this safety advisory (McCarrell et al. Mental Health Clinician 2019; Texas Tech University School of Pharmacy).

Dementia with Agitation Pharmacological Rx

Chamomile extract up to 1500 mg daily in 1-3 divided doses (my first line, research support for anxiety disorder)

Lavender extract 80mg once or twice daily (my first line, research support for anxiety disorder)

Citalopram: Lancet Commission 2017 (my first line amongst traditional prescription drugs)

Risperidone approved in five countries (Europe [2008], UK, Canada, New Zealand, Australia) but not US

Risperidone first line amongst antipsychotics. European Academy of Neurology 2020

Risperidone, aripiprazole, haloperidol: European Academy of Neurology guidelines 2020

Harvard Shore Algorithm

Chen A et al. Harvard South Shore Algorithm for management of behavioral and psychological symptoms of dementia. Psychiatry Res 2021 (I don't agree with many recommendations in this algorithm)

Emergent setting:

first choice IM olanzapine

second choice IM haloperidol

third choice IM lorazepam

Urgent setting:

first choice ODT risperidone or aripiprazole

second choice prazosin

third choice ECT

Non-urgent

trazodone

donepezil and memantine

escitalopram and sertraline

second generation antipsychotic

prazosin

carbamazepine



Brexpiprazole approved by FDA for treatment of AAD

Tampi et al. Drugs Context 2022. Prazosin if ChEI, memantine, antidepressants, atypical antipsychotics ineffective or not tolerated. rTMS

Prazosin alpha one adrenergic antagonist used for hypertension. Hypotension, dizziness and falls common. Ensure 2L or more daily fluid intake and monitor for orthostatic hypotension and falls. 1mg prazosin qhs. Increase by 1mg every 3-7 days. Bid, tid or qhs (smaller dose in day time). 6mg max daily dose

Note: in adults, for PTSD related nightmares, up to 16mg has been studied in RCTs.

Benzodiazepines: avoid except for prn short term use for severe anxiety. May cause disinhibitions and paradoxical agitation

Valproate: no better than placebo, more adverse effects

Haloperidol: avoid except for delirium. American Psychiatric Association guidelines 2017

Cannabis, THC. Not supported by research. Risk of delirium, lethargy, falls

Canadian experts published a sequential drug Rx algorithm that mentions gabapentin and as needed trazodone they use in inpatient geriatric psychiatry patients with dementia and severe aggression. Davies et al. Sequential drug treatment algorithm. Journal of Psychopharmacology 2028.

first line Risperidone (0.5mg start, may go to 1mg. Max 1.5. Half of this in frail patients)

second line Aripiprazole or Quetiapine (aripiprazole 2.5mg initial dose, target of 10mg, may reach 12.5) (Quetiapine 12.5mg, target 100, max 200, half if frailty)

third line carbamazepine (100mg daily, 200 after 3 days, 300 after 4 more days)

fourth line citalopram (10mg, after a week 20)

fifth line gabapentin (200mg bedtime, up to 900mg, max 1800)

sixth line prazosin (1-6 mg, start at bedtime)

seventh combination or ECT

trazodone prn 25 mg every hour max 150. May reach 300 daily

lorazepam prn 0.5, max 2mg daily

Trazodone for BPSD: Tampi and Jeste. American Journal of Psychiatry 2022 Review of pharmacological treatment of BPSD doesn't mention trazodone. Trazodone is high-risk medication due to sedation, falls, orthostatic hypotension. Safer than antipsychotics but not as effective and antipsychotics have only modest benefits

Namaste

Staging of Alzheimer's Disease Dementia

Name of the patient:

MOCA score (date) 0-30	FAQ score (date) 0-30	Katz index (date) 0-6	FAST* Stage (clinical judgment)

MOCA: Montreal Cognitive Assessment measures cognitive function (high score = high function).

SLUMS: Saint Louis University Mental Status (recommended if one is not certified in MOCA administration, certification [online training offered at their website] for MOCA costs \$125). SLUMS is not as well researched as MOCA but the score of MOCA similar to SLUMS.

FAQ: Functional activities questionnaire measures instrumental activities of daily living (IADL) (high score = low functioning)

Katz index: Measures basic activities of daily living (BADL) (high score = high functioning)

4 stages (brief description):

Mild cognitive impairment: Decreased performance in demanding employment and social settings, decreased job function evident to co-workers, difficulty traveling to new locations, decreased organizational capacity. Can pay bills, manage dinner for guests, manage finances, travel to familiar places. MOCA generally 23-25 but not normal (26 and above). FAQ low. Katz index: 6

Mild dementia: Difficulty paying bills, managing dinner for guests, managing finances, traveling to familiar places. Can recall their own address and telephone number, know where they are and what day it is. MOCA generally between 18-22. FAQ generally six or higher. Katz index 6.

Moderate dementia: unable to recall their address and telephone number, get confused about where they are and what day it is, can dress themselves but may wear the same clothes unless supervised, requires assistance in wearing proper clothing for the weather or event. Can remember significant details about themselves and their family. MOCA generally between 10-18. FAQ 12 or higher. Katz index 4-5

Severe dementia: can remember their own name but difficulty with names of close family members, can recognize familiar faces even if they have trouble naming the person or identifying their relationship. Need help dressing properly, have major changes in sleep patterns (e.g., day night reversal), trouble controlling bladder and or bowels. MOCA generally below 10, FAQ close to 30; Katz index 0-3

*FAST dementia staging: Functional Assessment Staging Test

AAD and stages of Dementia: AAD increases in prevalence with advancing of dementia.

Palliative care and hospice may be appropriate for agitation in patients with severe dementia.

Age-Friendly Hospital System (AFHS)

4Ms of AFHS: 4Ms framework can be used to provide comprehensive and person-centered delirium care to older adults

- What Matters (aligning intensity of AAD management with patient goals, engaging family and friends in AAD care)
- Medications (especially avoiding deliriogenic medications, rational deprescribing)
- Mentation (routine depression, delirium and trauma screening across all settings)
- Mobility (avoid out of bed with assist, minimize catheters and restraints)

Institute for Healthcare Improvement: <https://www.ihl.org/initiatives/age-friendly-health-systems/resources-and-news>

Namaste

Tomorrow will bring good news: Dementia Friendly Hospitals

A stab went through her
so sharp that my patient
sobbed and clutched
at her belly.
“Just sleep,
tomorrow will bring good news,”
she kept repeating
like a mantra,
coordinating the words
with her breath.
She slept fitfully.
When she woke,
pale light of morning
was slanting
through her window.
She felt
as sick and achy
as if she had
not slept at all.
Her tummy
was still tied
in a knot.
“Just breathe slowly,
today will bring good news,”
She kept repeating
like a mantra.



This is my patient’s daughter. My 69-year-old patient with mild dementia was in the ICU for cardiac arrhythmia. She recovered beautifully to the surprise of all of us and was discharged home. I was teaching the daughter mantra meditation and mindful breathing.

Many individuals with dementia come out of the ICU in more advanced stage due to brain injury caused by underlying medical issues that required ICU plus trauma of being in a hospital and ICU – especially if the hospital doesn’t have HELP program and dementia friendly hospital practices. They often need to be discharged to a nursing home rather than home and may never return home 😞

HELP – Hospital Elder Life Program: For Delirium prevention through the American Geriatrics Society

Top 5 dementia friendly hospital practices:

- routine consult with dementia team – dementia physician / nurse practitioner expert (e.g., consultant psychiatrist) plus at least one of the following: chaplain, nurse, social worker, neuropsychologist, occupational therapist (addressing ageism and dementia-ism being a top priority)
- one to one with a trained staff
- supportive family educated and involved as much as the family can
- individualized strengths based routine bio-psychosocial spiritual culturally appropriate care plan that includes early mobilization with intensive physical therapy, continuous daily meaningful activities schedule and night time sleep enhancement
- close collaboration with Hospitalist team and HELP program team to prevent delirium, falls, pain, constipation, dehydration, de-conditioning and frailty

AAD in hospitals / Dementia Friendly Hospital: 10 Key Interventions to Reduce Stress of Hospitalization for Patients with Dementia

- Ambulate them frequently (preferably a few minutes every hour)
- Take positive risks and take persons with dementia outdoors, especially to spend time in natural settings. Get them out of the hospital / facility (e.g., to a garden or a labyrinth).
- Keep soothing instrumental background music (preferably personalized) in the room
- Use robotic pets when appropriate (e.g., for patients with advanced dementia who may not be able to recognize that these are robotic pets)
- Have (warm) fidget blankets available to calm them if they are restless
- Use pictures that have been identified as being of interest to the patient to help distract them during personal care or when they are agitated.
- Sing to the patients during personal care to ease their stress
- Encourage family members, friends, volunteers and chaplains to visit them daily (and preferably stagger the visits so that, ideally, only one person is visiting at a time) in person or virtually (e.g., skype)
- Engage them in continuous pleasant activities (ideally, create an individualized strengths-based daily pleasant activity program)
- Frequently (at least three times a day) provide soothing hand, neck and back massages with soothing lotions (e.g., lavender lotion).

Delirium Care Score*

Category	Criteria	Points
Physical activity	Intensive physical therapy	4
	Regular physical therapy	2
	Walking 1000 steps daily	1
	Less than 1000 steps daily	0
Occupational therapy (OT)	Intensive OT	4
	Regular OT	2
	No OT	0
Sleep	7 or more hours at night	3
	5-7 hours at night	1
	Less than 5 hours at night	0
Intravenous lines	Removed	2
	Still in	0
Foley	Removed	2
	Still in	0
Social interactions – family, volunteers, chaplain, other staff	3 or more hours a day	2
	1-3 hours	1
	Less than one hour	0
Sunlight / bright light	2 or more hours a day	2
	1-2 hours a day	1
	Less than one hour a day	0
Meaningful strengths-based activity schedule	2 or more hours a day	2
	1-2 hours a day	1
	Less than one hour a day	0

*Created by the author – evidence-informed. It has not been formally researched.

Max score 21; Shoot for 21 for every patient. The better the score, the more likely one could prevent delirium. Hospitalized patients with dementia are at very high risk of delirium. Delirium increases risk of death, length of hospital stay, decline in functioning requiring discharge to a nursing home and low likelihood of returning back home.

Inspired by McCance Brain Care Score, McCance Center for Brain Health, MGH

<https://www.massgeneral.org/neurology/mccance-center>

References and Resources

1. Jordano et al. Effect of physical and occupational therapy on delirium duration in older emergency department patients who are hospitalized. JACEP 2023.
2. Lange et al. Non-Pharmacological Nursing Interventions to Prevent Delirium in ICU Patients—An Umbrella Review with Implications for Evidence-Based Practice. Journal of Personalized Medicine 2022.

Personalized Multicomponent Nondrug Rx for Delirium Prevention

- Collaborative de-escalation
- Early mobilization with intensive PT / OT
- Ensure adequate hydration and nutrition
- Remove restraints, in-dwelling catheters, IV as soon as is feasible
- Hearing and vision aids
- Calm, low stimulation environment
- Lavender or other soothing lotion to arms four times a day and as needed
- Soothing personalized music in the background
- Assisted walking three times a day
- Bright light and or sunlight 20 minutes a day
- Family engaging patient in meaningful activities
- Gentle care*



*American College of Surgeons Best Practices for Geriatric Trauma 2023

Resources

To assess for medical conditions causing agitation including medication-induced agitation:

Saint Alphonsus Memory Center

Boise Nampa Eagle

Telehealth appointment available

No referral needed. Self-referral accepted.

208-302-5400 Boise

208-302-6000 Nampa Eagle

Free eBook titled *Improving Brain Health* available at the website. Links to podcasts on dementia topics available at the website

<https://www.saintalphonsus.org/specialty/memory-center/>

Primary care provider of the person with dementia can also do this assessment.

Individual counseling (for family caregiver) and guidance regarding behavior management strategies

Laura LaForte LCSW

206-953-3708

<https://www.lafortetherapy.com/>

Connection Club Adult Daycare

Dick Eardley Boise senior center

208-608-7578

Dementia and Creativity Sessions

Erika Shaver-Nelson, MA

208-724-4754

Family education on Behavior Management Strategies

Family Caregiver Alliance Website: Behavior Management Strategies

High quality videos and quick reads: <https://www.caregiver.org/caregiver-resources/caring-for-another/behavior-management-strategies/?via=caregiver-resources,caring-for-another>

Telephone support and guidance of community resources

- 988 suicide and crisis line
- 211 Idaho care line
- 800-898-9626 Alzheimer Association 24/7 helpline

Case Management Respite Education regarding Dementia

Community Care Program

Regarding dementia

208-898-9626

Ccp@a3ssa.com
[Www.a3ssa.com](http://www.a3ssa.com)

Family caregiver wellness and resilience education and training
Powerful tools for Caregivers workshop
<https://www.agingstrong.org/powerful-tools-for-caregivers>
208-947-4283

Family support and respite
Family Caregiver Navigator
<https://caregivernavigator.org/>
208-426-5899

Family assistance for community resources (e.g., transportation)
Saint Alphonsus Community Health Worker program
208-367-4482

Websites

The DICE approach online training program. <https://diceapproach.com/>

International cognitive therapy stimulation (CST) center
Saint Louis University's Geriatric Education Program offers CST
<https://www.slu.edu/medicine/internal-medicine/geriatric-medicine/aging-successfully/cognitive-stimulation-therapy.php>

Music and Memory Program. <https://musicandmemory.org/>

Dementia Friends, Idaho. Idaho Department of Health and Welfare.
<https://healthandwelfare.idaho.gov/dementia-friends>

Community of Dementia Education. <http://community.abcdementia.org/>

Book for patients and their families

1. Mayo Clinic on Alzheimer's Disease and Other Dementias. 2020. Jonathan Graff-Radford MD, Angela Lunde MA.
2. Mayo Clinic: Day to Day Living with Dementia. A Mayo Clinic Guide for offering care and support. Angela M. Lunde, M.A.
3. Agitation associated with Dementia management. eBook by Abhilash Desai MD. Available upon email request.



Other resources

1. Movement for Memory program at Tomlinson South Meridian YMCA (group exercise program for individuals with MCI): (208)-344-5502. Ext 524.
2. Blue Mood Senior Counseling – Teletherapy: <https://bluemoonseniorcounseling.com>
3. Grannie on the Move: (208)-288-2220
4. Area Agency on Aging: (208) 898-7060
5. AGS Beers Criteria 2023. American Geriatrics Society. List of potentially inappropriate medications in the elderly. Rational deprescribing of medications that are potentially inappropriate in the elderly is a key intervention in prevention and treatment of AAD. <https://agsjournals.onlinelibrary.wiley.com/doi/10.1111/jgs.18372>
6. Anticholinergic burden calculator. ACB calculator. Provides anticholinergic burden for many medications using 1-3 points, 3 being most anticholinergic. Reducing anticholinergic load of medications is a key intervention in prevention and treatment of AAD. <https://www.acbcalc.com/>
7. DAWN method dementia care. <https://thedawnmethod.com/wp-content/uploads/2020/11/DAWN-Dementia-Care-Specialist-Handbook.pdf>

Resources for Dementia Training

Free

1. Health Resources and Service Administration HRSA Dementia modules (free):
<https://bhw.hrsa.gov/alzheimers-dementia-training>
2. Johns Hopkins. Living with Dementia: Impact on Individuals, Caregivers, Communities and Societies. <https://www.coursera.org/learn/dementia-care> 18 hours to complete.
3. Dementia Training Australia. Includes modules on behavior change, pain management, medication management. <https://dta.com.au>
4. REACH certified caregiver support coaches.
https://www.caregiver.va.gov/REACH_VA_Program.asp

Not Free: Certification available

1. Alzheimer's Association Dementia Training (not free). Provides a certificate.
<https://www.alz.org/professionals/professional-providers/dementia-care-training-certification>
2. Certified Dementia Practitioner. National Council on Certified Dementia Practitioner
<https://www.nccdp.org/cdp/>
3. National Certification Board for Alzheimer's Care
<https://ncbac.net>
4. American Health Care Association – AHCA
<https://educate.ahcancal.org/CARESprogram>
5. Dementia Care Specialists. Crisis Prevention Institute
<https://www.crisisprevention.com/Our-Programs/Dementia-Care-Specialists>

STAR-C VA Manual for Challenging Behavioral Management Strategies

Citation: Karlin, B. E., Teri, L., McGee, J. S., et al (2017c). STAR-VA Intervention for Managing Challenging Behaviors in VA Community Living Center Residents with Dementia: Manual for STAR-VA Behavioral Coordinators and Nurse Champions. Washington, DC: U.S. Department of Veterans Affairs

https://www.mentalhealth.va.gov/healthcare-providers/docs/STAR-VA_Manual.pdf

Dementia Bibliotherapy: Books recommended to improve lives of individuals with Alzheimer's and other dementias and their family members, friends and carepartners

Mayo Clinic on Alzheimer's Disease and Other Dementias. Jonathan Graff-Radford MD, Angela Lunde MA. 2020. Mayo Clinic Press. Excellent first book for individuals with mild memory problems who are worried that they may have dementia and family members of individuals with dementia. High-quality, relatively easy to understand information of complex topics as well as many practical tips and guidance to get early accurate diagnosis and live well.

Day-to-Day: Living with Dementia: A Mayo Clinic guide for offering care and support. Angela M. Lunde, M.A., offers essential caregiving guidance, including practical tips and resources, techniques for working through difficult emotions, and strategies for managing common dementia-related challenges.

Dementia Home Care. How to prepare before, during, and after. Tracy Cram Perkins. Excellent resource, filled with wise and practical guidance for caregivers to do everything they can to improve well-being of their loved one with dementia, including prevention and effective management of agitation and BPSD. Tracy Cram Perkins also conducts workshops in Oregon, Washington and Idaho. <https://tracycramperkins.com>

STAR-C VA Manual for Challenging Behavioral Management Strategies

Citation: Karlin, B. E., Teri, L., McGee, J. S., et al (2017c). STAR-VA Intervention for Managing Challenging Behaviors in VA Community Living Center Residents with Dementia: Manual for STAR-VA Behavioral Coordinators and Nurse Champions. Washington, DC: U.S. Department of Veterans Affairs

https://www.mentalhealth.va.gov/healthcare-providers/docs/STAR-VA_Manual.pdf

Navigating Dementia: A workbook for family caregivers. Free. Excellent resource for all caregivers, especially those living in Idaho.

<https://healthtools.dhw.idaho.gov/collections/brain-health-alzheimer-s-and-dementias>

When your aging parent needs help: A geriatrician's step-by-step guide to memory loss, resistance, safety worries, and more. Leslie Kernisan, MD, MPH and Paula Spencer Scott. 2021

Travelers to Unimaginable Lands. Dasha Kiper. One of the best books for family caregivers to find deeper understanding about why caregiving and doing the right thing is SO HARD.

Living with Memory Loss: A Basic Guide by University of Washington Memory and Brain Wellness Center. This essential resource is downloadable (for free) from their website under the Resources tab, either the full handbook, or separate chapters. Excellent for patients with mild to moderate dementia and their family members.

https://depts.washington.edu/mbwc/content/page-files/LWML-Handbook_reduced_2_27_17.pdf

Before I Forget: Love, Hope, and Acceptance In Our Fight Against Alzheimer's. B. Smith & Dan Gasby. Excellent resource to promote positive approach to living with dementia.

The Alzheimer's Solution: A breakthrough program to prevent and reverse the symptoms of cognitive decline at every age. Dean & Ayesha Sherzai, M.D. Codirectors of the Brain Health and Alzheimer's Prevention Program at Loma Linda University Medical Center. Useful for patients with mild dementia who wish to slow down cognitive decline.

The Spectrum of Hope: An optimistic and new approach to Alzheimer's Disease and other Dementias 2017, by Gayatri Devi MD, neurologist and the Director of the New York Memory and Healthy Aging Services. Many cases with remarkably positive outcomes are discussed. Excellent for patients with mild dementia and their family members to learn about ways to slow cognitive decline.

Seven Steps to Manage Your Memory by Andrew Budson and Maureen O'Connor. Oxford University Press, 2017. Excellent resource to differentiate normal memory loss from memory decline due to dementia and many cases with positive outcomes are shared. Excellent for patients with mild dementia

Aging Together: Dementia, Friendships and Flourishing Communities. By Susan McFadden and John T. McFadden. Johns Hopkins Press. 2011. Excellent book to improve emotional and spiritual wellbeing of patients in all stages of dementia and their loved ones and improve community understanding and support.

Dementia-Friendly Communities. Why we need them and how we can create them. Susan H. McFadden. Jessica Kingsley Publishers. 2020. Excellent book to understand what "dementia friendly" means and to improve community and understanding and support. Best first resource to begin to create dementia friendly communities in your community.

Creative Care. A revolutionary approach to dementia and elder care. Anne Basting. 2020. Excellent book to improve emotional and spiritual wellbeing of individuals with all stages of dementia through creative expression and engagement.

On Vanishing: Mortality, Dementia, and What It Means to Disappear. Lynn Casteel Harper. 2020. New York, NY: Catapult.

Dementia Reimagined: Building a Life of Joy and Dignity from Beginning to End. Tia Powell. 2019. New York, NY: Avery.

Dancing with Elephants: Mindfulness Training for Those Living with Dementia, Chronic Illness, or an Aging Brain (How to Die Smiling). Jarem Sawatsky. 2017. Toronto, ON: Red Canoe Press.

In Love: A Memoir of Love and Loss. Amy Bloom. A poignant book about a wife's journey in assisting her husband with dementia to receive Medical Aid in Dying / Euthanasia.

My Father's Brain: Life in the Shadow of Alzheimer's. Sandeep Jauhar. 2023. A beautifully written book about a son's journey in helping his father and family will well with dementia. The author was featured on NPR's *Fresh Air* by Terry Gross. Awesome interview (available on Podcast)

With the End in Mind: Dying, Death and Wisdom in the Age of Denial. Kathryn Mannix

Navigating Dementia: A workbook for dementia caregivers. Idaho Department of Health 2024.
<https://healthtools.dhw.idaho.gov/collections/brain-health-alzheimer-s-and-dementias>

Dementia Medical Poems. Abhilash Desai. These poems are not for the faint of heart. I am happy to send this by email upon request.

Major Neurocognitive Disorders (Chapter 3) and Psychosocial Spiritual Wellness Care Plan (Chapter 13). *Psychiatric consultation in long-term care. A guide for healthcare professionals*. Abhilash Desai and George Grossberg. Cambridge University Press. 2nd Edition. 2017. Excellent resource for healthcare professionals, especially those working in long-term care communities.

One Day Mindfulness Millionaire: Living Mindfully – A light-hearted primer for the uninitiated. Abhilash Desai MD and Faith Galliano Desai Ph.D. eBook available at <https://store.bookbaby.com>. Excellent resource (my unbiased view LOL) to begin to develop skills to live mindfully and develop a simple daily meditation practice. Mindful living and meditation can help both the person with dementia and their family / friends live with less stress and more joy.

Namaste

Arts on Prescription for Dementia Care: Resources

Book

Creative Care. A revolutionary approach to dementia and elder care. Anne Basting. 2020.
Excellent book to improve emotional and spiritual wellbeing of individuals with all stages of dementia through creative expression and engagement.

Websites

1. TimeSlips (<https://www.timeslips.org>) creative storytelling. Online training course available. At least one long-term care staff should be trained in *TimeSlips*
2. Center for Arts in Medicine. <https://arts.ufl.edu/sites/creating-healthy-communities/resources/arts-on-prescription-a-field-guide-for-us-communities/>
3. American Medical Association. How Improv is helping patients with Alzheimer's disease. <https://www.ama-assn.org/delivering-care/public-health/how-improv-helping-patients-alzheimers-disease>
4. Improv artists Karen Stobbe and Mondy Carter TedMed video. Using Improv to improve life with Alzheimer's. https://www.youtube.com/watch?v=GciWltvLo_s

Dr. Desai Books, book chapters and Podcasts

1. *Psychiatric Consultation in Long-term Care: A guide for healthcare professionals*. Abhilash Desai and George Grossberg. 2nd Edition. Cambridge University Press. 2017. It has info on STAR model to safely address AAD.
 - a. Chapter 3: Dementias / Neurocognitive disorders
 - b. Chapter 12: Psychiatric aspects of rational deprescribing
 - c. Chapter 13: Psychosocial spiritual wellness care plan
2. *One Day Mindfulness Millionaire – Living Mindfully: A lighthearted primer for the uninitiated*. Abhilash Desai MD and Faith Galliano Desai PhD.
<https://store.bookbaby.com/book/one-day-mindfulness-millionaire>
3. *Overcoming Anxiety, Depression and Anger*. Non-pharmacological interventions to manage stress, anxiety, depression and anger. eBook available upon email request.
4. *Mindfulness and Meditation*. eBook available upon email request.
5. *Fearless Strong Patient Kind – Short meditations to manage stress and become resilient*. eBook available upon email request.
6. *Chronic pain management without opioids in older adults*. eBook available upon email request.
7. *Delirium-related agitation in hospitalized older adults*. eBook available upon email request.
8. *Dementia Prevention*. eBook available upon email request.
9. Desai AK, Galliano Desai F, McFadden S, Grossberg GT. *Experience and perspective of the person with dementia*. Editors: Marie Bolts and James Galvin. In *Dementia Care: An Evidence Based Approach*. Springer Publishing, NY, NY. 2016; pp 151-156
10. GeriPal podcast. Alex Smith and Eric Widera. Transforming the culture of dementia care: Anne Basting, Ab Desai, Susan McFadden, and Judy Long. Dec 2, 2022. Must hear.
11. Saint Alphonsus Wellcast. Ageism: Combating common myths surrounding aging. 7/27/2023.
12. Saint Alphonsus Wellcast: Unlocking the mind: exploring modifiable risk factors for dementia. 6/15/2023.

Dementia Physician Experts in Idaho

Eastern Idaho

Scott Christensen MD, Geriatrician
Intermountain Medical Clinic
1951 Bench Road, Suite B Pocatello, ID 83201
Phone: (208) 238-1000
Dr. Christensen can do telemedicine visits

Northern Idaho

Susan Melchiore MD, Geriatrician
One Site for Seniors
296 W. Sunset Ave, #14-15
CDA, ID 83815
Phone: 208-967-4771
Dr. Melchiore can do telemedicine visits

Central Idaho

Jennifer Lewis MD, Geriatrician
211 Forest Street McCall Idaho.
Phone: 208-634-2225
Dr. Lewis can do telemedicine visits.

Southwest Idaho

Kara Kuntz MD, Geriatrician and team
Saint Alphonsus Memory Center,
Boise, Eagle, Nampa
Phone: 208-302-5400; 208-302-6000
Memory Center team can do telemedicine visits

Supporting Caregiver Wellbeing : Key to Prevention and Reduction of AAD

If caregivers are well, they are able to interact with the person with dementia in positive ways that prevent and reduce AAD. Healthcare professionals can provide education and skills training in the following areas to promote caregiver wellness.

1. **Mindfulness:** It is important for family and friend caregivers to approach their loved one with dementia in a mindful way. Mindfulness means that the caregiver is paying attention to the loved one non-judgmentally. Mindfulness is a journey and memory of past negative interactions with the person with dementia and worries about the future make it very difficult for the caregiver to be in the present with the loved one. Non-judgmental presence by the caregiver helps the person with dementia to feel secure and valued. Being present also allows the caregiver to become aware of numerous small positive interactions and experiences with the loved one that they can cherish. I encourage family members to engage in mindfulness training.
2. **Validation:** It is important for the caregivers to validate the experiences and feelings of the person with dementia. Authentic (sincere) validation helps the loved one recognize that they are being heard and understood and not ignored. Caregiver burnout is the most common reason for failures on the part of the caregivers to provide validation. I encourage caregivers to track their own level of burnout and take steps to prevent it and address it head on.
3. **Trust:** It is important for caregivers to trust the perspectives of the person with dementia. Persons with dementia have brilliant perspectives and all of us (not just family caregivers) need to recognize that and allow them to lead us as often as being led in their journey to live well with dementia. Negative cultural stereotypes (e.g., persons with dementia don't know what is going on so there is no reason to listen to them) is the key reason caregivers (both family and professional) fail to inquire their point of view or learn to listen to and see the creative ways the person with dementia is navigating challenges and seeking happiness.
4. **Embracing imperfection:** There are no road maps, only general guidelines that other caregivers and healthcare professionals can provide to the caregivers. Caregiving is complex, ever changing in its rules, and impossible to perfect. Caregivers need to be kind to themselves and not let their "numerous mistakes" and "frequent errors" get in the way of living and caring for self and loved one with kindness and forgiveness.
5. **Sense of humor:** It is not uncommon for the caregiver's sense of humor to be the first casualty of stress related to caring for their loved one with dementia. It is crucial for the caregiver to appreciate the tremendous value a healthy sense of humor has in living well with dementia. Healthy sense of humor is the strongest expression of spiritually defeating dementia.

The Healing Power of Mindful Care-Partnering

Are you (like us) a caregiver struggling with the responsibilities and stress of caregiving? Have you wondered how on earth do some caregivers find the role of caregiving a blessing? Are you amazed at how some caregivers tend to their responsibilities effortlessly and continue to be cheerful day in and day out? Yes, these remarkable individuals do exist, and, we have had the good fortune to have met them in our professional life (as a psychiatrist [AKD] treating patients from ages 5 and up, and child and adolescent psychologist [FDG]) as well as in our personal life. We have been looking for a path towards becoming better caregivers for some time now.

This long essay is aimed at helping caregivers (family [e.g., parents, siblings] and professional [e.g., staff in nursing homes]) of persons having dementia (PHD) improve their capacity for compassion, creativity during caregiving, effectiveness of their efforts, and at the same time improve caregiver's own sense of wellbeing. Caregivers work hard to improve quality of life of PHDs but often experience frustration, helplessness, hopelessness, stress, and burnout. We have discovered that an approach that blends mindfulness with the concept of care-partnering can not only improve our skills in improving wellness and positive experiences of PHDs but also prevent burnout and promote our emotional and spiritual growth. For many caregivers, mindful care-partnering comes naturally, without any knowledge or training. For the rest of us, focus and effort in developing skills of mindful care-partnering are necessary.

Mindfulness is bringing one's awareness to the present moment, with intention, to whatever one is experiencing (e.g., feelings, sensations, thoughts) with an attitude of kindness and curiosity. It is a skill and as such, can be developed much more easily than generally recognized. Mindfulness is an excellent way to become familiar with the workings on one's mind and minds of others (especially of PHD). Intimate familiarity with the workings of one's own mind and that of others opens up doors of healing and wellness that have otherwise remained obstinately closed.

Mindfulness is paying attention in a particular way – on purpose, in the present moment, and nonjudgmentally.

- Jon Kabat Zinn

Care-partnering includes all traditional aspects of caring for another person (e.g., helping them with daily activities) but also involves awareness of the PHD's capacity to partner and collaborate with caregivers and the unique gifts caregivers receive from PHDs as well as from the very act of caring. Care-partnering also goes a step further in recognizing that the PHD is the expert in how best to have her/his needs met and thus, **it is crucial to be led by the PHD** at least as often as leading the PHD towards safety, better ways of adapting to life's challenges and positive experiences.

Henceforth, all caregivers will be called care-partners.

Mindful Care-Partnering

It is easier to understand mindful care-partnering by understanding three common aspects of unmindful care-partnering. These are: autopilot, auto- reaction and premature cognitive commitments.

Autopilot

As you (the care-partner) embark on mindful care-partnering, you will quickly notice that your mind wanders to many different places/situations as you go through the task at hand (say for example, taking a walk with the PHD). It is typical for our minds to jump from paying attention to the task at hand to having imaginary conversations, plans, worries, replaying memories, and a host of other thoughts. One can say that our mind keeps wandering into the land of thoughts and thinking. You may finish the walk and may not be able to remember what areas of the park you walked and what conversation you have had with the PHD. This happens automatically because it is a natural tendency of our brain to go on autopilot. Autopilot requires much less energy and intentional activity takes up much more energy so given a choice, brain will always switch to autopilot to conserve energy (a strategy that improved survival of our hunter-gatherer ancestors). Mindful care-partnering involves gently bringing your wandering mind to the present moment, becoming aware that you are walking with the PHD, that you are holding their hand, and becoming aware of the green landscape around you. Mindfulness in such situations involves catching oneself having these thoughts, minimizing or withholding any negative judgment or criticism for being distracted and intentionally bringing our focus back to the present. You can be certain that your mind will wander again, and you can once again bring your mind gently to the present. Being present with the PHD in such a way will improve sense of value the PHD has for herself/himself and improve PHD's sense of connectedness with you. Improved sense of one's value and sense of connectedness are two most basic requirements for any significant and sustained healing and wellness to occur.

The faculty of voluntarily bringing back a wandering attention over and over again is the very root of judgment, character, and will. No one is compos sui if he have it not. An education which should improve this faculty would be the education par excellence.

– William James (*Principles of Psychology* 1950; p.424) Note: *Compos Sui* meanings *master of oneself*

Auto-reaction

As you become aware of your emotions during care-partnering, you will notice that you often react automatically from emotion first rather than pause, reflect and then respond. Once again, the brain under strong emotions (especially negative emotions such as fear or anger) will tend to respond immediately based on perceived threat. Brain's initially perception of threat involves a part of the brain called amygdala and amygdala is biased towards over-reacting (guided by the goal of increasing survival). By being mindful of our brain's (specifically amygdala's) tendency to over-react, you can develop skills to inhibit the immediate auto-reaction, pause and reflect taking in any additional information our senses are registering and

contrasting the event with any past experience with similar events we may have, attempting to see from the point of view of the PHD, and then responding. Your pre-frontal lobe plays a key role in mediating all these actions (inhibiting auto-reaction, pausing, reflecting, responding). Depending on the situation, all these actions may take only a few seconds or several minutes or even longer.

Premature Cognitive Commitments (PCC)

Our brains are programmed to come to quick conclusions based on minimal information (because such function provided survival advantage). Such conclusions are key examples of premature cognitive commitments (PCCs) (a term coined by Dr. Ellen Langer, psychologist in her book *Mindfulness*). Judgmental thinking is typically based on PCCs. This tendency of our brain is valuable in emergency situations but can be counter-productive and at times even destructive in day-to-day situations involving caring. As you become more aware of your thoughts and feelings during caring, you will be able to catch yourself in such acts of prematurely committing to an understanding of what is going on (especially challenging behaviors). For example, the PHD is having an anger outburst and you quickly decide that this is “manipulative, attention seeking behavior” or that the PHD is “just being mean”. Many PCCs involve harsh judgment about ourselves (e.g., “I am a terrible caregiver”) or catastrophic predictions (e.g., “this resident with dementia is going to tear down the place”). PCC will push you to react as if this conclusion was absolutely correct and there was no alternative explanation for the behavior or alternative future scenarios (especially positive ones). PCC will further increase intensity of negative emotions that triggered them in the first place. Auto-reaction and PCCs by care-partners often make the behavior of the PHD worse. Mindful care-partnering will slowly but surely help you become aware of how often our PCCs are incorrect. As you learn to pause, take in the context, get to know the narrative of the PHD (how the PHD got to this point), your understanding of challenging behaviors will become more nuanced, what needs to be done to address the challenging situation will become clearer, and your success in addressing the challenging behavior will greatly improve.

Benefits of Mindful Care-Partnering

As you delve into this practice of mindful care-partnering, you will become aware of your fears, expectations, and judgments and how those color how you relate to the PHD. Mindful care-partnering will also help you see the situation from PHD’s point of view. Mindful care-partnering is all about honoring relationships, connectedness, and a sense of belonging. Your relationship with PHD may feel chaotic or different from the ideal you want. You may find yourself drifting through life on “autopilot,” constantly worrying about the future or feeling upset (guilty, resentful) about the past instead of living in the here and now. This method of caring teaches you to stay “in the present” and stay connected with the PHD as well as yourself in kinder and softer ways.

Regular meditation practice (e.g., 30-minute Breath Awareness Meditation early in the morning before starting one’s day; at least a few minutes of Breath Awareness Meditation when experiencing strong negative emotions [e.g., anger]) and mindfulness practices throughout the day (e.g., mindful eating, mindful walking) has been shown to dramatically improve one’s sense

of wellbeing and inner strength in just eight weeks of daily practice. Yoga, Tai Chi and Qi Gong are other mindfulness-based practices (often called mind-body practices) that promote psychological and spiritual wellness and make us more effective care- partners. Meditation and mindfulness practices increase our emotional and spiritual resilience (emotional and spiritual bank-balance) and lower our risk for burnout, depression and persistent anxiety. Every time we engage in meditation and mindfulness practices, we are depositing money in our emotional and spiritual bank! As we build this bank balance, hassles of daily life will seem mere annoyances rather than “terrible” events, and we will bounce back from traumatic events faster and without becoming demoralized. We will be less likely to dwell in self-pity or resentment and more likely to be aware of many things we can still be grateful for. We will find improved capacity to be patient, to see silver lining in clouds and make lemonade from lemons that life gives us (again and again). We will be able to make ourselves do things we don’t want to do (e.g., regularly exercising, eating healthy foods, having a good sleep routine, taking time to enjoy simple things in life [HYGGE {Danish art of contentment, comfort and connection}]) and we will also be able to more easily restrain ourselves from doing things we should not (e.g., putting self or others down under the influence of strong negative emotions). Meditation and mindfulness practices will help us laugh at our foibles with light-hearted spontaneity and avoid taking life too seriously. We will be able to let go of materialistic attachments and move towards a simpler and easier life where awareness of being alive and surrounded by love will be enough reason to be happy.

From Knowledge to Skills to Practice

Mindful care-partnering challenges you to examine your expectations. Your fears may motivate you to try and direct the PHD in certain ways and often will blind you to what is truly in their best interests. PHDs have their own trajectories, beliefs, ideas, and opinions, often different from ours, and what we think theirs should be. When you challenge yourself to pay attention to the present moment and see caring as collaboration, an artistic endeavor, you gain opportunities to truly see PHDs, to understand and appreciate them, and solve problems with them rather than for them.

Everyone has times where inner musings (inner chatter, conversation with oneself in our minds) take over, but this means we lose opportunities to connect with the PHD by being blind to the present moment. The key is in paying attention to the small things, like a child, fully embodying every moment, as opposed to life being a movie in our minds or trying to match it to our expectations.

You can think of mindful care-partnering as an opportunity to get to know yourself better and to accelerate your own psychological and spiritual growth. A moment of mindful care-partnering may allow you to catch yourself and realize an opportunity to change direction. When you pay attention to the present you may recognize that some thoughts or fears are not based in reality and liberate yourself to a more productive course of action.

As with most skills, mindful care-partnering takes time and practice. Even small changes are profoundly healing and transformative. Some examples of small steps are being aware of your

breath, the feeling of your hands, or your own body language, the feel of PHD's hand in yours. The simplest method of becoming mindful is to get connected with our senses. Bring your awareness to your breathing, for example, in the belly or the nostrils, to focus on one thing at one time. Practicing this at a moment of tranquility, and drawing on this experience when a conflict happens, will help you respond mindfully to the conflict instead of reacting emotionally, and find better ways of dealing with it.

Instead of preparing for situations in the future, or using a cookbook approach, mindful care-partnering asks that you trust yourself to be aware of the next moment and find a solution when that moment comes. The goal is not to eliminate chaos and negative feelings; these are a natural part of life filled with caring responsibilities. The goal is to be kind and curious when those moments arise.

It is crucial to give yourself credit for the little moments of success and accept yourself and others with all the imperfections. Choosing to engage in mindful care-partnering is empowering yourself to be present for the challenges and successes.

Source:

One Day Mindfulness Millionaire: Living Mindfully – A Primer for the Uninitiated. Book by Abhilash Desai and Faith Galliano Desai. Available as eBook.

Sheer Terror

I was mumbling
in indecipherable shrinkspeak
as I tried to
crawl out
of a state of stunned disbelief.
My thoughts
a mush of rampant flashes.
My inner debates
raging over strategies
that changed by the minute.
Tears started to roll out.
Not tears of sorrow,
but of sheer terror.
My stomach flipped
I wanted to throw up.
My body shook
to toes as
my heart raced away.
Where are you mom?
Where have you
wandered off to?



The plight of a psychiatrist caregiver whose mother (my patient) has dementia and had wandered away from home. After 2 longest hours of daughter's sheer terror, my patient was found, safe and sound, several blocks away.

Wandering is a common AAD and Alzheimer's Association website as excellent strategies for prevention and management. <https://www.alz.org/help-support/caregiving/stages-behaviors/deambulacion>

Unthinkable Future

“Sorry. I am being rude,
talking about you
in front of you.”
My patient with dementia
was pacing.
She plunked herself
into the chair
and tucked her hair
behind her ears.
Husband’s health was
declining rapidly.
He had no words.
His soul felt too heavy.
His wife in an ALF?
That future was unthinkable
at this moment,
and untenable
when it arrived.

His body revealed nothing
of his psychic wounds.
Wounds that ran deep
and felt permanent.
“Ah Assisted Living Facility,
a place of boundless tranquility”
he quipped.
“Humor is a good start.
But we need more than a strong heart.
No one can predict the future.
Let’s live in the possibility
that there is an alternate destiny.
Let’s focus on getting you
back to healthy.”



ALF = assisted living facility / community

“You back to healthy” = getting the caregiver husband back to healthy – less stressed, less worried, positive and hopeful as much as is possible in the given context.

His wife was having lot of agitation at home, not sleeping, asking the same questions again and again and at times, not recognizing him and demanding he leave as otherwise she will call 911. And she had called 911. By the time the police came, she had forgotten her concerns.

Anything but dementia

Her clothes were brighter
than a field of wildflowers
with rich reds
and sunny yellows,
countless shades of
green and blue,
deep blacks
and grey and purple.
I had never seen
such colorful elegance before.
We sat on a bench
outside, all bundled up.
The air had begun to get cold.
She liked sitting here.
The sun dipped below
the tops of the trees.
We watched a dragonfly
move lazily amongst the reeds.
“Why would they
name it dragonfly?
It looks nothing
like a dragon”
she said.
We chatted about
this and that
and more this
and more that.
Anything but
her husband’s Dementia,
her struggles keeping him home,
his hallucinations,
his anger,
her guilt preventing her
from asking her only son
for help,
her fears about future,
and her grief



It is hard for many family caregivers to talk about their emotional pain. That is okay. It is important just to be with them and talk about this and that. This also promotes healing.

My World

I am a dementia caregiver.
My world is
Desolate.
Not a single living soul.
Not a bird.
Not a fly.
In my world, waves roar
for no one in particular.
Where all events
are beyond comprehension.
Not a single logical thought.
Just reflections and reverie,
sinister at times
and yet
also filled with desire
to look forever
at the monotonous movements
of the ocean waves.
I have become a prisoner
of my own meditations,
engulfed
by an overwhelming sense of powerlessness,
facing
an inescapably bitter fate



Caregiver sadness, grief, despair, demoralization and depression are real. We should do everything we can to help. Caregiver journey typically is a lonely journey much of the time. Caregiver depression is one of the key factors increasing the risk of repeated visits of the person with dementia to ED for AAD emergencies.

Long buried sorrow

What is her yelling?
A sign, a signal,
a symptom of moral anguish
calling our souls
to understand her plight?
My patient had never learned
to experience her feelings
as there was no one
in her childhood or later
who accepted her fully,
who understood
and supported her.
And now with advanced dementia,
long buried sorrow
that could never be expressed
is set free and
only touch and soothing voice
can do the miracle
of bringing her some solace.
No meds please,
no meds.



My 82-year-old patient with advanced dementia living in a nursing home. The staff (well-meaning) asked me if an antidepressant would help. Trauma-informed care plan was created and implemented and it did help her.

Past trauma (includes emotional neglect) is under-appreciated and under-recognized in persons with dementia experiencing AAD. Let's make inquiry about past trauma and detailed understanding of its context a routine in assessment of AAD.

Restraints

Another patient with advanced dementia
in restraints.

Physical

Chemical

Again

for trying to leave.

I still cannot believe
that conditions so deplorable
exist in our country's hospitals.

Perhaps I am naïve.

There is no humanity
in our current system of health care.

And no one cares.

No one is watching.

At least no one
with any real power



Many of us who work in the hospital experience secondary trauma of seeing our patients with dementia and AAD in restraints. Dementia Friendly Hospital Systems and Practices within Age-Friendly Health Systems is the answer. We have the power. All we need is courageous leaders to provide emotional support to the clinical team and adequate funding to make this a reality.

Thanx

My patient smiled,
a smile that stopped me
in my tracks.
I found the smile
unexpectedly pleasant.
A vigor,
a curious sweetness
in it.
There was also youth in it,
a wild hope.
Did all my patients
with dementia
have all this in them?
Have I been blind
for 24 years?
I sat next to her,
closed my eyes
and breathed quietly.
I opened my eyes,
turned towards her
and said "Thanks"



This is my 93-year-old patient with advanced dementia in a nursing home. I thanked her for opening up my eyes to the rich inner life persons with dementia have that I have not been fully aware of. Not all persons with dementia develop AAD.

24 years = my being a geriatric psychiatrist

Delirium on Dementia

What exactly happened, Doc?
He doesn't remember anything.

He was drifting
in dream filled delirium.
Confusion interspersed with
bouts of panic.
Terror blazing in his eyes,
courtesy hallucinations.
Only after intravenous medicine
did his inner chaos settle
and rambling settled into
coherent thinking.
His hip was on fire
and in just one hour
blossomed into a raging inferno.
A shot of opioid
settled that.
The unspoken horrors
of delirium
after hip fracture.
It's a good thing
he doesn't remember anything.
Some have PTSD
from such a horrific experience.



My patient with moderate stage Alzheimer's dementia fractured his hip after a fall. Emotionally he is doing well now. Dementia has accelerated from all this stress.

His wife asked me the question and I was explaining what happened.

His wife upon my guidance spent several hours every day with him. This was key to his recovery. Unfortunately, she remembers everything and watching his agony remains a stressful memory. With prayers, mindfulness, family support and support groups, she is doing better each day.

An Angel

The nurse aide
washed the sweat
from his face
with a warm, damp cloth.
Dressed him
with deft, gentle hands.
Wheeled him
down to the dining hall.
He was as light
as a bundle of rags.
The aide was determined
to put some muscle on him.
“Don’t you worry.
I will make sure,”
the aide assured
his wife of 67 years.
“Then, you both
can plan your new adventure.”
The wife smiled, turned to me,
and said,
“She is an angel.”



My patient (90 years old with advanced dementia, lost a lot of weight) and his wife loved traveling to remote places, their “adventures.”

Countless certified nursing assistants (CNAs) and nurse aides provide AMAZING loving care to individuals living with dementia in the nursing home. I always inquire if the “BPSD” or “AAD” is worse with certain staff and mild or absent with other staff. If yes, this would indicate that it is the loving staff approach and knowing the person with dementia well to quickly identify the cause of their distress that is needed, not psychiatric medications.

A Blessing for Caregivers

May the love in your soul guide you

May the courage within you overcome fears about caregiving

May the heart within you conquer the pain involved in caregiving

May you be given the best education and training to overcome challenges in this journey

May you have the commitment to care with compassion, to learn from failures, to be patient, and be the best caregiver you can be

May you have great respect for yourself

May you show growing compassion and patience towards yourself as you come to realize how much the wellbeing of (name of the person needing care) depends on you.

May you have the wisdom to hear

The unspoken gratitude (name of the person needing care) has for you

And above all, may you be given the wonderful gift of meeting the beauty that is within you

May you be blessed, and may you find life Enriched by your efforts of caregiving.

Adapted from John O'Donohue's poems

Namaste

When Is Enough, Enough? Personal Reflections on the Threats and Ills Facing Persons living with Dementia

Abhilash Desai MD

Why do the terrible deprivations that befall the millions of persons living dementia not routinely keep the rest of us awake at night? The reasons cover a wide range of sociocultural forces, from apathy by the medical community to the fragmented health care system to lack of adequate funding by the government. Running deep are some dominant currents: of identity, in particular, the concern that despite the fact that each of us carries multiple identities, there are forces at play which strive to straitjacket us into just one, typically a narrative identity (an identity that relies solely on neurocognitive functions, especially memory); of autonomy, especially why it is so important to the idea of freedom and justice (autonomy routinely deprived to persons living with dementia); and of inequality, notably in the context of “jaw-dropping” advances in biomedical research which have brought enormous longevity dividends for the few while leaving millions to cope on their own with poor cognitive health. At the heart of the tragedy is the injustice meted out to the individuals living with dementia in long-term care facilities—plagued by their lack of effort to meet the most basic mental health need, the fundamental right to a life lived with dignity and companionship.

Being a physician, I focus my lens on medical education. Let me remind you that, while the United States is home to more than 6 million persons living with dementia, of which more than 1 million are taking antipsychotic medication (typically used as chemical restraint and carrying dangerous risks of swallowing difficulty and stroke), it also boasts the largest number of world-class medical schools and universities. In the case of medical education, despite producing many of the world’s most eminent physicians, most of our country’s population living with dementia struggle to receive basic good-quality physical and mental health care.

Much health care to persons living with dementia is now provided by physicians and advanced practice providers (APP [e.g., nurse practitioners, physician assistants]) who have minimal education and skills training in management of agitation in the context of dementia. Furthermore, physician and APP clinical practice is seriously compromised (in terms of time spent with patient and family) by poor reimbursement for preventive and palliative services. Persons living with dementia who cannot afford to live at home have to rely on a long-term care system that is short of virtually all resources (e.g., poor quantity and inadequate training and support of direct care staff, very low salaries with minimal health benefits of certified nursing assistants and nurses). Much of the payments from our government to the nursing homes disappears somewhere (no one seems to know where – or a few people do know but would like to keep it a secret) but definitely doesn’t trickle down to improve salaries of direct care staff. There is no transparency in long-term care financing and without transparency, radical changes that are needed in long-term care systems will not take place.

Of course, these are sweeping generalizations that mask islands of excellence in both sectors, but the exceptions do not make the rule. The fundamental question for those who are bewildered by the coexistence of world-class hospitals, complete with helipads and suites that

could make the Ritz Carlton blush, and decrepit long-term care facilities without qualified geriatric health professionals, is why does this not keep us awake at night? Perhaps the most distressing indicator of how immoral the health care system has become is the observation that, whereas our country invests heavily in costly high-tech biomedical devices, medications (the latest being Lecanemab [Leqembi] and Donanemab [Kisunla] for early Alzheimer Disease), and surgical interventions as a means to help people live 1-2 years longer, caring for persons living with dementia has become one of the leading causes of poverty for the person and their families.

What explanation could there be for this appalling situation? It seems as if our society has no social imperative to care for cognitively diminished people, and the physician and APP community (researchers, clinicians, and educators) have – for all practical purposes – divorced themselves from this cause. It seems that we physicians and APPs have chosen to deal with this injustice by simply looking away. Perhaps the indifference of the physician and APP community is because we are besieged with helplessness and burnout; more repugnant is the possibility that some simply don't care.

Most disheartening of all, for physicians and APPs with geriatric expertise, is the recognition that the medical community not only has distanced itself from this injustice but also actually has contributed to it. Whether this takes the shape of the physician / APP who treats their patient living with dementia with a sense that their situation is hopeless, or the physician / APP who ignores their patient with dementia completely and directs interaction to the caregivers accompanying the patient, or the physician / APP who prescribes unnecessary and inappropriate medication, or the surgeon who subjects the person with dementia to dangerous surgeries and procedures, the fact remains that physicians / APPs have lost their moorings to their original purpose: to address human suffering in an ethical, evidence-based, and dignified way. Even the professional societies that govern medicine have not achieved their rightful role in generating social realization.

This overarching division between the physician community and the persons living with dementia and the silence with which it is tolerated, not to mention the smugness with which it is sometimes dismissed, should keep us awake at night. Most tragically, these deprivations are not hard to overcome, as it requires what every physician / APP has (or should have): compassion. After all, medical schools are the world's factory of brilliant, creative, skillful, and (at least when they were medical students) kindest of all professionals. Of course, the physician / APP community does occasionally become sufficiently seized by injustice to protest, alongside fellow patients (with dementia) who live without dignity or support. But this action has been only when the injustice has come too close for comfort, rather than out of solidarity with cognitively diminished individuals. It is no accident that the recent outrage around the use of antipsychotic medication for persons with dementia (and the associated increased risk of stroke and mortality) was precipitated by the findings that two-thirds of persons with dementia are receiving antipsychotics unnecessarily or inappropriately. Of course, persons living with dementia (especially those who live in long-term care facilities) commonly experience excess disability and suffering due to unnecessary and/or inappropriate prescription of many

dangerous medications (not just antipsychotics), but there is no comparable outrage for that cause. The same could be said about aggressive and burdensome medical care, a horror that haunts the last months of life of persons with dementia but emerged as a mass movement only when its high cost became apparent and an impediment to the financial security of the cognitively privileged and, in particular, the government.

We need, first and foremost, a clear-headed understanding of what most ails persons living with dementia. We must identify the obstacles to overcome and acknowledge that there is something astonishing and perplexing about quiet acceptance, with relatively little political murmur, of the continuation of the misery of the least-advantaged people in our country. The complete exclusion of cognitively diminished individuals from daily social interactions with cognitively privileged individuals is one major reason why there is no national compact to address the injustice of iniquitous health care. Dementia-friendly communities, a compassionate and innovative approach for all persons living with dementia, offer a potent solution to this challenge. If we leave aside the fundamental principle of justice as the driver for dementia-friendly communities, an often-cited concern is that that we cannot afford them. Yet, such an attitude also ignores the basic economics that public investment in innovative and humane social solutions is the primary driver for the economic success of caring for persons with dementia in many communities (and, indeed, in the United States, in communities like Fox Valley in Wisconsin and communities in Seattle, Washington). The idea that financing dementia-friendly communities should be left to the market is perhaps the most perverse of all arguments, because buying innovative social solutions is not the same as buying a car or a television; the enormous asymmetry of information and power renders persons with dementia and their family members highly vulnerable to exploitation and vitiates the efficiency of market competition.

Perhaps one way to force action on this injustice might be to require all cognitively privileged individuals to befriend at least one person living with dementia. Although this may sound churlish, such a move would remind those who contribute to the injustice, even if only by their inaction, of how a person with dementia lives. And dies. It is time for the physician / APP community to make the injustice of health care for persons with dementia the focus of its mission for the development of a more humane future for all.

Inspired by the perspectives of Dr. Vikram Patel (psychiatrist), "How do we sleep at night?" *Lancet* 2015.

Eight new models to help people with dementia age in place

Agitation, depression, anxiety, aggression, insomnia and irritability is often an expression of the unmet need of the person with dementia to want to age in place (and not be placed in an assisted living community or a nursing home). Trying to meet this need often increases caregiver burden.

The following eight new models have been described by Joanne Kaldy in *Caring for the Ages*, August-September 2024 issue published by PALTmed (Post-Acute and Long-Term Medical Association). They are:

1. Home and Community Based Services (HBCS)
2. Implementation of Universal Design Principles. The principles were developed by the Center for Excellence in Universal Design. The seven principles are: equitable use, flexibility in use, simple and intuitive use, perceptible information, tolerance for error, low physical effort, and size and space for approach and use.
3. Smart homes (e.g., everything from light switches to thermostats to security systems and door locks controlled remotely via a smartphone app).
4. Guiding an improved dementia experience (GUIDE) model of dementia care in primary care and memory clinic practices.
5. House-sharing model
6. Senior housing cooperatives
7. The Village Model
8. PACE: the program for all-inclusive care for the elderly.

By proactively working on creative ways to help individuals with dementia age in place, we will avoid many “behavioral emergencies,” trips to ED and agitation episodes. This ideally needs to begin as soon as is possible after the diagnosis of dementia.

Four secrets in plain sight

Dr. Lloyd Lederer, in his book titled *Improving Mental Health: Four Secrets in Plain Sight*, shares the following four secrets:

- Behavior serves a purpose
- The power of attachment
- Less is more
- Chronic stress is the enemy

Application to prevention and treatment of AAD:

Behavior serves a purpose: As mentioned before, agitation is an expression of an unmet need and at the same time, it is often an attempt of the person with dementia to meet their unmet need, to solve a problem that is bothering them.

The power of attachment: Time and again, I have seen that “agitation” clears up when a wonderful caregiver is caring for the person with dementia and “agitation” returns when a different caregiver is caring. Many caregivers are attuned to the person with dementia, have taken time to develop trust and attachment. The person with dementia finds much calm and relief in the presence of a person they are deeply attached to.

Less is more: As mentioned earlier, one of the key interventions for prevention and management of AAD is to rational de-prescribing of their medications. Less medications is more mental health and joy in living.

Chronic stress is the enemy: Persons with dementia at baseline are under a lot of stress because navigating our complex modern life with significant cognitive impairment becomes very stressful very quickly. Anything and everything we can do to reduce their stress, help them experience long periods of calm and relaxation, make it easier for them to exercise their strength and help them in their areas of challenge will go a long way to prevent and reduce AAD.

Dialectical Behavioral Therapy (DBT) for Dementia Family Caregivers

DBT (in individual and group settings) may help many caregivers who are struggling to be more positive, calm, patient and loving. Positive, calm, patient and loving approach can prevent and reduce AAD.

The four key components of DBT are:

- Mindfulness
- Distress tolerance
- Emotional regulation
- Interpersonal effectiveness

Holistic Dementia Care Medicine: 11 Domains

#	Type	Description
1	Psychoeducation	Improve brain health literacy and address incorrect understanding and unrealistic expectations from psychiatric medications
2	Medical evaluation and workup	Identify and correct reversible medical (e.g., pain, dehydration, hearing and vision deficits, dental problems) causes of neuropsychiatric symptoms
3	De-prescribing	Identify and de-prescribe medications causing neuropsychiatric problems and medications that are unnecessary
4	STEPS	Support system (family and professional care partners) Training Empowerment Praise Support to improve healing and therapeutic approaches and prevent or discontinue counter therapeutic approaches and interventions
5	Nidotherapy	Improve physical environment and engagement with outdoors and nature (includes occupational therapy assessment)
6	Lifestyle medicine	Improve brain healthy lifestyle (diet, exercise, socialization, sleep, meditation, mind-body exercises, cognitive stimulation)
7	PERMA	Positive emotions, Engagement, Relationships, Meaning, Accomplishment (positive psychology science-based interventions)
8	Emotional regulation skills training	To prevent and reduce dysregulated emotional states in the person with dementia and their care partners
9	Applied behavior analysis (ABA) based interventions	Also called ABC intervention (antecedents, behavior, consequences) to identify antecedents to agitation and address them more effectively so that the person with dementia doesn't try to address them in ineffective or harmful ways.
9	ACT	Acceptance Commitment Therapy – for the person with dementia and their care partners to accept the need for holistic approach and commit to it.
10	DEIBA	Diversity, Equity, Inclusion, Belonging, Anti-Ableism Includes Anti-Ageism and Anti-Dementiaism Includes addressing social determinants of health and bolstering community resources
11	Peer-led interventions	Peer-led and peer-supported interventions including support groups and advocacy groups

Key Resources:

1. Saint Alphonsus Memory Center, Boise, Idaho. <https://www.saintalphonsus.org/specialty/memory-center/>
2. The DICE Approach. <https://diceapproach.com>
3. ABC Dementia - Community Dementia Education. <https://community.abcdementia.org>

4. Laura LaForte Therapy. <https://www.lafortetherapy.com>
5. University of Pennsylvania Positive Psychology Center. <https://ppc.sas.upenn.edu/learn-more/perma-theory-well-being-and-perma-workshops>
6. Stanford Lifestyle Medicine.

Off label interventions / treatments

Off label interventions / treatments are used extensively in clinical practice, in every specialty of medicine, are often more effective than FDA approved interventions, cheaper and as effective as FDA approved interventions, safer than FDA approved interventions, don't receive FDA approval because of enormous cost of FDA approval process, and physicians should prescribe off label interventions for indications that they believe are in the best interest of the patient.

SUL-B meditation

Find someone with advanced dementia you can do this meditation with. Sit at eye level. Soften your gaze. Hold their hands. Say the words and imagine them responding to you.

I see you
I am seen

I understand you
I am understood

I love you
I am loved

I be-friend you
I have a friend



“Agitation” is often an expression of the person with dementia feeling that they are invisible, that no one understands what they are going through, that no one loves them and they have no friend 😞

SUL-B time at home with visitors

SUL-B rounds in post-acute and long-term care homes (e.g., nursing homes, assisted living communities, PACE [program for all-inclusive care of the elderly])

SUL-B pause during medical visits

Please email me your experience with SUL-B meditation and please give permission to share your response with the wider world.

**Best Practices in the Management of Severe Aggression in Individuals Living with Dementia
Healthcare Systems need to radically change how they address this serious problem!**

Best Practice #1: Prevent / avoid visits to the emergency departments (EDs) and hospitals. EDs and hospitals are NOT appropriate places to manage severe aggression in persons living with dementia (PLWD) unless the cause is an acute medical issue that requires ED / hospital care or there is imminent danger to self and or others (the latter can be quickly addressed in the ED). Continued stay in the ED / hospital causes more harm than good and, in most situations, causes trauma to the PLWD as well as to healthcare professionals caring for them in the ED / hospital. For the PLWD, the harms due to trauma rapidly accumulate, the longer they spend time in the ED / hospital. The trauma is even higher for PLWD in moderate to severe stage compared to mild stage. ED and hospital stay should be as short as is feasible. EDs and hospitals should strive to be Age-Friendly Systems and Dementia-Friendly EDs and Hospitals (includes Geriatric EDs).

Best Practice #2: Team-based care. Hospital and outpatient team (working collaboratively) consists of healthcare professionals with training and expertise in caring for PLWD, with geriatricians and geriatric psychiatrists as team co-leaders. Teams should follow a bio-psychosocial approach, focusing on prevention of behavioral emergencies and helping them live the best life possible. Team should include a nurse, chaplain, nurse's aide, an occupational therapist, PCP (Primary Care Provider) and other professionals (e.g., social workers, recreational therapist).

Best Practice #3: Create and follow the (evolving) Crisis Plan / Safety Plan. All points of care (ED, hospital, outpatient) follow the Psychiatric / Behavioral Care Plan including Crisis Plan / Safety Plan (created by the team) that includes recommended collaborative de-escalation strategies (e.g., as needed medications, behavioral interventions, environmental interventions).

Best Practice #4: Go upstream. Don't wait till the problems are severe and treatment refractory

Best Practice #5: Collaborative geriatric psychiatric care via telemedicine. This will allow geriatric psychiatrists to be available to a much larger population and all settings of care including urgent care.

Best Practice #6: 12-Domain Holistic Care (Psychoeducation [about realistic expectations from psych meds], Comprehensive medical assessment and ongoing care, Comprehensive psychiatric assessment and ongoing care, rational deprescribing, occupational therapy and recreational therapy-based interventions, lifestyle medicine based interventions, positive psychology – PERMA+ based interventions, verbal collaborative de-escalation skills training, Nidotherapy [physical environment that is adjusted to the person's sensory and other needs], staff / caregiver training-empowerment, praise, support [STEPS], ecological interventions [peace officer and ED collaboration], and judicious short-term use of psychiatric medications if necessary).

New and Old Research

Severe aggression and mortality risk: Research from Belgium indicate that severe aggression in individuals with dementia is associated with greater mortality risk (more likely to die within one year) as compared to those with mild or no aggressive behaviors. Van den Bulcke L, et al. November 13, 2023. JAMDA. Clinical implications: Very important to discuss goals of care and What Matters – quality of life over quantity of life discussions.

Massage therapy for AAD/BPSD: Six weeks of 20-minute daily massage reduced aggression and levels of a stress biomarker in a Japanese study. American Journal of Alzheimer's Disease and Other Dementias 2010 (Suzuki M et al).