Confronting Challenging Behavior in the Patient with Dementia

Pamela Tronetti DO, AGSF
Medical Director, Aging Services
Parrish Medical Center
Dementia

- A group of diseases which cause a progressive loss of the ability to organize, to plan ahead, to interact with the world and to function independently.
Alzheimer’s and vascular dementia make up 80% of all cases

Other causes include Lewy-body dementia, Fronto-temporal dementia, Primary Progressive Aphasia, Normal Pressure Hydrocephalus, Creutzfeld-Jakob disease, Alcohol–related Dementia, Cerebral Amyloid Angiopathy, infectious and metabolic dementias etc.
Certain behaviors accompany the brain damage that occurs in dementia, including anxiety, agitation, apathy, belligerence, confabulation, confusion, depression, egocentricity, fearfulness, insecurity, insomnia, lack of insight, paranoia, restlessness, repetition, sun-downing and wandering.
What we hear from families

- “I tell her something and 5 minutes later she asks me the same thing.”
- “He won’t let me out of his sight. I have to go tinkle with the door open.”
- “He’s up all night rummaging around.”
What we hear from families

“She’s hitting the caregivers and they are threatening to quit.”

“He thinks someone comes in at night and moves things around in the pantry.”

“He hasn’t taken a shower in months and he gets belligerent if we insist.”

“She says she needs to go home and see her mom.”
There are certain behaviors that are part of the progressive losses of dementia.

Education, rather than medication, is often the key to dealing with them.

(Most times, we need both.)
Caregiver Education

- Dementia Specialist (adult day care, senior agency)
- Caregiver Support groups
- The 36Hour Day (book)
- Alz.org or Caregiver.org
Loss of insight

- Patients lose the capacity to recognize losses
- Diagnosis is often delayed unless there is someone else to describe events
- Distant relatives think the patient is fine based on conversations.
New information is seen, heard, tasted, smelt or felt. It is eventually sent to the hippocampus which stores it.

In patients with dementia, the new information is never stored so it is as if it never happened.

Repetition

- Whiteboard
- Notebook
- Maximize hearing

“He just sits and stares at the TV.”

Executive function—the ability to plan ahead and organize—is lost because of damage to frontal lobes.

*medical work up for any new symptoms
Apathy

- Non pharmacologic treatments
  
  Schedule the day:
  "The calendar says…” “The clock says…”
  
  Day care offers stimulation and activities
Apathy

“Can’t you give him something for energy?”

“Is he depressed?”

Dolder CR, Davis LN, McKinsey J.

Apathy vs. Depression

- Depression is common, especially in vascular dementia
- Geriatric sensitive depression screening
- Depressed patients may stress their losses while dementia patients minimize.
- Consider an activating anti-depressant
Restlessness

- They always need to be busy
- They always want to go somewhere
- They always are asking “What’s next?”
- Caregivers become exhausted
Often high energy people

- Simple chores, arts and crafts, spinners, busy boxes, busy blankets
- Day care offers stimulation, activities
Anxiousness versus restlessness

Medication is last resort
“I got mom an easy-to-use phone and she can’t figure it out.”

“Dad put the shuttle into space and now he can’t attach a hose to a sprinkler.”
Sometimes medications can boost or restore abilities

Safety is job one

The “what if” questions
Insecurity

- “She won’t let me out of her sight.”

- Explanation: “You are their lighthouse. When you are out of sight, the world doesn’t make sense.”
The flipside is that the caregiver will insist that the person will not accept any other help including day care.

The people in day care and assisted-living are trained to use distraction and other tools to make the patient feel secure.
Confabulation

- From the Latin fabulosus - from the fable
  - “I went to school there.”
  - “I used to have a horse like that.”
Confabulation

- The production of fabricated, distorted, or misinterpreted memories about oneself or the world, without the conscious intention to deceive.

The patient believes they are telling the truth

“Does it matter?”

Unless there is impending danger, go with the flow.
Irritability

- Patients get frustrated by their inabilities
- Patients get frustrated by being told what to do all the time, usually by the same person
Irritability

- Simplify, de-clutter
- Use external organization (labels)
- Deflect the boss role to the doctor, the calendar, another authority figure, etc
- May need anxiolytic or anti-depressant
Disinhibitions

- Using foul language
- Sexually suggestive comments
- Racist comments
- Other inappropriate comments (weight or disabilities)
- Sexual acting out/hypersexuality
Avoid activities which fuel the behavior

Calm limit- setting as appropriate
Disinhibitions

- Business card “The person with me has Alzheimer’s disease/ dementia. Thank you for your patience.”
- Professional letter – especially for travel
Disinhibitions

- Memantine (Namenda) sometimes helps this and other behaviors
- Acting out, especially in a congregate living situation, requires medication, usually antipsychotics.
- May need psychiatric consult
“He thinks that what is going on in a TV show is happening to us.”

- Avoid news programs, crime dramas, and horror shows
- Block the stations if necessary (blame the cable company)
- Classic movies and TV shows are okay
When a person with dementia is experiencing a delusion, hallucination, or catastrophic reaction, or cannot comprehend the reality of a situation, a caregiver may use therapeutic fibbing and diversion to avoid causing further undue anxiety.

Many people bristle at the thought of “lying to their loved ones.”

The dressing room analogy

The “varnished” truth
The therapeutic fib

- Defuse and distract
- Vague answers
- No sense of time
- Word choices ("bib, adult day care, diapers")
Doctors tell the truth
We do not withhold information
We choose our words carefully
Wandering

- High - set locks
- Door alarms
- GPS/ID bracelet
- Activities to offset the wandering
- Environmental change

“What are they looking for?”
Identified triggers:
- Sun-downing
- Bathing
- Chaotic situation
- Family events/holidays
- Loss of attention (egocentricity)
Defuse and redirect
Calm orderly routine
Limit caffeine and sugar
Minimize events, holidays, and celebrations
Put someone else “in charge” of some activities (bathing, medication)
Ask the tough questions:

“Does your loved one get agitated?”

“Do they ever hurt you or threaten to?”
Agitation

Stress patient and family safety:

- “It’s not them, it’s the disease.”
- “Don’t be afraid to call 911.”
- “You’re not doing it to him, you are doing it for him.”
Hallucinations

- Visual or auditory
- Often accompanies visual or hearing impairment along with the dementia
- Misperceptions are a factor
Charles Bonnet syndrome – visual hallucinations in patients with significant vision loss. Generally people, children, or “elves” are seen but silent.

Auditory hallucinations – music or someone whispering upsetting things
Maximize vision and hearing
Evaluate lighting, furnishings, curtains
Socialization and human interaction
Environment - the patient may need to move to a supportive living situation
Medications such as antipsychotics may be needed for frightening hallucinations.
Belief that is firmly maintained despite being contradicted by reality or rational argument

May be reduced with treating the underlying dementia

Antipsychotics
Home is not my present address.

Home is where I raised my children.

Home is where I grew up.

Home is where the world makes sense.
We tend to visualize ourselves in our 30s. Therefore, this old man must be my father or older brother. These middle-aged people are siblings – not my children.

Capgras phenomenon – the loved one has been replaced by a duplicate.
“My parents need me.”

- To tell or not to tell
- Redirect
- Ask questions
- “I remember…”
Do’s and don’ts

- Never ask “Why did you do that?”
- Never ask, “Don’t you remember?”
Do’s and don’ts

- Except in matters of safety, never argue with the patient who has dementia.

- You are trying to reason with someone who is literally un-reasonable.

- You’re trying to argue with the disease, and the disease will always win.
Do’s and don’ts

- Except in matters of safety, don’t focus on “re-orienting” the patient
- Re-orientation doesn’t work, but Validation does

(thank you Naomi Feil)
Do’s and don’ts

- You need to meet the patient where he or she is.
- This is the new normal.
Medications for Dementia

- Acetylcholinesterase inhibitors
  - Aricept (donepezil)
  - Razadyne (galantamine)
  - Exelon (rivastigmine) – patch
Acetylcholinesterase inhibitors

- Side effects – G.I. upset, diarrhea, weight loss, QT prolongation (ekg, cardiac eval.)
- Aricept (donepezil) can worsen night-time leg cramps and nightmares. (Sometimes morning instead of evening dosing helps.)
Persistent activation of central nervous system N-methyl-D-aspartate (NMDA) receptors by the excitatory amino acid glutamate has been hypothesized to contribute to the symptomatology of Alzheimer’s disease. Memantine is postulated to exert its therapeutic effect through its action as a low to moderate NMDA receptor antagonist which binds preferentially to the NMDA receptor channels.

Package insert information
Memantine

- Used in moderate to severe dementia
- Significant positive effects on agitation/aggression, irritability, mood lability
- Caregivers relayed significantly less agitation – related distress

- Behavioral effects of memantine in Alzheimer disease patients receiving donepezil treatment
  - Jeffrey L. Cummings, MD, et al
  - Neurology July 11, 2006 vol. 67 no. 1 57-63
Memantine

Side effects:

- Elevated blood pressure
- Diarrhea
- Headache
- Fatigue
- Confusion (“opening doors in the brain that were once closed.”)
Speaking from personal experience, I tend to prescribe this drug prior to instituting antipsychotics for behaviors such as hallucinations, delusions, agitation, and paranoia.
Irritability, agitation, anxiety

- May respond to anxiolytics or antidepressants.
May have a paradoxical effect, making anxiety and confusion worse

- Start low and go slow

- Alprazolam (Xanax) 0.25 mg – ½ to 1 pill once or twice a day as needed. (Some patients need it routinely each afternoon to prevent sun downing.)
Clonazepam (Klonopin)

May be needed for patients with REM sleep behavior disorder if melatonin fails to control symptoms

(REM sleep behavior disorder is very common in Lewy-body dementia)
Antidepressants

- Symptoms of depression may include irritability, especially in men
- May be more palatable for patient’s families than anxiolytic
Antidepressants

Christopher White, M.D., JD, Patricia Wigle, Pharm.D., BC PS. Answers to your questions about SSRIs. *J Fam Pract.* 2010 January;59(1):19-24

The most sedative SSRI
Fluvoxamine and paroxetine are the most sedating of the SSRIs.

The most activating SSRI
Fluoxetine and sertraline are more activating and preferred in depressed patients with apathy, lack of energy, or hypersomnia. And they are least preferred in patients with anxiety and insomnia.

The best SSRI for anxiety
Escitalopram has potent anxiolytic-like effects.

http://www.emedexpert.com/compare/ssris.shtml
Limit caffeine after 2 pm including chocolate, tea and cola

Lavender oils and sprays

Natural options may contain melatonin, valerian, chamomille etc. (Midnite, Alteril, Calms forte, Somnapure)
Sleep aids

- Avoid any other OTC sleep meds – they contain diphenhydramine (Benadryl), which can cause daytime drowsiness.
Sleep aids

- Evaluate sleep hygiene
- TV or radio are ok
- Review risk / benefit ratio of sleep meds
- Our caregivers deserve a night’s sleep!
Sleep aids

- Trazodone (50 – 100 mg)
- Alprazolam or other short acting anxiolytics
- More sedating SSRI’s (mirtazepine)
- Temazepam
- “Use what you got” – cetirizine, memantine, beta blockers, other anti-depressants
Medication concerns

- “I don’t want them to be a zombie.”

- Compassionate answer: “It doesn’t feel good to be paranoid or scared or angry or agitated. Just like we treat physical pain, we treat emotional pain too.”
WARNING: INCREASED MORTALITY IN ELDERLY PATIENTS WITH DEMENTIA

- See Full Prescribing Information for complete boxed warning.
- Antipsychotic drugs are associated with an increased risk of death
- (These are) not approved for elderly patients with Dementia-Related Psychosis (5.1)
Elderly patients with dementia-related psychosis treated with antipsychotic drugs are at an increased risk. Analyses of seventeen placebo-controlled trials (modal duration of 10 weeks) largely in patients taking atypical antipsychotic drugs, revealed a risk of death in drug-treated patients of between 1.6 to 1.7 times the risk of death in placebo-treated patients. Over the course of a typical 10-week controlled trial, the rate of death in drug-treated patients was about 4.5%, compared to a rate of about 2.6% in the placebo group.
Although the causes of death were varied, most of the deaths appeared to be either cardiovascular (e.g. heart failure, sudden death) or infectious (e.g. pneumonia). Observational studies suggest that, similar to atypical antipsychotic drugs, treatment with conventional antipsychotic drugs may increase mortality. The extent to which the findings of increased mortality in observational studies may be attributed to the antipsychotic drug as opposed to some characteristic(s) of the patients is not clear. (Drug) is not approved for the treatment of patients with dementia-related psychosis.
Antipsychotic off-label use

- Document other options tried
- Document risk of leaving the behavior untreated
- Document review of black box warning and family consent
- Consider written consent form before prescribing this medication
Antipsychotics

- Low-dose high potency
- haloperidol, risperidone
- Could start with 0.25 – 0.5 mg twice a day and increase every 3 days based on family reports.

- Side effects - drug-induced Parkinson’s symptoms, anxiety, insomnia, dizziness, weight gain, etc
Antipsychotics

- High-dose low potency
- Seroquel (quetiapine)
  Could start with 12.5 mg b.i.d. and/or 25 mg HS and increase every three days based on family reports

- Side effects - sedation, weight gain, dry mouth, headache
Behavioral concerns are often a bigger burden than the memory deficits.

Caregiver education is crucial.

Dementia specialists and caregiver support groups can offer a wealth of information, resources, and therapy.
Therapeutic environments like day care or a memory unit can provide socialization, routine, and appropriate stimulation.

Medications to treat dementia may also decrease the associated behaviors.

Psychoactive medications have a role in keeping the patient at home and reducing caregiver burden.
Thank you for your attendance and attention to this lecture

Questions?