

Dementia Care Transitions: Dead Ends, Detours, Denial

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Audience participation poll

True or False:

When it comes down to care, knowing the actual type of dementia is irrelevant?

Dementia, It's all the same, right?

- **Alzheimer's disease**
 - Short-term memory loss
 - Impairment of IADL/ADL
 - Language/word finding
 - Problems with planning & sequential tasks
- **Frontotemporal Lobar Degeneration (FTLD)**
 - Emotional & behavioral changes
 - Social disinhibition & decreased attention to hygiene
 - Executive function deficits
- **Dementia with Lewy Bodies (DLB)**
 - Fluctuations in alertness & attention
 - Increased lethargy, rigidity
 - Visual hallucinations
 - Parkinsonian motor symptoms
 - Sleep disturbance
- **Vascular Dementia**
 - Impaired judgment & planning
 - Caused by blockage & bleeds rather than accumulation of protein
 - Location of damage determines associated functional changes

(Alzheimer's Association 2012)

Key Transition Points

- Diagnosis
 - Normal aging
 - “Don’t say Alzheimer’s disease to mom”
- Driving
 - I’ve been driving since I was 15
 - I’ve never had a ticket
- Home-based services
 - I don’t need help I’m fine
 - I don’t want strangers in my home
- Residential care admission
 - It’s too expensive
 - I don’t want to live with those OLD people
- Each change represents a loss
 - Function
 - Independence
- Where there is anger look for fear
 - What is the underlying emotion?

Critical Considerations

- Confabulating
- Compensating
- Reverting to “historical truth”
- Remote v new memories
- Impaired insight v. denial
- Logic & reason rabbit holes
- Use maintaining independence as a motivator
- Viewing motives through a normal cognitive lens
- All behavior is communication & behavior makes sense
- Everyday is new
- Join in their world v. joining us in ours
- Resistance as a healthy defense

Critical Considerations Cont.

- Start early
- Revisit often
- Start with an agreed upon goal
- Provide choices
- Maintain a practical focus
- Complexity = confusion
- Divert focus from primary caregiver
- “Rotating bad guy”
- Art of therapeutic fibbing
- Sometimes the kangaroos are real!

Case Study-Introduction

- William and Rachel Taylor live in Moab Utah. William is an 82-year-old male and Rachel is 79. This couple retired and moved to Moab for their golden years. Approximately two years ago William had a serious heart attack that led to open heart surgery. During the surgery William experienced a stroke which left him with difficulties with mobility and speech.
- He has increased confusion and noticeably increased memory problems, executive functioning and decision making changes and significant difficulties with ambulation.
 - What are the immediate red flag concerns in this case?

Case Study: Barriers to Care

- In spite of the complex health issues, William still believes that he can drive and he is driving around Moab. He repeatedly states, “I have never had a ticket and my driving is just fine.” He has become lost on several occasions in spite of the fact that he is travelling in well-known areas in their small town.
 - Why might Rachel fall prey to this line of reason?
 - How do we make in-roads with these blanket statements?

Case Study: Barriers to Care Cont.

- There are limited resources to provide in home health care supports in this rural community. William refuses having “strangers come in to his home.” Further stating, “I do not need their help and they will just rob me blind.”
 - How might using independence as a primary goal help with this conversation?

Case Study: Barriers to Care

- Since his stroke he has increased depression and has become sedentary and socially isolated. He has decreased energy, decreased interest in activities, depressed mood, withdrawal, decreased appetite, anhedonia, short term memory loss. He refuses to discuss his mood and states, “depression and mental health issues are a conspiracy of the left-wing liberals and treatment is for sissies.” He has a beloved gun collection and refuses any suggestions of moving the guns to his son’s house for safe keeping.
 - Why treat depression if someone already has dementia?
 - What can families do to reduce the risks related to firearm possession?

Case Study: Barriers to Care

- William's entire family and his physician have strongly suggested that he needs to transition into a memory care unit. He is adamantly opposed.
- "They will take all of my hard earned money!"
- "Take me behind the barn and shoot me already!"

ADDRESSING BEHAVIORAL SYMPTOMS

Anger & Aggression

- Physical discomfort?
- Fatigue?
- Overstimulation?
- Poor communication/approaches from assisting individuals
- Don't get upset
- Limit distractions
- Redirect
- Change pace
 - Alzheimer's Association (ALZ.ORG)

Anxiety & Agitation

- Relocating?
- Changes in environment (i.e. travel)?
- Changes in caregiver arrangements?
- Create a calm environment
- Avoid environmental triggers
- Simplify tasks/routines
- Exercise
- Listen to the frustration
- Reassure
- Check your agitation/energy level

- Alzheimer's Association (ALZ.ORG)

Hallucinations & Delusions

- Is it upsetting?
- Is there a reversible cause?
- Are there sensory changes (i.e. hearing loss)?
- Respond calmly
- Reassure
- Redirect
- Change the environment (i.e. change rooms)
- Check for sounds or lighting that may contribute
- Mirrors can be upsetting
 - Alzheimer's Association (ALZ.ORG)

Repetition

- Commonly occurring symptom of advanced AD
- Short-term memory loss causes inability to recall previous conversations
- Can express underlying anxiety
- Look for reasons behind repetition
- Focus on emotions not behavior
- Turn behavior into an activity
- Stay calm
- Provide the answer
- Redirect to another activity
 - Alzheimer's Association (ALZ.ORG)

Sleep Issues & Sundowning

- End of day exhaustion?
- Upset internal clock?
- Fatigued caregiver?
- Inability to separate dreams from reality
- Frequent awakenings?
- Early awakening?
- Wandering?
- Keep home well lit in evening
- Maintain schedule
- Avoid stimulants & large meals
- Plan more activities, avoid napping
- Safety proof the house to reduce fall risks
- Alzheimer's Association (ALZ.ORG)

Partners in Dementia Care

9 general areas addressed by PDC:

- Disease specific education
- Lifestyle suggestions
- Safety
- Legal/Financial
- Expanding the care support network
- Proactive use of respite
- Planning for the unexpected
- Planned living transitions
- Hospitalization & doctor visit planning

National & Regional Resources

- Alzheimer's Association
 - ALZ.ORG
 - Utahmemory.org
- Association for Frontotemporal Degeneration
 - Theaftd.org
- Lewy Body Dementia Association
 - Lbda.org
- American Parkinson Disease Association
 - Apdaparkinson.org
 - Utahapda.org
- Progressive Supranuclear Palsy
 - Curepsp.org
- Salt Lake County Aging Services
385-468-3200
- Davis Co Aging Services 801-525-5050
- Mountainland Aging Services
801-229-3800

Thank you!

Questions?

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