

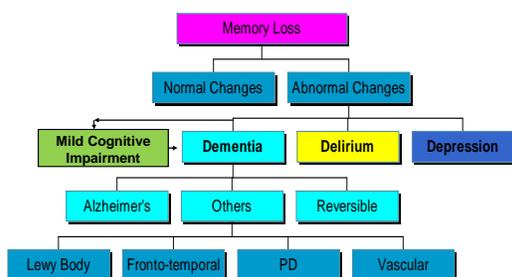
Person-Centered Care for People with Dementia

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Objectives

- Identify the 4 main components of person-centered care for PWD
- Define the role of various team members in dementia care
- Describe methods for optimizing family care for PWD

The 3 D's



Functional Assessment Stage (FAST)

| Stage of Cognitive Decline | Signs and Symptoms | Average Duration |
|----------------------------|---|------------------|
| 1: No cognitive decline | Normal functioning | |
| 2: Very mild decline | Benign forgetfulness, no change in MOCA | Prediagnosis |
| 3: MCI | Measurable change but no effect on function | 7 years |
| 4: Moderate decline | Trouble with new or complex tasks | 2 years |
| 5: Moderately severe | Major memory problems, IADLs affected | 1.5 years |
| 6: Severe | Forgets family, ADL problems | 2.5 years |
| 7: Very severe | Unable to communicate or walk | 2.5 years |

Reisberg, 1982, 1999

Goal Directed Care

- Goal directed care very different than disease (guideline) directed care
- Involves the person in the decision
- Honest about benefits and harms
- Requires adjustments - goals change
 - The disease changes
 - The person changes
 - The family changes

Talking About Goals

- What is most important in your life now?
- What experiences have you had with serious illness?
- Which fits your values?
 - Treat intensively even if it means suffering to try to extend life
 - Use medical treatments but stop if you are suffering, even if it means a shorter life
 - Use all measures to promote comfort, even if it means a shorter life
- Can you imagine a health situation that would be worse than death?
- Have you changed your mind about what is important over time?

Treatment of Dementia

- Medications
 - Primary symptoms - memory
 - Secondary symptoms - behavioral
- Improve health status
 - Treat illnesses
 - Stop damaging treatments (*Minimally Disruptive Medicine*)
- Educate patient and family
 - Counseling/support
 - “Positive person work”
- Control your destiny – advance care planning

Treatment Options for AD

- Acetylcholinesterase inhibitors (*early-moderate*)
 - Donepezil (Aricept) – generic available
 - Rivastigmine (Exelon) – generic available
 - Patch – no generic
 - Galantamine (Razadyne) – generic available
 - XR
- NMDA antagonist (*moderate to severe*)
 - Memantine (Namenda) – no generic
 - XR

Not for MCI – Cochrane Systematic Review, 2010

Approach to Rx Decisions

- Be honest with outcomes (15% effect size)
 - About 10% have a mild improvement
 - About 20% have a slower decline in function
 - The rest show no benefit
 - No effect on the progression of disease
 - Side effects (*GI, confusion, bad dreams, agitation, incontinence*) are common (30%)
 - 56% quit within 4 months
 - Costs about \$110/mo (generic) to \$500/mo
- Must monitor for effectiveness
 - MOCA (*AD – decline of 4 points/yr*)
 - Self- or family-report

Cochrane Review 2012

Improve Health Status

- Exercise
- Discontinue all non-essential drugs
 - “Medication debridement”
- Report and treat any sudden change in status
- Determine goals and values regarding management of other chronic conditions
 - Go Wish Cards

Medication Debridement

- Based on goals of care and stage (FAST)
- Maintain all drugs that support current quality of life
- Stop all non-essential drugs
- Consider stopping all drugs for prevention
- Avoid psychotropics, anticholinesterase, antihistamines

Success in treatment guarantees worse dementia

Patient & Family Education

- Simplify instructions
- Promoting remaining skills
- Fostering physical and mental activities
- Avoiding unnecessary challenges to the person – never argue “facts”
- Recognizing role of stress
- Focusing on the person, not the disease

“Dementia Reconsidered,” Tom Kitwood, 1997

Controlling Destiny

- Begin the values discussion early
- Naming and educating a surrogate
- Signing a advance directive form
 - Discussing specifics (normalize it)
 - End of course decisions
 - Infections - Antibiotics?
 - Dysphagia - Tube feedings?
 - Complications - Invasive treatment or hospitalization?
- Role of POLST?

www.MyDirectives.com

Choosing Wisely

- “Don’t recommend percutaneous feeding tubes in patients with advanced dementia; instead offer oral assisted feeding.”
 - AGS, AAHPM, AMDA
- Honest framing of the discussion
 - The final stage of life
 - Recall goals and values
 - Talk about the steps to be taken to reach those goals

www.ChoosingWisely.org

ACP Decisions Videos



www.ACPDecisions.org

Interdisciplinary Team

- Traditional care usually insufficient to meet person’s needs
 - MD/NP/PA
 - RN
 - SW
 - SLP/PT/OT
 - Music therapy
 - Psychology

Dementia Treatment

In this map, treatment is broken down into the specific areas speech-language pathologists and audiologists most commonly treat. Within each box, we have provided up to date information pertaining to the three components of EBP: external scientific evidence (i.e. evidence-based guidelines, systematic reviews), clinical expertise (i.e. consensus-based guidelines, ASHA policy documents) and client/patient perspectives (e.g. studies examining patient or caregiver assessment/treatment satisfaction). Boxes that appear gray do not have any evidence contained within them at this time; however, as new evidence becomes available, these boxes may become populated. Additional information related to this population may also be available in N-CSP's Compendium of EBP Guidelines and Systematic Reviews.

► Find out how the evidence maps can be used.



<http://ncepmaps.org/dementia/tx/>

A Little Music

- [Man in Nursing Home Reacts to Music](#)

Family & Community Resources

- Alzheimer's Association www.alz.org
 - 1.800.272.3900
- *The Best Friends Approach to Alzheimer's Care* by Bell & Troxel
- *Take Your Oxygen First*, by Gibbons & Laird
- Participate in a support group
- Referral for research?
 - National Alzheimer's Association
 - Local medical school

Advice From Experience

- A caring SLP who will answer questions is one of the most important “treatments”
- Provide hope and reality
 - Finding a “new normal”
 - Supporting best efforts
- Learn from your caregivers – they are the experts!
- Learn from your patients – living in the moment

Hope for the Future

- Personhood movement
 - Music <https://www.youtube.com/watch?v=fyZQf0p73QM>
- Changes to long term care
 - Eden Alternative <http://edenalt.org>
 - Greenhouse model <http://thegreenhouseproject.org>
 - Autumn Blossoms <http://autumnblissoms.org>
- Dementia Friendly Communities
 - http://www.dementiaaction.org.uk/joint_work/dementia_friendly_communities
 - <http://www.enablingenvironments.com.au>

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