



**Spring 2013 Geriatric Health Lecture Series on
Alzheimer's Disease and Related Issues**

Caregiving for Persons with Dementia

David LaFazia, PhD, MSW

Research Scientist

Department of Psychosocial and Community Health
University of Washington

Learning Objectives

By the end of this lecture, you should be able to:

- Identify changes in mood, health, and psychosocial function commonly experienced by caregivers of persons with dementia.
- Discuss the major triggers and consequences of problem behaviors in persons with dementia, as well as strategies for preventing or decreasing these behaviors.
- Identify the primary evidence-based intervention strategies that have been used to increase skill and enhance resilience in dementia caregivers.

A non-508-compliant streaming video of this lecture and related self-test is available on the NWGEC website ([Dementia Online Lecture, http://nwgec.org/educational-opportunities/lectures/online-videos/dementia-1/](http://nwgec.org/educational-opportunities/lectures/online-videos/dementia-1/)).

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Resilient Caregiving for Dementia Patients

Northwest Geriatric Education Center

Geriatric Health Promotion Telehealth Series

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David M. La Fazia, Ph.D., M.S.W.
Northwest Research Group on Aging
University of Washington

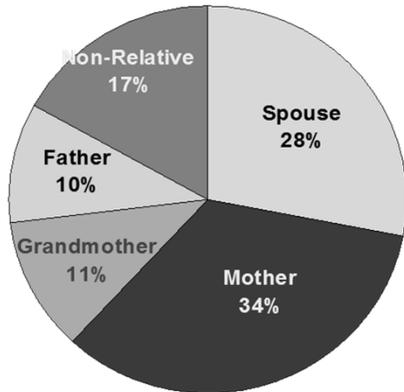


The Scope of Caregiving

- *There are more than 50 million caregivers in the United States*
- *40% of Americans over age 60 are caring for older or disabled adults*
- *On average caregivers spend 20 hours per week providing care*
- *14% of family caregivers are providing 40 hours or more of care per week*

AARP/National Alliance for Caregiving. [Caregiving in the U.S.](#) (2009)

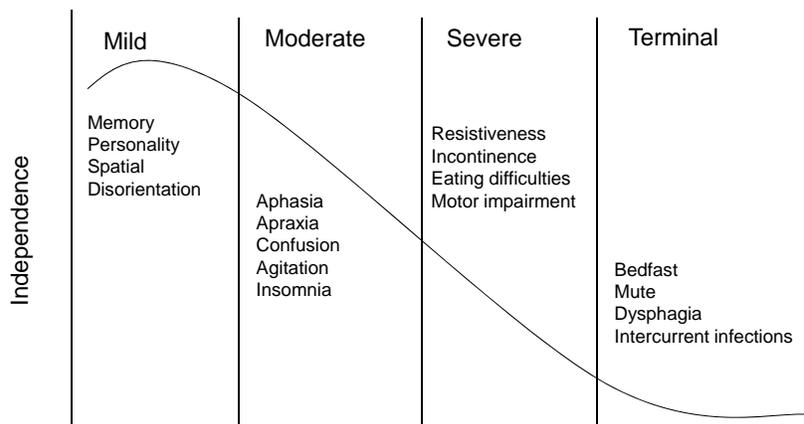
It's All in the Family: Who Needs Care?



AARP/National Alliance for Caregiving.
Caregiving in the U.S. (2009)

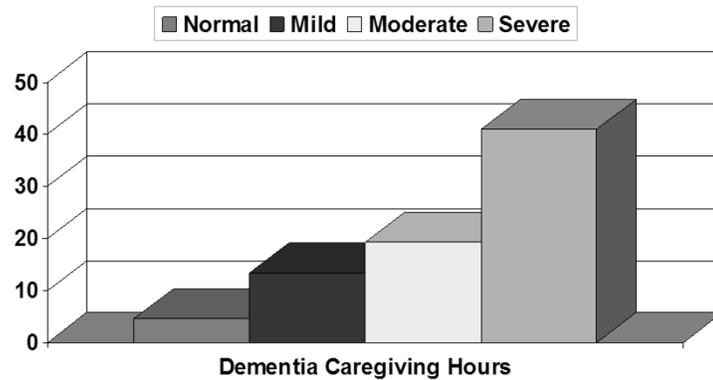
- 72% of care-recipients are 50 years or older (20% are 85 years or older)
- 65% are female
- 42% are widowed
- 85% take prescription medications
- 23% have Alzheimer's, dementia, or other mental confusion

Progression of Dementia



Bullock R. Alzheimer's Disease and Associated Disorders, 18 (supp. 1), S17-S23 (2004).

Time Spent Caregiving (Hours per Week)



Bullock R. *Alzheimer Disease and Associated Disorders*, 18 (supp. 1), S17-S23 (2004).

Caregivers - The “Unidentified Patient”

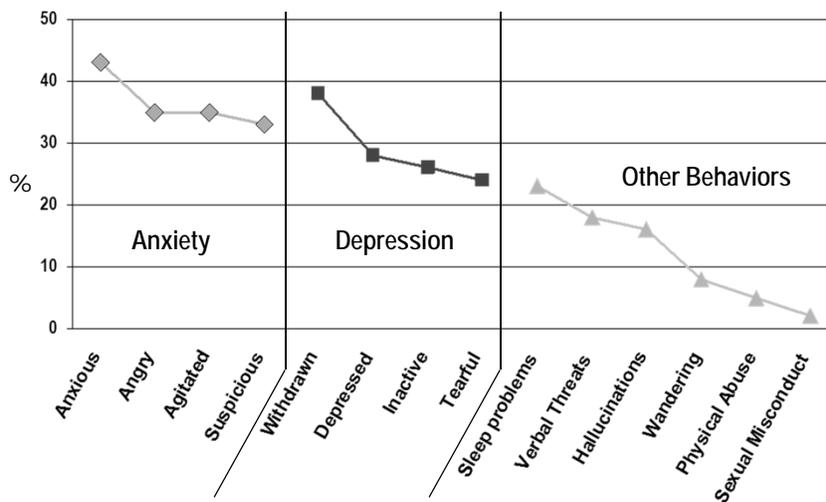
- Helplessness
 - Grief
 - Self-Doubt
 - Anger
 - Guilt
 - Anxiety
 - Sleep Disturbance
- 
- Diabetes
 - Hyperlipidemia
 - CHD
 - Obesity
 - Metabolic syndrome
 - Compromised immunity
 - HTN

Schulz et al., *Gerontologist*, 35, 771-791 (1995); Vitiliano et al., *Psychol Bull*, 129, 946-972 (2003).

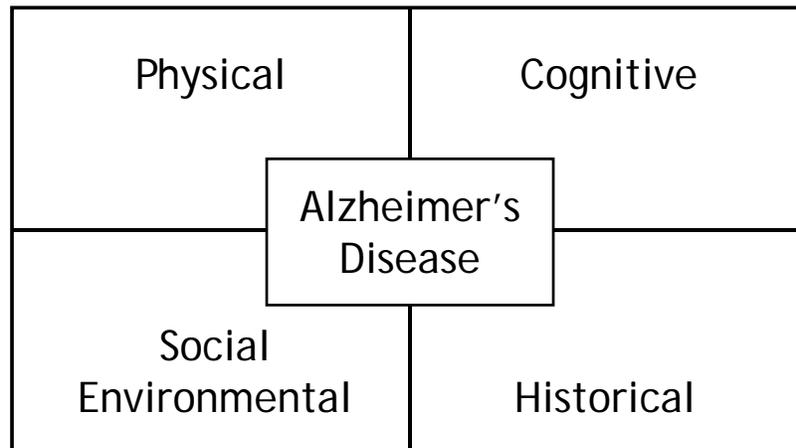
Behavior and Mood Disturbances in Dementia

- Occur in 70-90% of individuals at some point
- Increase as disease progresses from mild to severe stages
- Primary source of stress & burden to family caregivers
- Common cause of institutionalization
- May be difficult to treat, and require more than one intervention

Behavioral Challenges in AD (N=523)



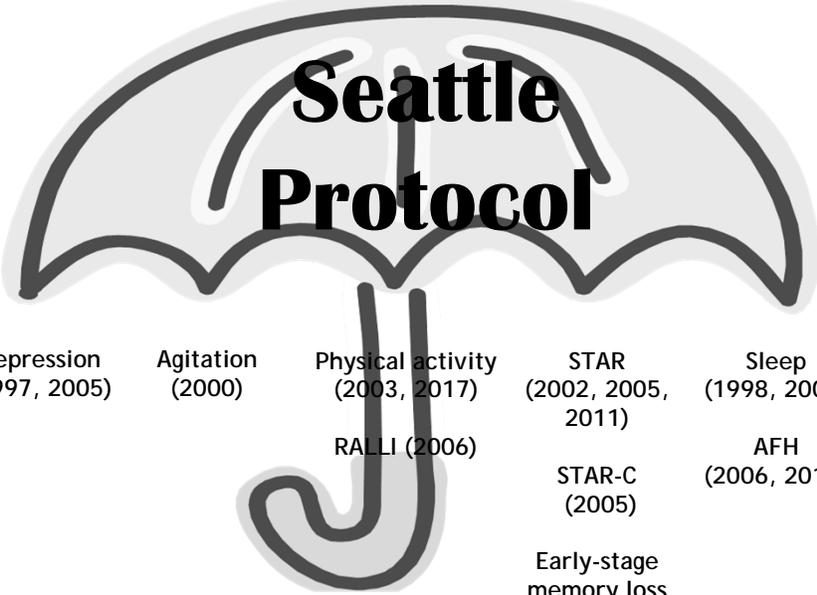
Causes of Behavioral Disturbances in Alzheimer's



Behavioral Treatments for Dementia

Reasons to Focus on Behavior

- Cannot alter cognition
- Can change behavior
- Can improve functional status
- Can increase quality of life for patient and caregiver



Seattle Protocol

| | | | | |
|----------------------------|---------------------|-----------------------------------|--|-----------------------|
| Depression (1997, 2005) | Agitation (2000) | Physical activity (2003, 2017) | STAR (2002, 2005, 2011) | Sleep (1998, 2005) |
| | | RALLI (2006) | STAR-C (2005) | AFH (2006, 2010) |
| | | | Early-stage memory loss (2006, 2014) | |

Teri, et al. 2005. [Research and practice in Alzheimer's disease and cognitive decline](#). Vol. 10, p.153-158. New York: Springer.

Seattle Behavioral Treatment Protocols

L. Teri, R. Logsdon, S. McCurry, J. Uomoto

- Partnership
- Standardized and individualized
- Skill building
 - Communication
 - Pleasant events
 - Problem-solve difficult situations
 - ABC's of behavior change
 - Maximize cognitive function
- Sustainability

The Caregiver/Care-Recipient Dyad

- Quality of life is influenced by mood, pleasant events, physical function, caregiver/care-recipient interactions, and cognition.
- A series of randomized clinical trials support the efficacy of psychosocial interventions targeting these factors for BOTH caregivers and individuals with dementia.
- What's good for the person with dementia is good for the caregiver and vice versa.

Seattle Protocol Studies

- Treatment of depression in persons with AD (Teri, et al., 1997, *J Gerontol: Psychol Sci*, *52B*, P159-P166)
- Treatment of sleep disturbances in dementia caregivers (McCurry, et al., 1998, *J Gerontol: Psychol Sci*, *53B*, P122-P129)
- Treatment of agitation in AD (Teri, et al., 2000, *Neurology*, *55*, 1271-1278)
- Increasing activity in AD (Teri, et al., 2003, *JAMA*, *290*, 2015-2022)
- Treatment for sleep disturbances in AD (McCurry, et al., 2005, *J Am Geriatr Soc*, *53*, 793-802)
- Training community consultants to help family caregivers (Teri, et al., 2005, *Gerontologist*, *45*, 802-811)
- Training staff caregivers in assisted living facilities (Teri, et al., 2005, *Gerontologist*, *45*, 686-693)
- Efficacy of early stage dementia support groups (Logsdon, et al., 2006, *Clin Gerontol*, *30*, 5-19)
- Treating sleep disturbances in adult family homes (McCurry, et al, *Geriatric Nursing*, 2009)

Sample Study Outcomes

- ✓ Reductions in care-recipient and caregiver depression (1998)
- ✓ Improvements in care-recipient physical function, depression; reduced institutionalization for behavioral disturbances (2003)
- ✓ Reduced care-recipient behavior problems; reduced caregiver depression, burden, and reactivity to behavior problems (2005)
- ✓ Improved care-recipient quality of life; reduced family conflict and caregiver reactivity to behavior problems (2006)
- ✓ Improved caregiver and care-recipient sleep, both among community dwelling and AFH residents (1998, 2005, 2009)

Practice Guidelines: the DANCE

- Don't argue
 - ✓ Verbal and nonverbal communication
- Acceptance
 - ✓ Realistic limitations
- Nurture yourself
 - ✓ Respite and asking for help
- Creative problem-solving
 - ✓ ABCs of behavior change
- Enjoy the moment
 - ✓ Pleasant events, laughter & uplifts



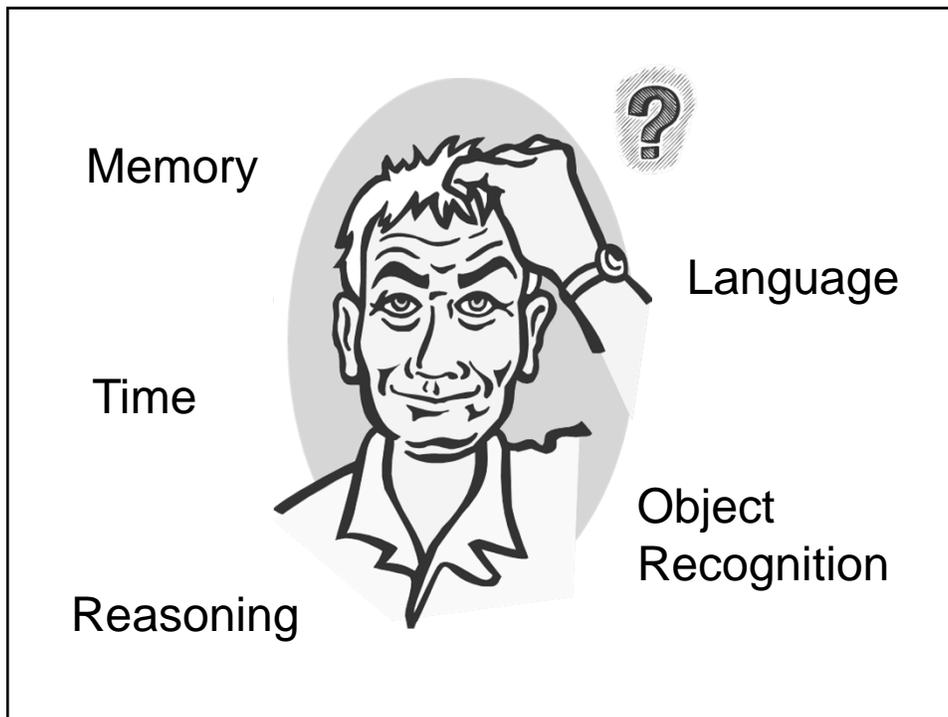
McCurry, S.M. 2006. *When a family member has dementia*. New York: Praeger Press

Communication: *Don't Argue!*

- Communication can make or break any relationship.
- Dementia affects both expressive and receptive language.
- As dementia progresses, communication becomes less verbal, more body language.

“Recently my mother had her hair done at the salon down the street. Afterwards, she insisted that her sister (who lives on the East coast) had given her the perm. Do you have any thoughts on these type of episodes (where the person with dementia adamantly denies an obvious reality)?”

- Caregiver



Communication

Early Stage

- Allow time for unhurried interactions
- Double-check instructions to make sure the person understands them
- Try using written instructions
- Avoid challenging the person, or do so in a non-threatening way
- Answer repetitive questions consistently

Mid-Later Stage

- Use a soothing voice
- Speak slowly and clearly (not loudly)
- Maintain eye contact and a pleasant facial expression
- Use non-threatening body language
- Do one task at a time
- Reduce distracting background noises

**“Listen with respect,
comfort and redirect.”**

Linda Teri, Ph.D.

**Listen with respect,
comfort and redirect**

- Listen: Eye contact; Focus on the person.
- Respect: Pay attention to non-verbal communication.
- Comfort: Pay attention to what the person is thinking/feeling; Let them know that you understand.
- Redirect: Attempt to change the subject; Try a different activity.

Acceptance: **Realistic Expectations**

- Dementia affects the way a person thinks, feels, makes decisions, and reacts.
- Persons with dementia do not have control over their symptoms.
- Dementia symptoms fluctuate, sometimes unpredictably.
- Because of their brain disease, persons with dementia may not realize how much help they need.

Realistic Expectations

Early Stage

- Obtain medical evaluation to rule out treatable causes of dementia
- Encourage person to be independent in normal routines
- Expect inconsistent gaps in ability
- Don't assume that changes are deliberate or due to "denial" or "lack of motivation"

Mid-Later Stage

- Regularly double-check driving, financial records, medications, diet, hygiene
- Share safety concerns with involved family or caregivers
- Don't expect the person with dementia to readily accept your help.
- Do expect to sometimes feel embarrassed, angry, or disappointed

Increasing Caregiver Knowledge

- McCurry S. When a family member has dementia: Steps to becoming a resilient caregiver. Praeger: Westport: CT (2006).
- Robinson A, et al. Understanding difficult behaviors. Eastern Michigan University: Ypsilanti, MI (1994).
- Lists of caregiver education materials that are continually updated and reviewed:
 - Alzheimer’s Disease Education and Referral Center (ADEAR) (www.alzheimers.org; 1-301-495-3311)
 - Alzheimer’s Association (www.alz.org; 1-800-272-3900)
 - Rosalynn Carter Institute for Caregiving (caregiver help page) (www.rosalynncarter.org/caregiver%20resource%20center/)
 - Ask Medicare website (www.medicare.gov/caregivers)

***Nurture yourself:* Take a Break When You Need It**

- “Check your own pulse first”
- Physical and emotional health: The best inoculation against burnout
- Who in your life wants to help but doesn’t know how?
- Find 10 minutes every day to do something that you love.
- Respite is good for caregivers and for persons with dementia

“I’ve been thinking a lot about what you said about taking vacations and not just staying at home waiting for Dad to die. And I’ve also noticed that my father-in-law is happy when one or both of us go out, too. I guess he doesn’t want to die to get rid of us for a few hours, either!”

- Caregiver

Nurture Yourself

Early Stage

- Stay involved in meaningful outside activities
- Exercise, exercise, exercise
- Maintain a careful diet
- Follow your doctor’s recommendations
- Find someone you can talk to about how you’re doing

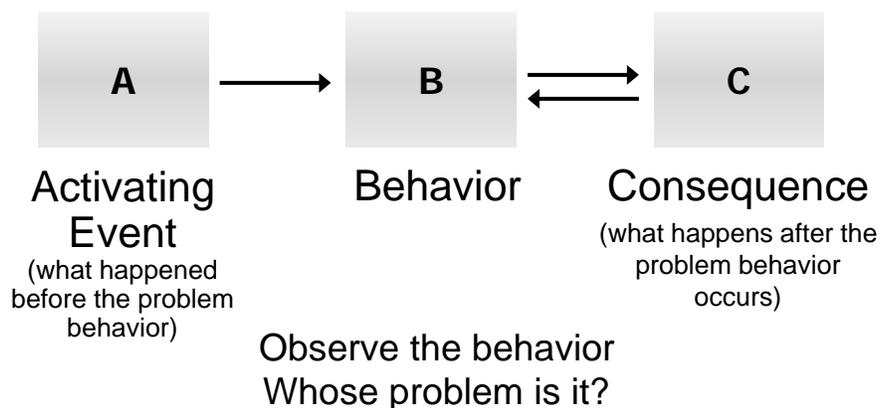
Mid-Later Stage

- 3 R’s: Regular respite and relaxation!
- Ask people to help you
- Let people help you when they offer
- Consider adult day programs

Community Resources

- Alzheimer' Association (www.alz.org; 1-800-272-3900)
- National Adult Day Services Association
(www.nadsa.org; 1-800-558-5301)
- National Association of Professional Geriatric Care
managers (www.caremanager.org; 1-520-881-8008)
- Area Agencies on Aging (AAA)
 - Includes Senior Information and Assistance, Senior Rights Assistance (www.seniorservices.org; 1-800-972-9990)
- Respite services
 - National respite locator (www.respitelocator.org)

Creative Problem-Solving: The ABCs of Behavior Change



Teri L. Logsdon RG. *Comprehensive Therapy*, 16(5), 36–42 (1990).

Changing the ABC's of Behavior

- “A”: Look for the antecedent
 - What happened before the behavior?
- “B”: Define and observe the problem
 - What is the current behavior?
 - Who does it happen around?
 - Where does it happen most?
 - When does it occur?
- “C”: Identify the consequence
 - What happened after the behavior?
 - How did others react?

A-B-Cs: Simple but Tricky

- Creative brainstorming is not always easy
- Behaviors can be influenced by more than one thing at a time
- The message being communicated is more important than the actual behavior
- Observation is critical and challenging
- The caregiver is always right

How the A-B-Cs Really Work

*Step 1. The Problem (B)
Happens*

Looking for Consequences

Step 2. Breathe.

Step 2^{1/2}. Notice: What Am I Doing? (C)

AM I:

- Upset – Arguing, yelling, restraining
- Comforting – Soothing, reassuring
- Ignoring - Redirecting
- Using logical reasoning

IS IT HELPING?

- If yes, keep it up!
- If no, try something (anything) else

Identifying Antecedents

Step 3. Reflect: What Was Going On Before the Problem Developed? (A)

- What was I doing?
- What was the person with dementia doing?
- What was going on in the environment (noise, other people, activity, meals, personal care, time of day, lighting)?
- How was I feeling (rushed, impatient, nervous, worried, sad, irritable, distracted)?

“I DON’T KNOW” - How can you find out?

- Keep a log
- Ask someone else to help observe

Common Triggers for Problems

- Pain or physical discomfort
- Infection
- Medication side effects
- Fatigue
- Over- (or under-) stimulation
- Caregiver communication style

Thinking Ahead

Step 4. Making a Realistic Plan

- Select problems that can be changed
- Select problems that occur frequently
- Triggers can be small
- Consistency is critical
- Give it time
- Ask others to help brainstorm

The best way to get a
good idea is to get
lots of ideas.

-Linus Pauling

Enjoy the Moment: **Finding the Gifts of Dementia Care**

- Laughter and love are good medicine
- Pleasant events improve mood and reduce behavior problems
- Look for the uplifts:
 - Why are you a caregiver?
 - What does your loved one give back?

Why Do Caregivers Do It?

- “I have a heart for the job”
- A sense of fulfillment or purpose
- Tangible evidence it makes a difference
- Wanting to give back to a loved one who is “still there”
- Cultural or family traditions (“we take care of our own”)
- What if this were my mom or dad (or me)??

Dran D. “A heart for the job”: Rewards of giving care to residential elderly in times of personnel shortages”. 15th annual Alzheimer’s Association Dementia Care Conference (2007).

“Alzheimer’s disease is not the end. Sometimes it can be a beginning...Memory Bridge believes people with dementia are still here, still reachable at depths of memory and presence beyond the ravages of Alzheimer’s disease, still able to love and be loved...”

- Memory Bridge: The Foundation for Alzheimer’s and Cultural Memory <http://www.memorybridge.org/#>

Increasing Pleasant Activities

- What did the person enjoy in the past?
- What does he/she enjoy now?
- How can tasks be modified to accommodate current abilities?
- Who is available to help with these activities?

Pleasant Events Schedule: AD

© 1995 R. G. Logsdon, Ph.D. & L. Teri, Ph.D.

Instructions: This schedule contains a list of events or activities that people sometimes enjoy. It is designed to find out about things your relative has enjoyed during the past month. Please rate each item twice. The first time, rate each item on how many times it happened in the past month (frequency); the second time, rate each event on how much your relative enjoys the activity.

| Activity | Frequency | | | Enjoy | | |
|---|------------|--------------|-----------------|------------|-----------|--------------|
| | Not At All | 1 to 6 Times | 7 or more Times | Not At All | Some-what | A Great Deal |
| 1. Being outside | | | | | | |
| 2. Shopping, buying things | | | | | | |
| 3. Reading or listening to stories, magazines, newspapers | | | | | | |
| 4. Listening to music | | | | | | |

Sample Activity Categories

- **Structured physical activity:**
 - ❖ Exercise, household or yard chores, hobbies, anything that expresses creativity
- **Life story notebook:**
 - ❖ Capturing reminiscences in a way that they can be shared with others
- **Memory notebook:**
 - ❖ Simple instructions for doing things that matter

G Hersch, T Miller. "An activity-based intervention for early stage dementia". 15th annual Alzheimer's Association Dementia Care Conference (2007).

**Every Interaction can
be a Pleasant Event!**

Obstacles to Activities

- Lack of time or money
- Plan is too complicated, more trouble than it's worth
- Negative behaviors interfere with pleasant activities
- Caregiver is burnt-out
- Participant refuses to participate

“ [I want] the right to refuse any activity or program that I don’t find entertaining. ”

Robert Davis

My Journey into Alzheimer’s Disease, 1989

Advantages of Behavioral Treatment

- Addresses interpersonal and environmental causes of behavioral disturbances.
- No interactions with other medications or side effects.
- Empowering for caregivers and individuals with dementia.
- Gives caregivers tools they can use in future situations.

Partnering With Family Caregivers

- Family caregivers are the “experts” about their relative.
- Therapists are “consultants” who provide specific information about dementia and associated problems.
- It is often necessary to work with other family members in addition to other health care providers.

Characteristics of Resilient Caregivers

- Energy, desire, ability to do things differently
- Willingness to ask for and accept help from others
- Flexibility in thinking and problem solving
- Sense of humor
- Patient, but able to be firm
- Belief that things can change
- Good prior relationship with patient

Keys to Getting There

- Stay in touch with your values
 - Finding purpose and meaning in your role
- Perfection is not the goal
 - “Good enough” caregiving
- Remember you are not alone
 - Who wants to help?

The Seattle Protocols Core Research Team

Linda Teri, PhD

Rebecca Logsdon, PhD

Sue McCurry, PhD

David La Fazia, PhD, MSW

June van Leynseele, MA

Amy Moore, MS

Ken Pike, PhD

Martha Cagley, MA

Cathy Blackburn, BA

Cat Olcott

And the many persons with dementia and family caregivers who have shared their lives and experiences with us.

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