

# Resilient Caregiving for Dementia Patients

*Northwest Geriatrics Workforce  
Enhancement Center*

*ADRD Geriatric Lecture Series*

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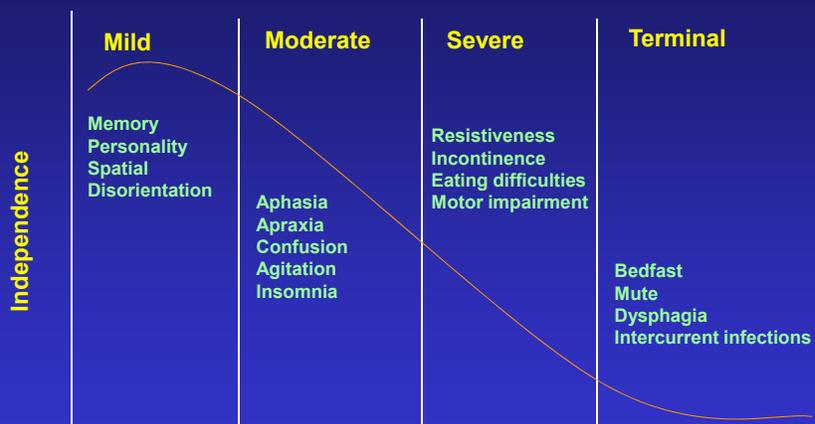
***“There are only four  
kinds of people in the  
world: those who have  
been caregivers; those  
who are currently  
caregivers; those who  
will be caregivers; and  
those who will need  
caregivers.”***

*- Rosalynn Carter*

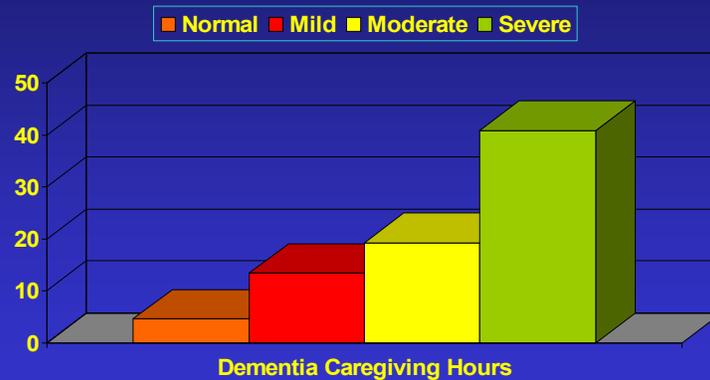
## The Scope of Caregiving

- *There are more than 40 million caregivers of persons age 50 and older in the United States*
- *26% are caring for someone with Alzheimer's or dementia*
- *On average caregivers spend 20 hours per week providing care*
- *21% of family caregivers are providing 40+ hours or more of care per week*

## Progression of Dementia



## Time Spent Caregiving (Hours per Week)



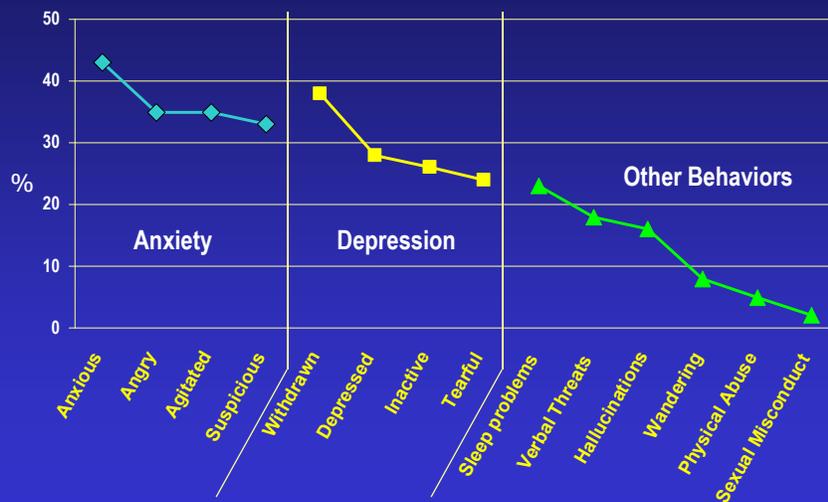
## Caregivers - The "Unidentified Patient"

- Helplessness
  - Grief
  - Self-Doubt
  - Anger
  - Guilt
  - Anxiety
  - Sleep Disturbance
- 
- A circular diagram consisting of four arrows forming a clockwise cycle. The arrows are colored blue, yellow, red, and blue, starting from the top and moving clockwise.
- Diabetes
  - Hyperlipidemia
  - CHD
  - Obesity
  - Metabolic syndrome
  - Compromised immunity
  - HTN

## 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 caregivers
- Common cause of institutionalization
- May be difficult to treat, and require more than one intervention

## Behavioral Challenges in AD (N=523)



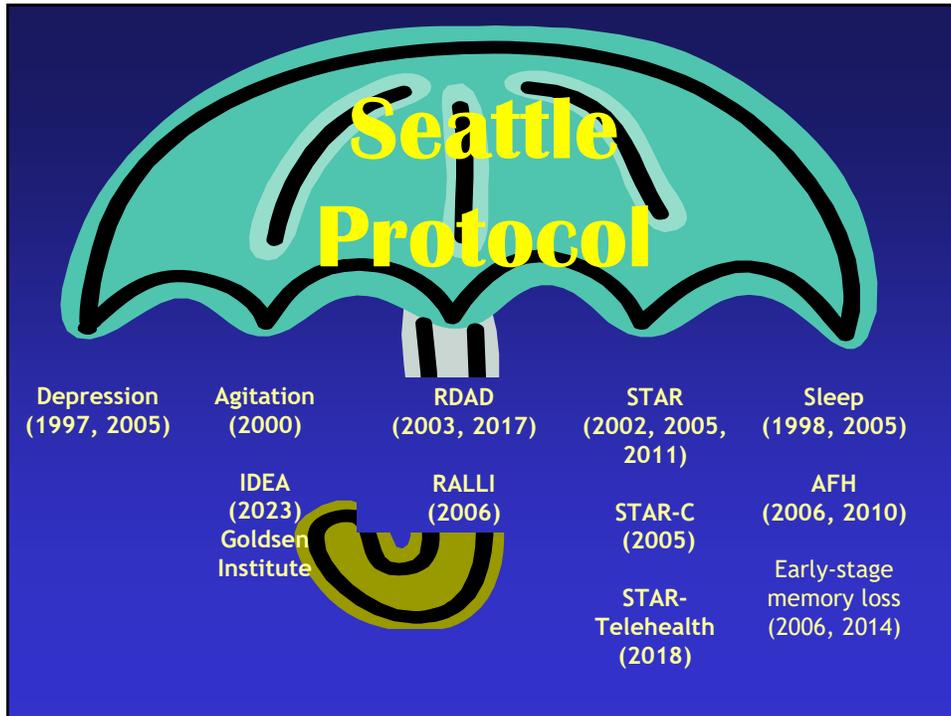
## Behavioral Treatments for Dementia

### *Reasons to Focus on Behavior*

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

## 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 Behavioral Treatment Protocols

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

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

## Sample Study Outcomes

- ✓ Reductions in care-recipient and caregiver depression (1998, 2003, 2005)
- ✓ Improvements in care-recipient physical function, depression; reduced institutionalization for behavioral disturbances (2003, 2014, 2018)
- ✓ 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, 2018)
- ✓ Improved caregiver and care-recipient sleep, both among community dwelling and AFH residents (1998, 2005, 2010)
- ✓ Reduced caregiver stress and improved care-recipient physical functioning, behavior problems, and depression for LDBTQ+ older adults and caregivers (2022)

## Case Example: Sleep Disturbances

Mrs. A is an 81 year old woman with Alzheimer's disease who lives with her adult daughter. She is getting up during the night and dressing at around 2 - 4 am. She frequently removes her undergarments and leaves them in the toilet or in a fish tank that is in the hallway. She recently left the house in a thin nightgown and was very chilled when her daughter got her back inside. The daughter is overwhelmed and exhausted - thinking she may not be able to keep mom in her home.

## 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



## 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.

## 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

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

Linda Teri, Ph.D.

## **Listen with respect, comfort and redirect**

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- **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.

**“If, when we speak to you, we repeat the same things over and over again, do not interrupt us. Listen to us. When you were small, we had to read to you the same story a thousand and one times until you went to sleep.....**

© 2005-2006 <http://ParentsWish.com>

## 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

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- 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: Some practical suggestions for coping with Alzheimers disease and related illnesses. Eastern Michigan University: Ypsilanti, MI (2007).
- Lists of caregiver education materials that are continually updated and reviewed:
  - Alzheimer’s Disease Education and Referral Center (ADEAR) ([www.alzheimers.org](http://www.alzheimers.org); 1-301-495-3311)
  - Alzheimer’s Association ([www.alz.org](http://www.alz.org); 1-800-272-3900)
  - Rosalynn Carter Institute for Caregiving (caregiver help page) ([www.rosalyncarter.org/caregiver%20resource%20center/](http://www.rosalyncarter.org/caregiver%20resource%20center/))
  - Ask Medicare website ([www.medicare.gov/caregivers](http://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

## 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

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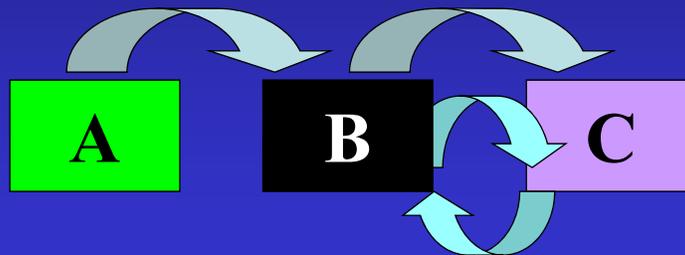
## Community Resources

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

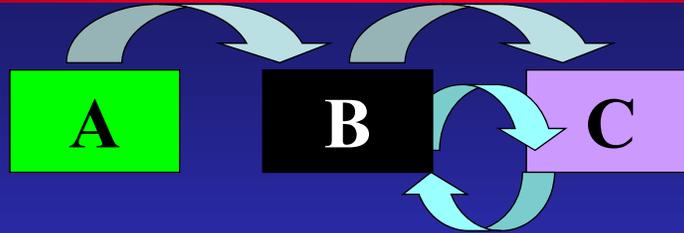
## Creative Problem-Solving: The ABCs of Behavior Change

### *Problem Behaviors Occur in Three Parts*

- Antecedent/Activator = A triggering event.
- Behavior = The behavior itself.
- Consequence = The response to the behavior.

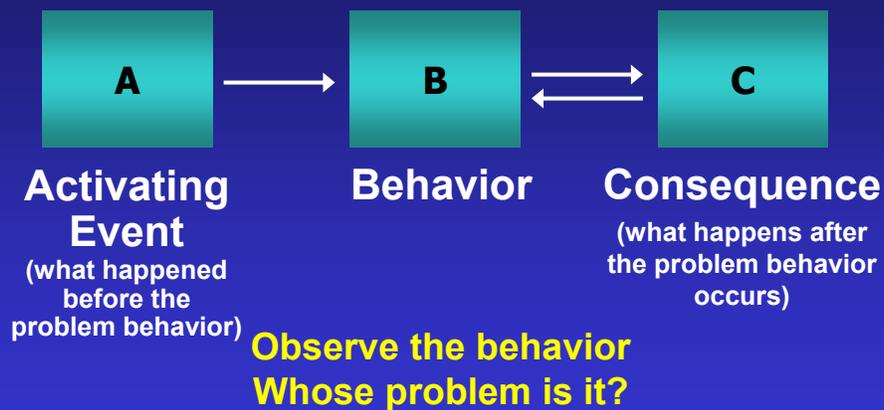


## Rationale for Using the ABCs



- To prevent a behavior from happening (*by changing the activator*)
- To keep a current behavior from getting worse or continuing (*by changing your response, the consequence*)
- To reduce the probability of the behavior occurring in the future (*by changing both activators and consequences*)

## 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<sup>1/2</sup>. 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

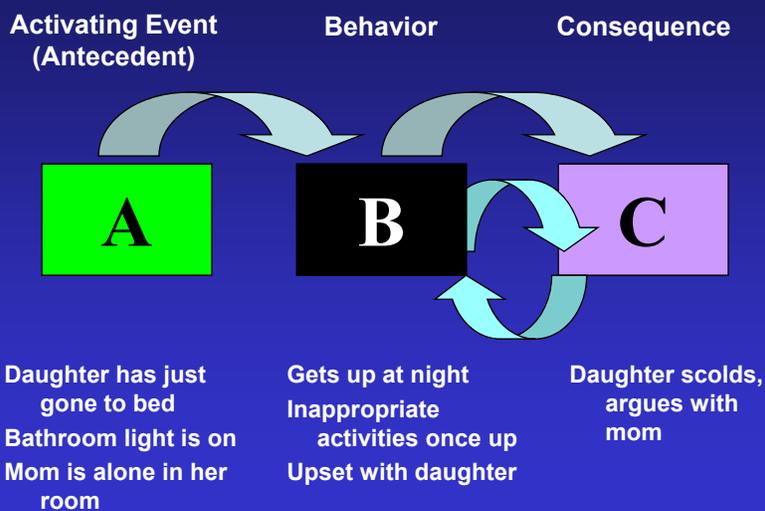
## Common Triggers for Problems

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

## Case Example: Sleep Disturbances

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## The A-B-C's of Problem Solving



## 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

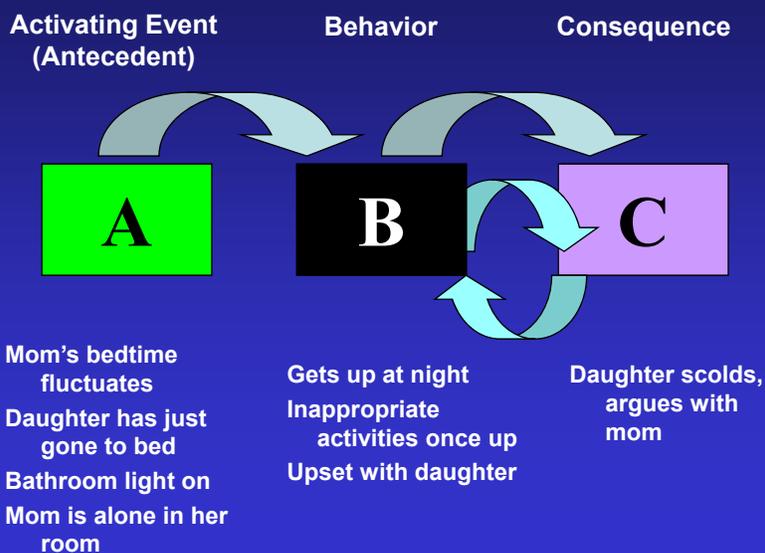
**The best way to get a  
good idea is to get  
lots of ideas.**

**Linus Pauling**

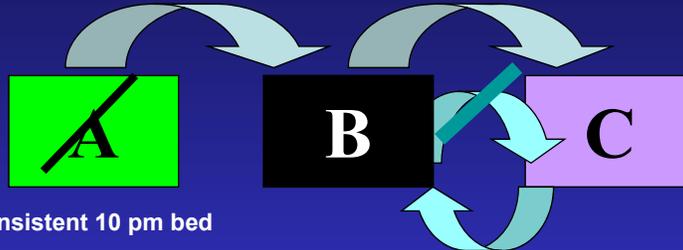
## Brainstorming Ideas

- Check with physician to see if any of mom's medications or medical problems are waking her up at night.
- Install alarm system on outside doors.
- Eliminate late afternoon and evening napping.
- Move fish tank out of the hallway near the bathroom.
- Give mom a snack before bed so to make sure she's not hungry during the night.
- Switch to adult incontinence undergarments.
- Establish consistent bed, rising times.
- Increase daytime physical and social activity.

## The A-B-C's of Problem Solving



## A-B-C Approach



- ❑ Set consistent 10 pm bed time
- ❑ Night lights
- ❑ Moved fish tank
- ❑ Started in adult day several days/week
- ❑ Eliminated evening naps
- ❑ Put child monitor in mom's room

- ❑ Mom is redirected quickly back to bed
- ❑ Sleep improvements: Total increased sleep time; fewer awakenings during the night

- ❑ Daughter gets up when she hears mom go into bathroom
- ❑ Stopped scolding, using angry tone

## 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)??



*“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

**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
- Care-recipient 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 carers 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?

## Acknowledgements

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

*Thank you*

## Selected 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)

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