Resilient Caregiving for Persons with Dementia

UW Elder-Friendly Futures

Gerontology Conference

September 12, 2013

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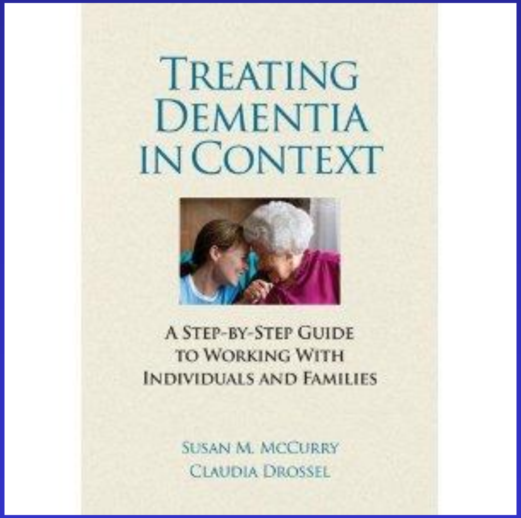
Disclosure Statement

Some content from this presentation will be derived from books that Dr. McCurry has written on dementia care.

WHEN A FAMILY MEMBER
HAS DEMENTIA



TREATING
DEMENTIA
IN CONTEXT

A STEP-BY-STEP GUIDE
TO WORKING WITH
INDIVIDUALS AND FAMILIES

SUSAN M. MCCURRY
CLAUDIA DROSSEL

“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

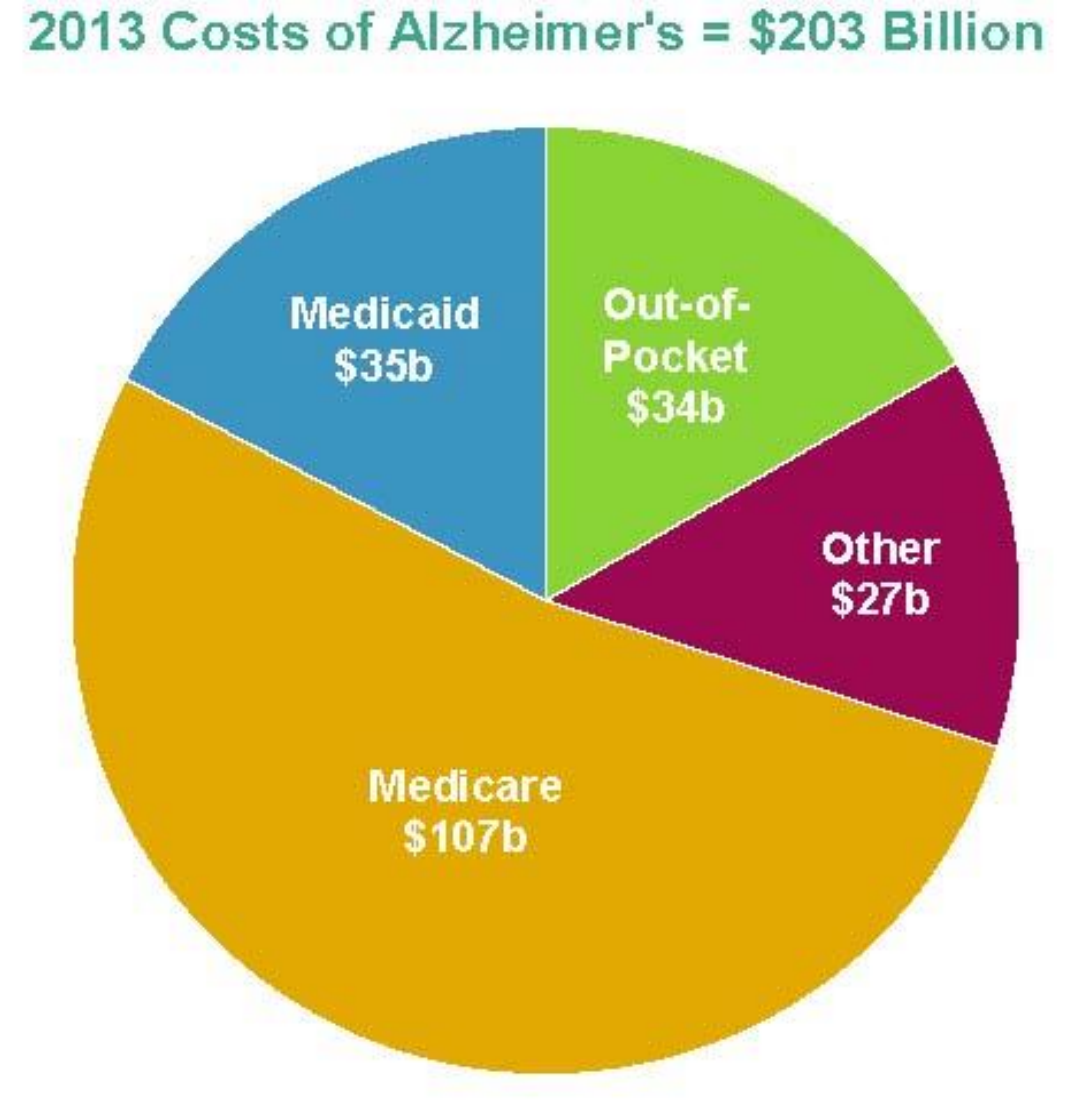
Dementia as Chronic Illness

- **Alzheimer’s disease & dementia affects the fastest growing segment of our population**
- **One in 8 older Americans has Alzheimer’s disease**
- **Nearly half (45%) of persons age 85 and older have AD**
- **Individuals are being diagnosed earlier and will most likely live with the disease for many years**

The Toll on Families is High

- Families provide the bulk of care for older adults with dementia
- In 2012, 15.4 million family and friends provided 17.5 billion hours of unpaid care
- Nearly 15% of caregivers are long-distance caregivers, living an hour or more away
- More than 60% of caregivers rate their emotional stress as high or very high

The Costs Are Staggering

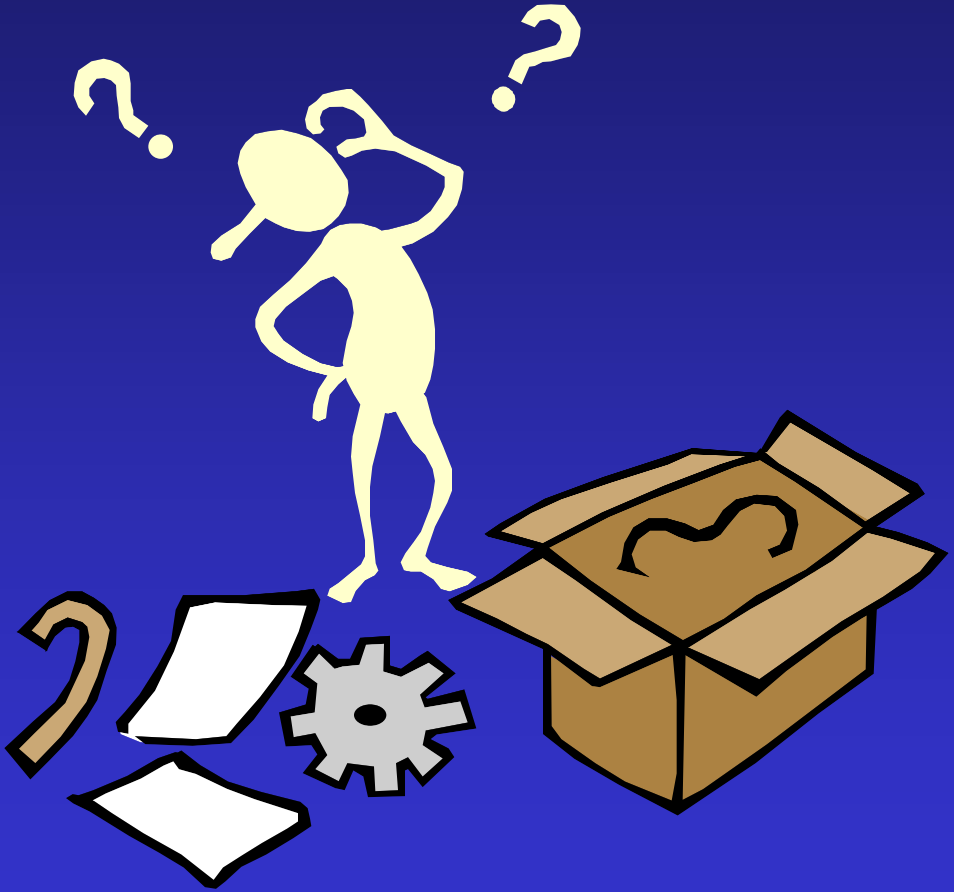


Alzheimer's Association: 2013 Alzheimer's Disease Facts & Figures

Behavior and Mood Disturbances Are Widespread

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

So What Can We Do To Help???



Give Behavioral Treatment a Try

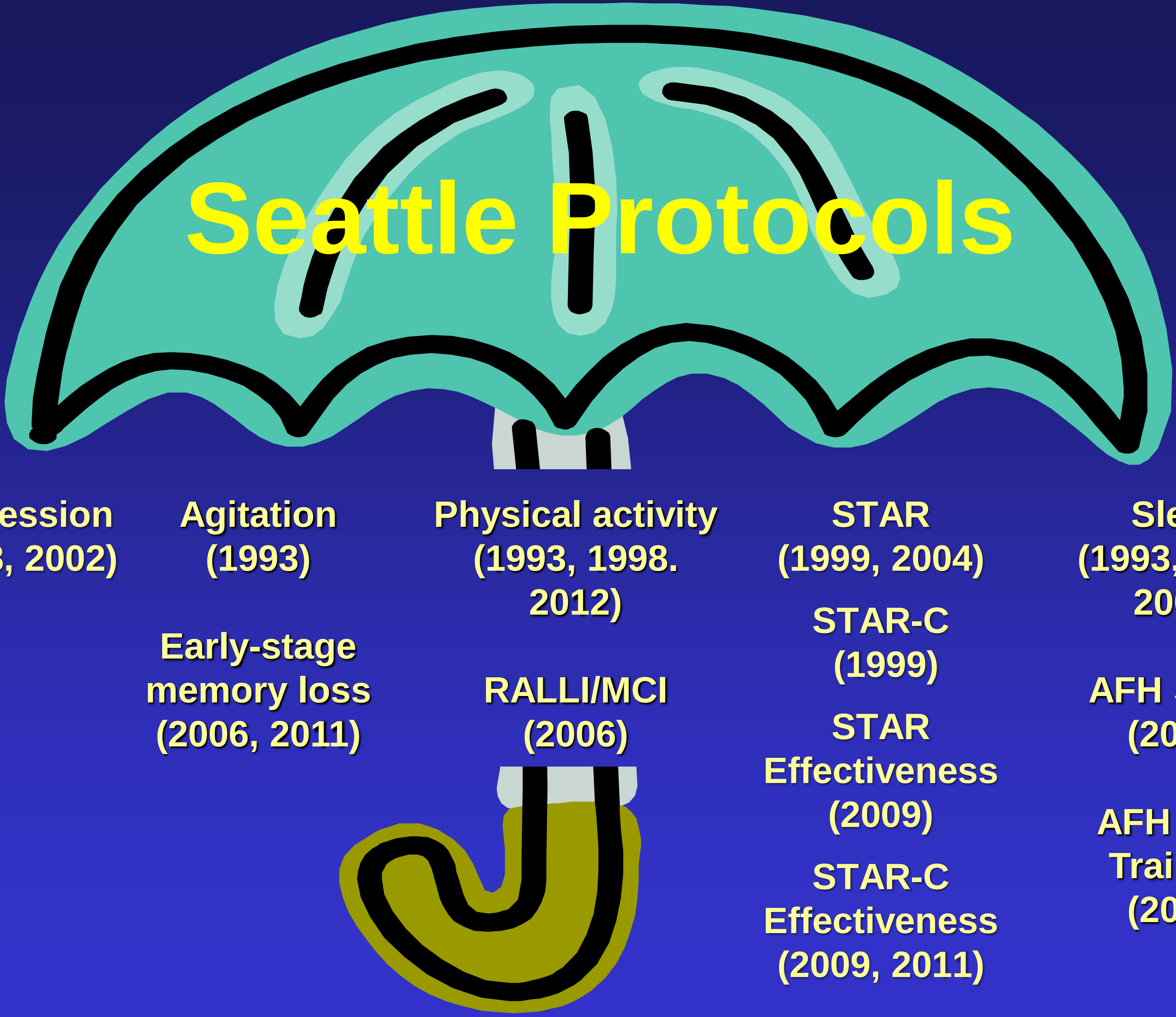
Several international and national professional associations and government policies have recommended non-pharmacological interventions as the first-line treatment for the mood and behavior changes associated with cognitive decline.

Behavioral Treatments for Dementia

Reasons to Focus on Behavior

- Cannot alter brain disease progression
- <u>Can</u> change behavior
- Can improve functional status
- Can increase quality of life for patient and caregiver

Seattle Protocols



Depression
(1988, 2002)

Agitation
(1993)

Early-stage
memory loss
(2006, 2011)

Physical activity
(1993, 1998.
2012)

RALLI/MCI
(2006)

STAR
(1999, 2004)

STAR-C
(1999)

STAR
Effectiveness
(2009)

STAR-C
Effectiveness
(2009, 2011)

Sleep
(1993, 1998,
2005)

AFH Sleep
(2006)

AFH Staff
Training
(2009)

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 yet individualized
- Skill building
  - Realistic expectations
  - Communication
  - ABC's of behavior change
  - Problem-solve difficult situations
  - Pleasant events
- Sustainability

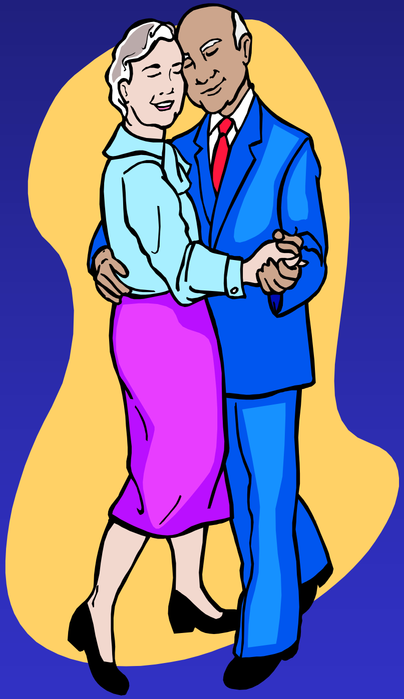
The Caregiver/Care-Receiver Dyad

- Quality of life is influenced by mood, pleasant events, physical function, caregiver/care-receiver 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.

Sample Study Outcomes

- **Reduced care-receiver and caregiver depression (1998)**
- **Improved care-receiver physical function, depression; reduced institutionalization for behavioral disturbances (2003)**
- **Reduced care-receiver target behaviors; reduced caregiver depression, burden, and reactivity to behavior challenges, both in the community and in AL settings (2005; 2013)**
- **Improved caregiver and care-receiver sleep, both among community dwelling and AFH residents (1998, 2005, 2011, 2012)**
- **Improved quality of life for persons in early stages of dementia; reduced family conflict and caregiver reactivity to behavior changes (2010)**

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.
- As cognitive decline progresses, nonverbal communication is more important; is your body sending the message you intend?
- Rapport building trumps information gathering or accuracy of facts
- Whenever there is a problem, check to see if there is a communication breakdown.

Watch Nonverbal Cues: Be Polite!

Patience	Don’t be in a hurry. Say/do one thing at a time. Focus on the relationship more than content.
Organization	Use prompts and reminders as needed. Don’t keep people waiting. Make sure prosthetics are handy.
Laughter	Smile! Try to be pleasant and engaging. Don’t be afraid of friendly humor. Sincere praise is a gift.
Ignore what you can	“Pick your battles.” Don’t correct or admonish unless the person is doing something unsafe or unhealthy. Watch for ageist stereotyping.
Tone of Voice	Cultivate a warm and respectful style. Try not to sound “bossy” or patronizing. Would *you* want to be talked to this way???
Eye Contact	Look directly at the person. Stand or sit at eye level. Smile/nod to acknowledge you heard what was said.

McCurry S, Drossel D. (2011). Treating dementia in context: A step-by-step guide. APA Press.

“Listen with respect, comfort and redirect.”

Linda Teri, Ph.D.

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,

Knowledge is Power

- McCurry S. When a family member has dementia: Steps to becoming a resilient caregiver. Praeger: Westport: CT (2006).
- McCurry SM, Drossel C. Treating dementia in context. Washington DC: APA Press (2011).
- Robinson A, et al. Understanding difficult behaviors. Eastern Michigan University: Ypsilanti, MI (1994).
- Online caregiver education materials that are continually updated and reviewed:
  - –NIH Senior Health (http://nihseniorhealth.gov/alzheimerscare/afterthediagnosis/01.html)
  - –Alzheimer's Association (www.alzwa.org; 1-800-848-7097)
  - –Area Agencies on Aging (AAA; www.seniorservices.org; 1-800-972-9990)

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 <u>and</u> 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

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

Activator:

What happened before the behavior?

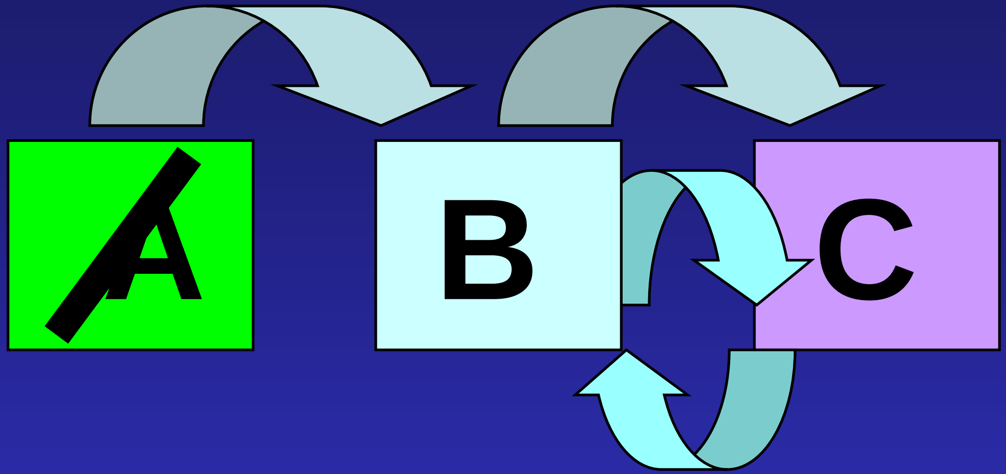
Behavior:

What exactly was the person with dementia doing? Paint a verbal picture!

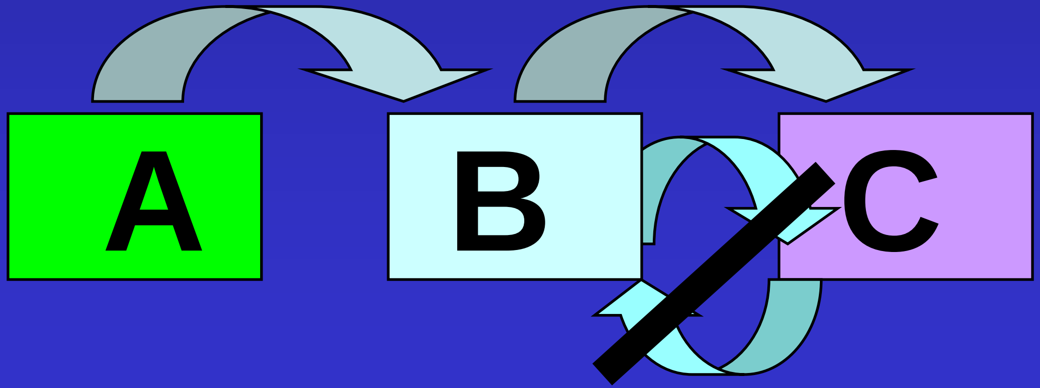
Consequence:

What happened after the behavior?

Goals of the A • B • Cs



Identifying and changing activators can prevent a behavior from happening



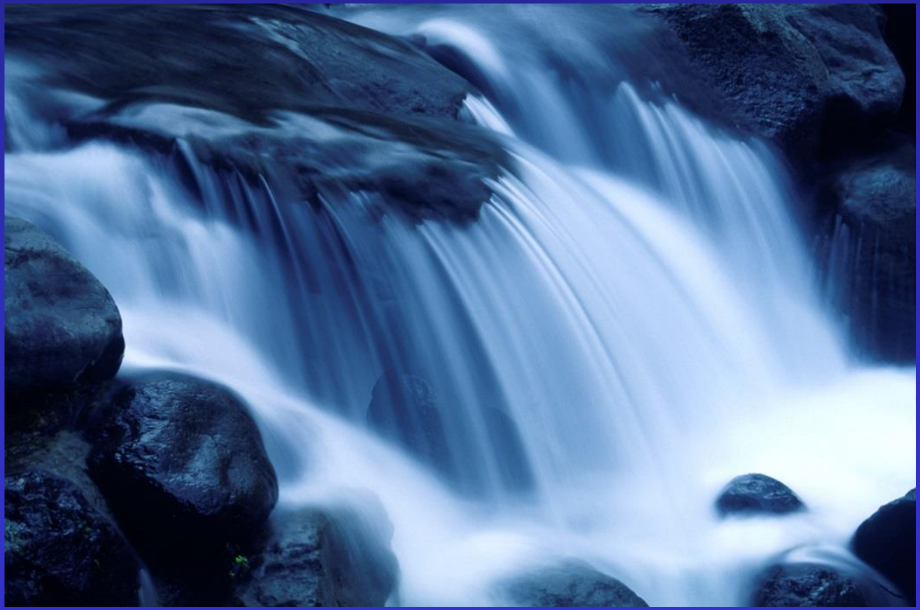
Changing your response to behaviors can reduce their duration, severity, and probability of occurring in the future

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

Activators in Dementia

Physical	Cognitive
Social Environmental	Historical

Behavior of Concern

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

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 <u>my</u> 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).

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

Instructions: This schedule contains a list of events or activities that people sometimes enjoy. It is designed to find out about things <u>your relative</u> 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.

	Frequency			Enjoy		
Activity	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-baseed intervention for early stage dementia”. 15th annual Alzheimer’s Association Dementia Care Conference (2007).

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

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.

Limitations to Behavioral Treatments

- Not crisis management.
- No treatment works for all people all of the time.
- Consistency is important, so everyone involved in care needs to be on board with the plan.
- Both caregiver and care-recipient factors influence what behavioral interventions are feasible and effective.

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

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June van Leynseele

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

Research on the Seattle Protocols has been funded by the National Institute of Mental Health, National Institute on Aging, the Alzheimer's Association, the States of Oregon and Washington, and the University of Washington