

# Behavioral Management in AD: An Evidence-Based Approach

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ADRD Geriatric Healthcare Series  
Northwest Geriatric Workforce Education Center

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1

## Neuropsychiatric Behaviors and Family Care

- Alzheimer's disease & dementia affects the fastest growing segment of our population
- Families provide the bulk of care for older adults with dementia
- Mood and behavior problems are the main reason families become unable to provide care
- Mood and behavior problems significantly and adversely affect individuals with dementia and their caregivers

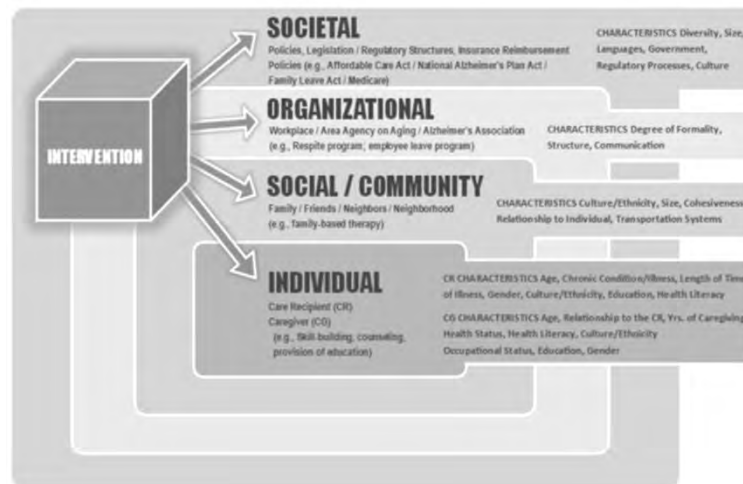
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## Why Behavioral Treatment?

- Medications can only do so much
  - Don't always work
  - Can cause unwanted side effects
  - Can be expensive
  - Don't solve the underlying problem
- Behavioral treatments
  - Can be individualized to each person
  - Empower caregivers
  - Help you see the "big picture"
  - Are useful at every stage of disease

3

## Framework for Care Interventions



Retrieved from: <https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol> 7/25/19 Research Protocol (downloadable .pdf)

4

# There Are Many Options

From PubMed, 5/6/20

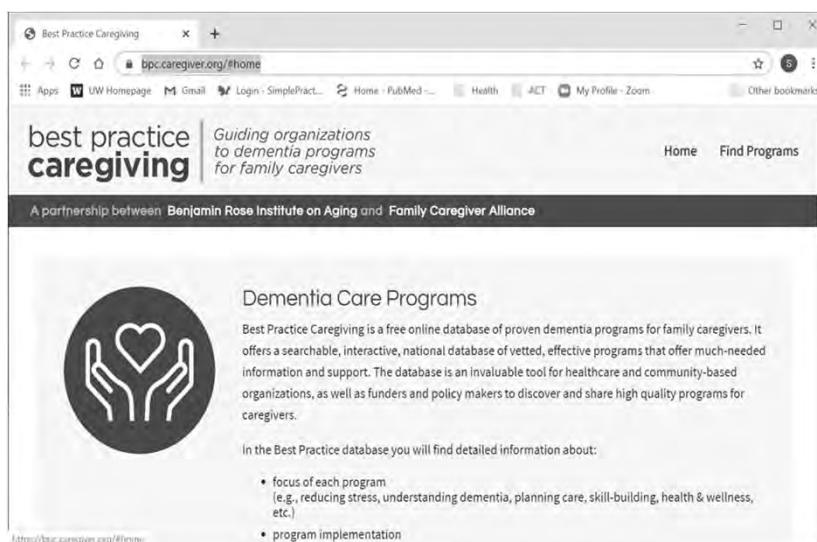
**(dementia or Alzheimer) AND evidence-based AND nonpharmacological AND (treatment or intervention) – 44 articles**

**(dementia or Alzheimer) AND (randomized controlled trial) AND nonpharmacological AND (treatment or intervention) – 76 articles**

**(dementia or Alzheimer) AND (review OR meta-analysis) AND nonpharmacological AND (treatment or intervention) – 221 articles**

5

# EBT Searchable Database

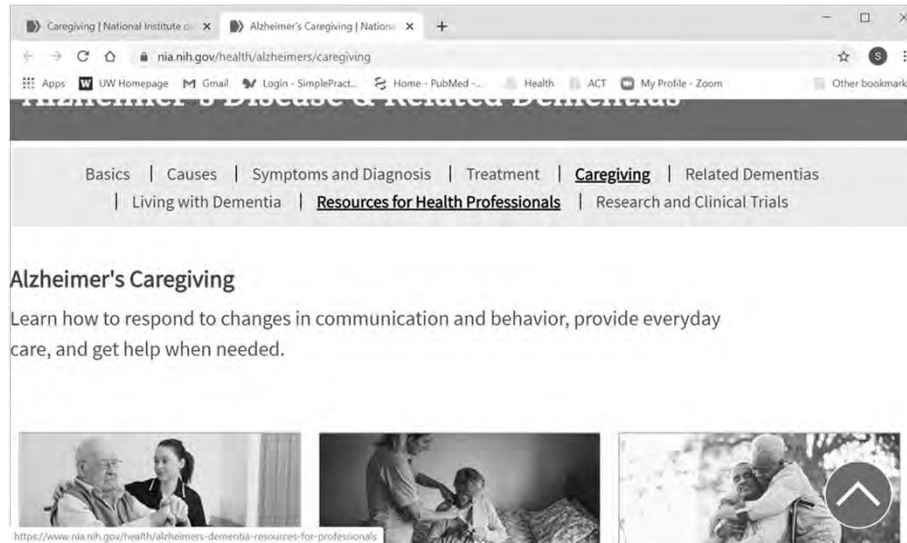


The screenshot shows the homepage of the Best Practice Caregiving website. The header includes the logo "best practice caregiving" with the tagline "Guiding organizations to dementia programs for family caregivers" and navigation links for "Home" and "Find Programs". Below the header, it states "A partnership between Benjamin Rose Institute on Aging and Family Caregiver Alliance". The main content area features a circular icon of two hands holding a heart, followed by the heading "Dementia Care Programs". The text describes the database as a free online resource of proven dementia programs for family caregivers, offering a searchable, interactive, national database of vetted, effective programs. It lists the following information available in the database:

- focus of each program (e.g., reducing stress, understanding dementia, planning care, skill-building, health & wellness, etc.)
- program implementation

6

# NIA Resources: Alzheimer's Disease



## A Few Key Reviews and Reports

Agency for Healthcare Research and Quality, 2019, Care interventions for people with dementia and their caregivers

<https://effectivehealthcare.ahrq.gov/products/care-interventions-pwd/protocol>

Gitlin & Maslow, 2018, Research Summit on Dementia Care final report. <https://aspe.hhs.gov/pdf-report/national-research-summit-care-services-and-supports-persons-dementia-and-their-caregivers-final-summit-report>

Livingston et al., 2017, *Lancet*, *390*: 2673-2734

Shultz and Eden, 2016, Families caring for an aging America. National Academies of Sciences  
<https://www.nap.edu/download/23606>

# STAR-Caregivers: An Evidence-Based Treatment

TREATING BEHAVIORAL SYMPTOMS

Training Community Consultants to Help Family Members Improve Dementia Care: A Randomized Controlled Trial

*STAR-Caregivers*  
A Community-based Approach for Teaching Family Caregivers to Use Behavioral Strategies to Reduce Affective Disturbances in Persons With Dementia

Linda Teri, PhD,<sup>1</sup> Susan M. McCurry, PhD,<sup>1</sup> Rebecca Logsdon, PhD,<sup>1</sup> and Laura E. Gibbons, PhD<sup>1</sup>

**Purpose:** We investigated whether community consultants could be trained to teach family caregivers a systematic behavioral approach for reducing mood and behavior problems in persons with Alzheimer's disease. **Design and Methods:** This study consisted of a randomized controlled trial; we randomly assigned 95 family caregivers and care recipients with Alzheimer's disease to STAR-caregivers (STAR-C) or control groups. Masked interviewers conducted assessments of baseline, after treatment, and after 6 months. Consultants were master's-level health care professionals who were currently practicing in community settings serving older adults. We assessed the extent to which consultants were able to learn and adhere to the treatment protocol, and the relationship between adherence and measures of caregiver mood, burden, and care recipient mood and behavior. **Results:** Community consultants were able to learn and adhere to the behavioral treatment protocol. Caregivers receiving STAR-C training showed significant improvements in depression, burden, and reactivity to behavior problems in the care recipient. There were also significant reductions in the frequency and severity of care recipient behavior problems, and improved quality of life. Results were maintained at 6-month follow-up. **Implications:** Community-based consultants successfully implemented a behavioral intervention with family caregivers of persons with

Alzheimer's disease. **Keywords:** Behavior management, dementia, caregiver training, community-based, evidence-based, family caregivers, mood, behavior problems, depression, burden, quality of life.

In the past, attention has been given to the training of family caregivers in the use of behavioral strategies to manage behavior problems in persons with dementia. However, it is difficult to implement such training in real-world practice settings. The purpose of this study was to investigate whether community consultants could be trained to teach family caregivers a systematic behavioral approach for reducing mood and behavior problems in persons with Alzheimer's disease. This study consisted of a randomized controlled trial; we randomly assigned 95 family caregivers and care recipients with Alzheimer's disease to STAR-caregivers (STAR-C) or control groups. Masked interviewers conducted assessments of baseline, after treatment, and after 6 months. Consultants were master's-level health care professionals who were currently practicing in community settings serving older adults. We assessed the extent to which consultants were able to learn and adhere to the treatment protocol, and the relationship between adherence and measures of caregiver mood, burden, and care recipient mood and behavior. Results: Community consultants were able to learn and adhere to the behavioral treatment protocol. Caregivers receiving STAR-C training showed significant improvements in depression, burden, and reactivity to behavior problems in the care recipient. There were also significant reductions in the frequency and severity of care recipient behavior problems, and improved quality of life. Results were maintained at 6-month follow-up. Implications: Community-based consultants successfully implemented a behavioral intervention with family caregivers of persons with

Translational Science

**Adopting Evidence-Based Caregiver Training Programs in the Real World: Outcomes and Lessons Learned From the STAR-C Oregon Translation Study**

Susan M. McCurry<sup>1</sup>, Rebecca G. Logsdon<sup>1</sup>, Jennifer Mead<sup>1</sup>, Kenneth C. Pile<sup>1</sup>, David M. La Frazia<sup>1</sup>, Laura Stevens<sup>1</sup>, and Linda Teri<sup>1</sup>

**Abstract**

**Objectives:** This article describes the translation and evaluation of STAR-Caregiver Training program (STAR-C), an evidence-based dementia caregiver training program, within the Oregon Department of Human Services. **Method:** Staff from two regional Area Agencies on Aging (AAAs) were trained to implement all aspects of STAR-C, including screening, recruitment of caregiver/care-receiver dyads, and treatment delivery. Masked assessments of caregiver depression, burden, and care-receiver mood, behavior, and quality of life were collected at pre-treatment, post-treatment, and 6-month

SGS

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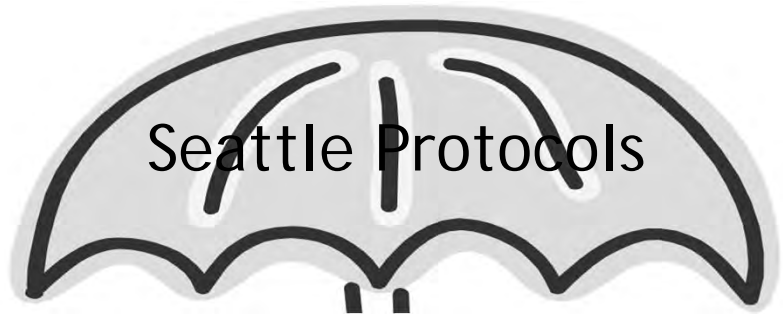
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REBECCA G. LOGSDON, PH.D., SUSAN M. MCCURRY, PH.D., AND LINDA TERI, PH.D.

*STAR-Caregivers program is an individual intervention to decrease depression & anxiety in individuals with Alzheimer's disease and their family caregivers. It is a weekly 12-session program followed by 3 monthly telephone calls. Additional mental health professionals were trained to provide the systematic STAR-Caregivers program and deliver it to family members who may be at risk for depression or anxiety. This article describes the STAR-C program and presents descriptive data on the extent to which consultants were able to learn and adhere to the behavioral treatment protocol.*

*© Alzheimer's disease, anxiety, behavior management, depression, dementia.*

9



- Depression (1988, 2002)
- Agitation (1993)
- Physical activity (1993, 1998, 2012)
- STAR (1999, 2004)
- Sleep (1993, 1998, 2005)
- Early-stage memory loss (2006, 2011)
- RALLI/MCI (2006)
- STAR-C (1999)
- AFH Sleep (2006)
- STAR Effectiveness (2009)
- AFH Staff Training (2009)
- STAR-C Effectiveness (2009, 2011)

\*Teri, et al. 2005. Research and practice in Alzheimer's disease and cognitive decline, Vol. 10, p. 153-158. New York: Springer.

10

## What is STAR-Caregivers (STAR-C)?

- Working with family member(s) of persons with dementia:
  - Teach them to be agent of change for person with dementia
  - Support them as they implement new skills
  - Help them take good care of themselves
  - Teaches five core principles of good dementia care

11

## STAR-C Core Components

- Dementia education/realistic expectations
- Good communication
- Behavioral problem-solving (ABCs of behavior change)
- Increasing pleasant events for persons with dementia and caregivers
- Caregiver self-care

12

## STAR-C: Original RCT Design

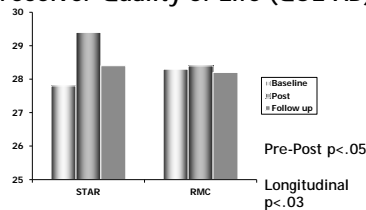
- 95 caregiver/care receiver dyads
- Treatment conditions:
  - STAR-C intervention (n=47)
  - Routine Medical Care (RMC) (n=48)
- 8 weekly in-home sessions + 4 monthly phone calls
- Assessments conducted baseline, 2, and 6 months
- Interviewers blind to treatment conditions

Teri, et al., *The Gerontologist*, 2005, 45 (6), 802-811.

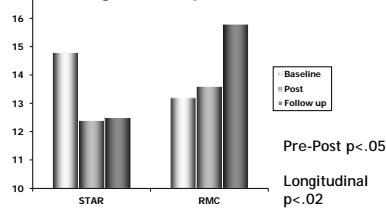
13

## STAR-C: Original RCT Results

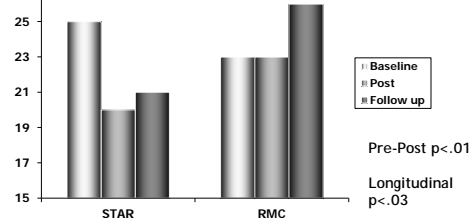
Care receiver Quality of Life (QOL-AD)



Caregiver Depression: CESD



Caregiver Burden: SCB



Teri, et al., *The Gerontologist*, 2005, 45 (6), 802-811.

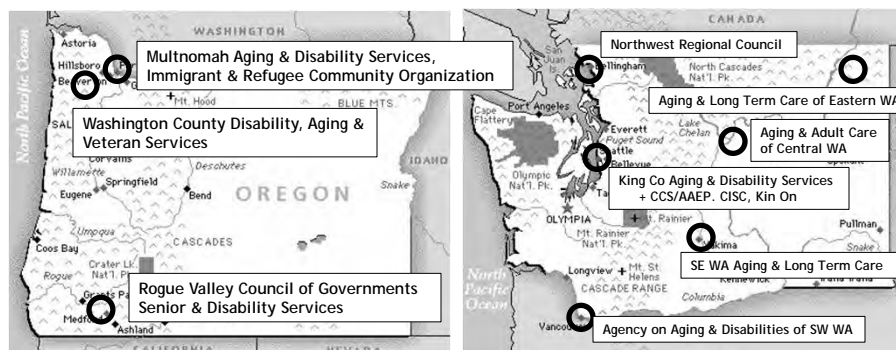
14

## STAR-C Continued to Evolve

- Consolidated number of in-person sessions reduces travel burden
- Originally tested with predominantly white, highly educated individuals
- Sociocultural factors can impact treatment
  - Literacy/reading skills
  - Cultural understanding of dementia symptoms and family involvement
- Now available in Spanish, Russian, Vietnamese, and Chinese

15

## STAR-C Oregon and Washington AAA Translation Sites



16

## Target Behavior Problems (n=178 dyads; 466 problems; Washington and Oregon)

	Frequency	Reaction
Session 1	3.1	2.7
Session 6	2.0*	1.2*

### Frequency:

0= Never occurred  
 1=Not in past week  
 2=1-2 times in past week  
 3=3-6 times in past week  
 4=daily or more often

### Reaction: (how much it

bothered caregiver)  
 0= Not at all  
 1=A little  
 2=Moderately  
 3=Very much  
 4=Extremely

\*Decreases in frequency and reaction  $P < .001$

- *" He was inexplicably kind this week... or maybe it was reflective of the changes I made in my own expectations and tone of voice... Hmmmm..."*

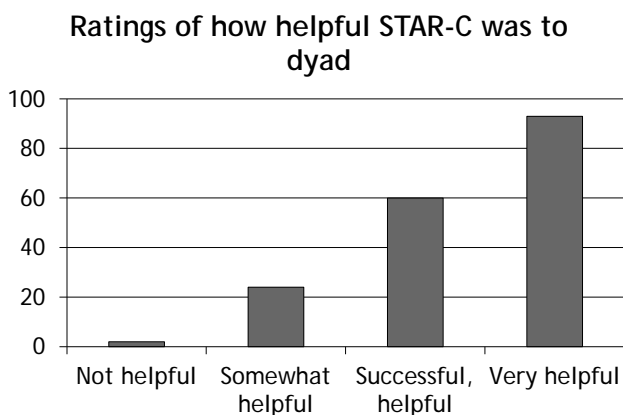


Results as of 5/1/20

17

## Coach Ratings of STAR-C Outcomes (n=179 dyads)

(n=179 dyads)



- *" The one-on-one coaching is a strength... While the program is scripted, it takes on the unique flavor of the caregiver/care receiver dyad."*

- *"We no longer have 'meltdowns' - bad behavior on both our parts in the afternoons... [My coach] gave me confidence to keep trying."*

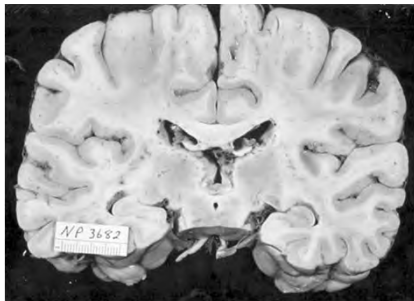
18

## STAR-C Core Components

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19

## Dementia is a Brain Disease

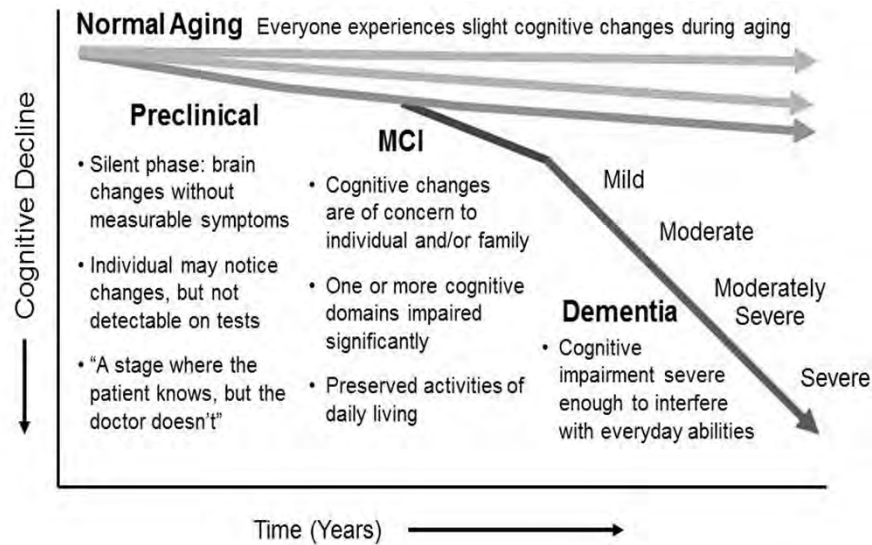


*Persons with dementia do not have control over their changes in thinking and behavior.*

Photographs courtesy of Dr. Thomas Bird, Seattle VAMC

20

## Symptoms Progress Over Time



<http://health.mashangel.com>

21

## Dementia Symptoms Are Variable

- No two people are alike ("If you've met one person with Alzheimer's disease, you've met one person with Alzheimer's disease")
- It is typical for symptoms to wax and wane
- This unpredictability and inconsistency is often what is most difficult for caregivers to accept

22

## STAR-C Core Components


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23

## Caregiver Skills: Good Communication

- Verbal communication = Simple requests, stated clearly, one-at-a-time
- Nonverbal communication = Eye contact, body position and movement, speech rate and tone

24



Anger Happiness Surprise

Disgust Sadness Fear

Is your verbal and non-verbal communication sending the same message?

25



**DON'T ARGUE**

26

## STAR-C Core Components

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27

## Behaviors are Observable Events

- “Behaviors” are *anything* a person does
- All behaviors have meaning and purpose, even when they seem to “come out of the blue”
- We focus on behaviors that we can count (see or hear)
- We also focus on improving challenging behaviors by changing the external physical and interpersonal environment

28

## What Does STAR-C Target?

### *STAR-C focuses on behaviors that:*

- Cause the care-receiver to be a danger to self or others
- Interfere with necessary care
- Decrease the care-receiver's quality of life or the QOL of those around him/her

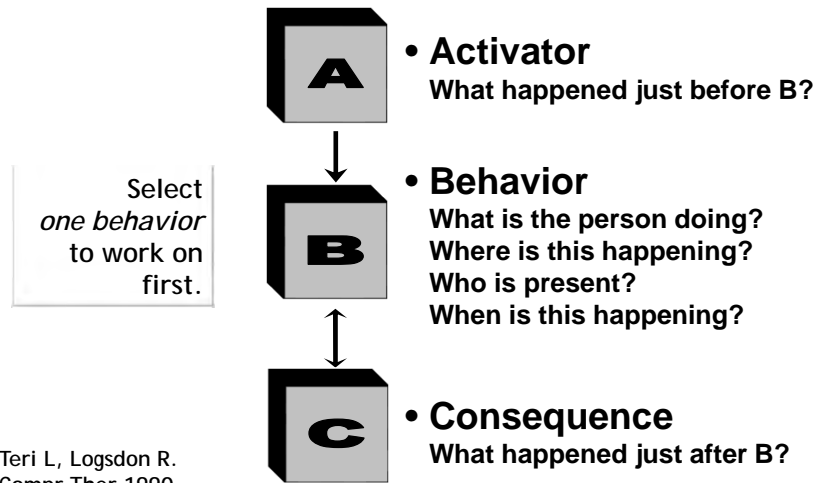
29

### *Common Behaviors That Can Be Challenging*

- Waking you or other family members up at night
- Expressing feelings of hopelessness or sadness about the future
- Crying and tearfulness
- Toileting in inappropriate places
- Getting lost inside or outside of the house
- Talking about feeling lonely
- Comments about feeling worthless or being a burden to others
- Arguing, irritability, and/or complaining
- Physically threatening or aggressive towards others
- Getting dressed incorrectly or inappropriately
- Not shaving, washing, brushing teeth, or showering
- Refusing to accept appropriate help with personal care
- Trying to leave (or leaving) the house
- Restlessness, fidgetiness, inability to sit still
- Asking the same question over and over
- Repeated requests for attention or help (includes nagging, pleading, calling out).
- Walking back and forth or wandering aimlessly
- Having temper outbursts, including verbal or non-verbal expressions of anger
- Grabbing or clinging to you or other people physically
- Following you around everywhere you go
- Seeing or hearing things or people that aren't there
- Not wanting to do activities s/he used to enjoy
- Doing activities "wrong" or unsafely (e.g., cleaning, laundry, cooking, driving)
- Accusing people of stealing

30

## ABCs of Behavior



31

## Rationale for Using the ABCs

- To prevent a problem 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 problem behavior occurring in the future (*by changing either activators and consequences*)

32

## Observation is How We Find Patterns



- Are there days that the behavior does *not* occur?
- Does it only happen around certain people?
- Does it have a cyclic pattern?
- Is it more likely under certain conditions?

33

## Observing Behaviors: The Four “W”s

### *What, Who, Where, and When*

- What exactly is the person doing?
- Who is around?
- Where is this happening?
- When (and how often) is it happening?

34

# Observing Behaviors: The Four "W"s

**A-B-C Problem Solving Plan**

**A** **Activator:** What happened before? \_\_\_\_\_  
\_\_\_\_\_

↓

**B** **Behavior:** What was the person doing? \_\_\_\_\_ *4 Ws: Which one behavior do you want to work on first???*  
*Where* did it happen? \_\_\_\_\_ ←  
*Who* was there? \_\_\_\_\_  
*When* did it happen? \_\_\_\_\_

↕

**C** **Consequence:** What happened after? \_\_\_\_\_  
\_\_\_\_\_

Teri, L, McCurry, SM, Logsdon, RG. STAR-C2 Caregiving consultant manual 2014 update

35

**A-B-C Problem Solving Plan**

**A** **Activator:** What happened before? \_\_\_\_\_ *What were possible activators (before the behavior)?*  
\_\_\_\_\_ ←

↓

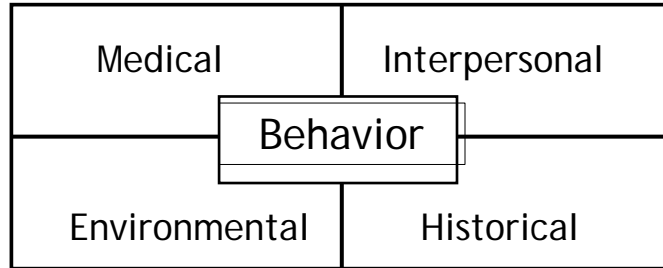
**B** **Behavior:** What was the person doing? \_\_\_\_\_  
*Where* did it happen? \_\_\_\_\_  
*Who* was there? \_\_\_\_\_  
*When* did it happen? \_\_\_\_\_

↕

**C** **Consequence:** What happened after? \_\_\_\_\_ *What were the consequences (that happened after the behavior)?*  
\_\_\_\_\_ ←

36

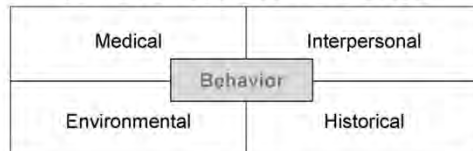
# Brainstorming Activators



*What are some common medical, interpersonal, environmental, and historical factors that might impact behavior?*

37

## Common Activators of Behavior Challenges



### Examples

#### Medical

Infection  
Pain or physical discomfort  
Adverse medication effects  
Incontinence or constipation  
Dehydration  
Fatigue or sleep deprivation  
Sensory loss

#### Interpersonal

Being asked too many questions  
Being bossed around  
Impatient, critical tone of voice  
Offering "help" when it's not wanted  
Frustration at not being understood  
Being rushed  
Being touched or held in ways that are frightening or confining  
Verbal reasoning and logical explanations

#### Environmental

Too much noise, activity, clutter, people, space  
Unfamiliar persons, places, things  
Startling movements, noise, or touch  
Insufficient lighting, visual contrast  
Changes in schedules and routines  
Being left alone for too long  
"Missing" objects or persons  
Lack of orientation cues

#### Historical

Cultural background  
Past habits and preferences  
Family and social routines  
Religious beliefs  
Family, work, and social roles  
Lifelong personality style  
Education and occupation  
Traumatic events

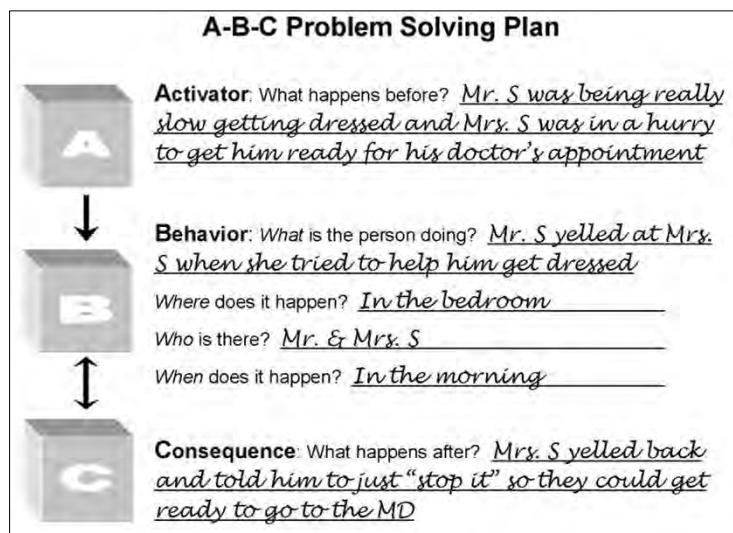
38

## Don't Forget Consequences!

- Caregivers (and STAR-C coaches) often focus only on activators - what causes or "triggers" behaviors
- Consequences are just as important
  - Consequences can cause a behavior to escalate
  - Responses to a behavior may also help the PWD avoid an uncomfortable situation, or to gain some desired attention. In that case, the PWD will be more likely to do that behavior again in the future

39

## Sample ABCs



40

## Get Active Problem-Solving

- Identify a realistic alternative to the problem behavior that you would like to work towards
- Think about activators: What happened before the behavior that could be changed? Pick 1 (or 2) things to modify and see what happens
- Think about consequences: How might you (or other people around) change your response after the problem behavior happens?
- How might communication be an activator or consequence in this situation?

41

## Sample Problem-Solving Plan

### Get Active: Making Change Happen!

How could you possibly change the activators?

1. Start getting ready earlier
2. Schedule MD appointment for later in the day
3. Be careful with my tone of voice getting him dressed
4. Lay out 1 set of clothes for Mr. S and let him dress himself even if it takes forever

How might you change the consequences?

1. Stay calm and pleasant, don't yell
2. Offer him a snack before leaving as soon as he's dressed

**Circle your best ideas to try this week!!!**



42

## STAR-C Core Components

- Dementia education/realistic expectations
- Good communication
- Behavioral problem-solving (ABCs of behavior change)
- Increasing pleasant events for persons with dementia and caregivers
- Caregiver self-care

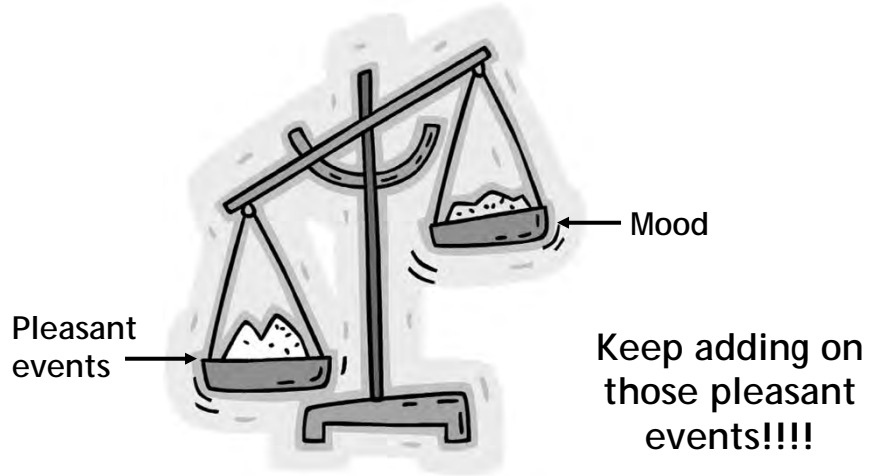
43

## Why Pleasant Events Matter

- Cognitive impairment leads to loss of pleasant activities
- Decreased pleasant events can lead to boredom, behavior problems, and reduced quality of life
- Caregivers can identify and implement pleasant events for the person with dementia and themselves

44

## Relationship between Mood and Pleasant Events



45

## Increasing Pleasant Events

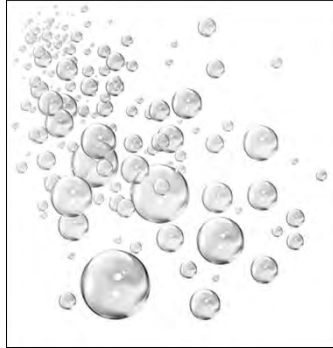


- What did the person enjoy in the past?
- What does he/she enjoy now?
- How can tasks be modified or broken into small steps to accommodate current abilities?

46

# Look For "Safety Bubbles"

*Situations where the person's dementia is not relevant*



- No pressure to remember people, places, events, or facts accurately
- Feelings of dignity and self-respect are maintained
- "Being with" is more important than "getting something done"
- Adult day programs can provide this for many people

47

**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 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			X		X	
2. Shopping, buying things			X	X		
3. Reading or listening to stories, magazines, newspapers			X			X
4. Listening to music	X			X		
5. Watching T.V.			X		X	
6. Laughing		X			X	
7. Having meals with friends or family			X			X
8. Making or eating snacks			X			X
9. Helping around the house			X	X		
10. Being with family			X			X
11. Wearing favorite clothes		X		X		
12. Listening to the sounds of nature (birdsong, wind, surf)	X					X
13. Getting/sending letters, cards		X			X	
14. Going on outings (to the park, a picnic, etc.)	X			X		
15. Having coffee, tea, etc. with friends		X			X	
16. Being complimented			X			X
17. Exercising (walking, dancing, etc.)			X	X		
18. Going for a ride in the car	X			X		
19. Grooming (wearing make up, shaving, having hair cut)		X			X	
20. Recalling and discussing past events		X				X

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48

## ABCs of Pleasant Events: Ideas to Remember

- A pleasant event is anything that can add pleasure *or meaning* to a person's day (not just "fun")
- Every interaction has the potential to be a pleasant event
- Pleasant events should be available, accessible, and frequent

49

## STAR-C Core Components

- Dementia education/realistic expectations
- Good communication
- Behavioral problem-solving (ABCs of behavior change)
- Increasing pleasant events for persons with dementia and caregivers
- Caregiver self-care

50

## Coping With Caregiving

- Caregiving is associated with physical, emotional, and social demands
- Resources are often available, but caregivers may be unaware of or reluctant to use them
- The system doesn't make things easy

51

## Caregiving and Pleasant Events

- Caregivers need pleasant events too!
  - Relationship between mood and pleasant events is true for everyone, not just persons with dementia
- Self-care requires respite
  - How is it possible to get a break in times of social isolation?

52

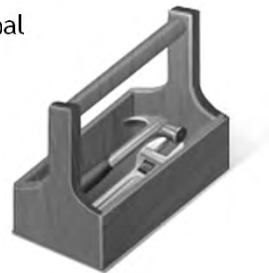
## Caregiver Resources

- Alzheimer's Association (national web site): [www.alz.org](http://www.alz.org)  
Washington State Chapter: [www.alzwa.org](http://www.alzwa.org)
- Washington State Aging and Long Term Support Administration (AL TSA/DSHS),  
Caregiver Resources: [www.adsa.dshs.wa.gov/caregiving/](http://www.adsa.dshs.wa.gov/caregiving/)
- Washington State Dementia Road Map: A guide for Family and Care Partners  
[www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan](http://www.dshs.wa.gov/altsa/stakeholders/alzheimers-state-plan)
- Washington State Community Living Connections/Area Agencies on Aging (local  
support services): [www.waclc.org/connect](http://www.waclc.org/connect)
- Alzheimer's Disease Education and Referral Center of the National Institute on  
Aging (ADEAR): [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)
- National Institutes of Health - federally and privately supported clinical  
research: [www.ClinicalTrials.gov](http://www.ClinicalTrials.gov)
- The Administration on Aging Alzheimer's Resource Room:  
<http://www.aoa.gov/ALZ/>

53

## STAR-C Tools

- Realistic Expectations
- Communication
  - Think of both verbal and nonverbal
- ABCs
  - Monitoring ABCs
  - Making a Problem Solving Plan
- Pleasant Events
  - Pleasant Events Planning
- Caregiver Self Care
  - Community Resources
  - Respite



54

# STAR-C Testimonials

<p><b>Realistic Expectations</b></p> <ul style="list-style-type: none"> <li>• "...letting go of the old, embracing the new and not take to heart the hurtful things. It's the disease - not my spouse. This was huge!"</li> <li>• "I have a much better understanding of Alzheimer's disease and have come to an acceptance that I've not had."</li> <li>• "...To not take everything that Mom says or does so personally."</li> </ul>	<p><b>Communication Skills</b></p> <ul style="list-style-type: none"> <li>• "...Listen with respect, comfort and redirect - Big!!!" "Genius!"</li> <li>• "Communication skills - especially being face to face when I talk to the patient."</li> <li>• "Learning to distract with comfort &amp; positive distraction."</li> <li>• "Don't argue."</li> </ul>
<p><b>ABC Problem Solving</b></p> <ul style="list-style-type: none"> <li>• "There is actually something I can do to help with difficult behaviors. The ABC is a great way to begin."</li> <li>• "The ABC program is helping me to better identify, understand and deal with my care receiver's anger."</li> <li>• Problem solving plan: Activator, behavior, consequence (worksheets were so helpful)"</li> </ul>	<p><b>Pleasant Events</b></p> <ul style="list-style-type: none"> <li>• "Really like the Pleasant Events brainstorm!"</li> <li>• "Hard to pick one. Maybe the importance of pleasurable experiences for both of us."</li> <li>• "...the importance of pleasurable experiences for both of us..."</li> </ul>

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