STAR-C2

Treatment of Mood and Behavior Challenges in Persons with Dementia

Caregiving Consultant Manual

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SESSIO	N OVERVIEW AND HANDOUTS
ALL SESSIONS	 Session Content Checklist (one for each client) STAB C Progress Note Form (one for each englien)
	 STAR-C Progress Note Form (one for each session) Understanding Alzheimer's Booklet (for Caregiver)
Session 1: Home Visit	Introduction to Behavioral Treatment of Dementia
	 Common Behaviors That Can be Challenging Bro Treatment Broblem Survey
	 Pre-Treatment Problem Survey Effective Communication
	 Practical Communication
	 Listen with Respect, Comfort and Redirect
	Homework: Understanding Alzheimer's, pp. 1-13
	 Realistic Expectations Handout
	 Problem-Solving Example
Session 2: Home Visit	Homework Review
	ABCs: Problem-Solving Challenges to Care
	 Knowing the ABCs Common Activators of Behavior Challenges
	 ABC Problem Solving Plan
	Homework: Understanding Alzheimer's, pp. 13-25
Session 3: PHONE CALL	 Checking in: readings, ABC plan, caregiver questions
Session 4: Home Visit	 Homework Review
	Why Pleasant Events Matter
	Negative Thoughts, Mood, and Behavior
	Increasing Pleasant Activities
	 Pleasant Events Schedule-AD Pleasant Events Brainstorm
	 Pleasant Events Branstonn Pleasant Events Plan
	Homework: Understanding Alzheimer's, pp. 25-33
	 ABC Problem Solving Plan
Session 5: PHONE CALL	 Checking in: readings, ABC plan, caregiver questions
Session 6: Home Visit	 Homework Review
	Coping with Caregiving
	Community Resources
	Review & Maintenance Plan Using STAR-C Tools
	 Post-Treatment Problem Survey APC Problem Solving and Pleasant Events Plans
	 ABC Problem Solving and Pleasant Events Plans Monthly Phone Calls Plan & Checklist (one for each client)
	Monthly I none cans rian & checkist (one for each chefit)

STAR-C2 Session Content Checklist

Please indicate with a checkmark what topics were covered in each session. Topics can be checked as many times as appropriate.

After the final session, indicate how helpful you think STAR-C2 was with this caregiver. *(Complete one form for each client.)*

STAR-C2 ID: _____

Treatment Session/Content	1	2	3 Phone call	4	5 Phone call	6
Pre-Treatment Problem Survey						
Dementia as Illness						
Realistic Expectations						
Practical Communication						
ABCs Introduction						
Problem Solving Example						
ABC Problem Solving Plan						
Pleasant Events						
Negative Thinking						
Caregiver Issues						
Maintaining Gains						
Post-Treatment Problem Survey						

How helpful do you think STAR-C2 was with this client?

Not helpful	Somewhat helpful	Successful/ helpful	Very helpful
0	1	2	3

Additional comments:

STAR-C2 Progress	Note For	m		
STAR-C2 ID Number Session Da				
1. Total session length (minutes):	🛛 Hom	e Visit	🗆 Pho	ne call
2. Who was seen (or talked to) during the ses □ Caregiver □ Care receiver □ Other: _			as apply	')
3. Rate caregiver homework completion:	Not attempted	Attempt	ed as	Not signed
a. Reading Assignments				
b. ABC Monitoring and/or Plan				
c. Pleasant Events Plan				
d. Other:				
ABC Problem Solving			Yes	No
ABC Problem Solving4. Was an ABC form completed during the session?				
<u>4</u> a. For new ABC plans this week:				
Did the target behavior happen this past week?			Yes	No
4 b. For previously developed ABC plans:				
How has the behavior changed since discussed it?	you first	Better	Worse	No change

STAR-C2 Monthly Telephone Content Checklist

STAR-C2 ID Number

Session



(Follow-up calls are intended to be less than ½ hour maximum)

Please indicate with a checkmark what topics were covered in each phone call. Also note the date of each call and how long it was.

Sample "primer" questions:

- How has the past month been going with (the care receiver)? Have any new challenges developed that you would like help problem-solving?
- Have you been using the ABCs to think about possible activators and consequences for behaviors? How is that working for you?
- Are you still scheduling regular pleasant events for yourself and (the care receiver)?
- Is there anything in general about caregiving or taking care of yourself that you would like to discuss?
- Do you have any questions about anything we talked about during the STAR-C2 visits?

Phone Call / Content	1	2	3	4
	Phone call	Phone call	Phone call	Phone call
Phone Call Date				
Phone Call Duration (mins)				
Dementia as Illness				
Realistic Expectations				
ABC Problem Solving Plan				
Practical Communication				
Pleasant Events				
Negative Thinking				
Caregiver Issues				

• When would be a good time for me to call next month?

SESSION 1 HANDOUTS

Practical Communication

1. Eye Contact

- \Rightarrow Look directly at the other person when speaking or listening.
- Move eyes spontaneously and naturally.

2. Body Position

- Sit or stand directly in front of the person. Be sure you have his or her attention before speaking.
- Place yourself on the same level with the other person as much as possible. Do not stand over someone who is sitting or lying.
- ☆ Position yourself close enough to be seen and heard clearly, usually about three to six feet away.

3. Face and Head Movements

- A Have a calm expression. Express changes on face appropriately.
- Nod appropriately and positively. Avoid a deadpan expression.

4. Hand and Arm Movements

- \Rightarrow Use hand movements for emphasis.
- \Rightarrow Use gentle touch to get or focus attention.

5. Speech Rate and Tone

- ☆ Speak slowly.
- \Rightarrow Form and say words carefully.
- \Rightarrow Use short sentences.
- Ask one question at a time.
 Wait for an answer before asking another question.



Be patient!

Listen with Respect, Comfort and Redirect

Listen

Make sure that the person KNOWS you are listening.

- \Rightarrow Make eye contact with the person.
- \Rightarrow Focus on the person; don't try to do two things at once.

Respect

Sometimes being too casual with a person can be viewed as disrespect.

- ☆ Watch your tone of voice; no one likes to be scolded or talked down to like a child.
- \Rightarrow Be careful when you talk about the person when he or she is in the room.
- ☆ Pay attention to the person's nonverbal communication. Does it seem like he or she is bothered by your communication style?

If so, try a different way of communicating.

Comfort

What we say and how we say it can provide a great deal of comfort to a person who is upset. Those who are anxious, agitated, or depressed can benefit greatly from comforting communication.

- A Don't pay as much attention to what a person is saying as to what the person may be thinking or feeling.
- \Rightarrow Let the person know that you understand.
- Persons with dementia who are anxious and depressed can't calm themselves down; they need help. A hug, a reassuring statement ("I will take care of you"), or even a "comfort item" such as a soft throw or pillow can be effective.

Redirect

Sometimes providing comfort is not enough. Try to redirect or distract the person from his or her problem behavior.

- Attempt to change the subject after you have shown respect and tried comfort measures.
- ☆ Try to involve the person in a distracting pleasant event.

Whatever you do, DON'T ARGUE!



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
- \Rightarrow Trying to leave (or leaving) the house
- ☆ Restlessness, fidgetiness, inability to sit still
- \Rightarrow 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

STAR-Caregiv	ers Pre-Tre	eatment	Problem Survey
STAR-C2 ID Number	Sessio		Session Date
upset you when it happened.	curred DURING TH Use the following	HE PAST WEEK scales to rate	would like help with. For each and how much it bothered or the frequency of each problem last time the problem occurred to
Frequency Ratings: 0 = never occurred 1 = not in the past week 2 = 1 to 2 times in the p 3 = 3 to 6 times in the p 4 = daily or more often Problem 1:	ast week	1 = a 2 = r 3 = v	atings: not at all a little moderately very much extremely
Frequency	Reaction I I I 0 1 2 3 4		
Problem 2:			
Frequency	Reaction Image: Image of the second		
Problem 3:			
Frequency	Reaction Image: Image		

REALISTIC EXPECTATIONS

When persons develop dementia, their cognitive and emotional changes develop gradually over a long time. For this reason, it is often difficult to know what they are still capable of doing and when they need extra help. Think about your own situation. What changes have you seen in your family member with dementia? What changes do you think s/he would say have occurred? What changes have friends, family, or professionals who know you both observed?

You may find, when you think about it, that each person would give a different answer. Perhaps your loved one would say, "I'm a little more forgetful than before, but it doesn't interfere in my life at all" – even though *you* see many examples of how it interferes! Or perhaps, a distant relative who hasn't seen your loved one in a long time notices many areas of decline that you haven't noticed in your continual, daily interactions. Who is correct? Who is seeing most accurately?

The answer is that you are probably all correct, at least in part. Although dementia is progressive, its day-to-day effects can be very inconsistent. A person with dementia may have trouble performing an activity today that yesterday s/he did with ease. S/he may remember one appointment and forget the next. As caregivers, we may come to believe that these inconsistent gaps in ability are because the person "just isn't trying," or "isn't motivated" or "is just doing things to annoy me." This is particularly true if, in the past, the person sometimes behaved in a similar way when s/he wasn't paying attention, or when the two of you were quarreling.

Nevertheless, it is important to understand that no matter how similar the actions of a person with dementia are to how he or she acted in the past, their behaviors do not now have the same meaning or causes. The person with dementia is increasingly incapable of fully understanding the consequences of their actions. Their disease may make them unable to remember mistakes they have made or to see how much they need help now from other people.

Persons with dementia have difficulty finishing what they start, or even starting things without guidance and support from those around them. They may say or do one thing when their intention was to do something totally different. Changes in mood are common symptoms. Even though the person may look the same as always, and uses some of the same words and actions to express their feelings and desires, changes in their brain caused by dementia interfere with their ability to fully understand what they are doing.

If you find yourself feeling disbelief that many of your family member's actions are unintentional, you're not alone. This reaction is normal. Nevertheless, it will help you care for yourself and your family member more effectively if you can remember that s/he has increasingly less control over his or her actions. Although remembering this won't stop you from getting angry sometimes or having feelings or resentment, embarrassment, or disappointment, you will get through these feelings more quickly.

With your STAR-C2 consultant, practice finding ways you can reinterpret some of your family member's actions. Then try it out during the week and see how these new interpretations change the way you respond when these difficult behaviors occur.



PROBLEM SOLVING EXAMPLE

- 1. **Behavior Problem:** Mr. B wanders away from the house when Mrs. B is busy with chores.
- 2. **Gathering Information:** This happened three times last week (Monday, Wednesday and Thursday).

3. Identify Activators and Consequences:

- a. **Activators:** Always in the late afternoon; always when Mrs. B is absent from view.
- b. **Consequences:** Mrs. B gets frightened and upset and goes looking for Mr. B; Mrs. B becomes angry when Mr. B is found; (usually walking toward the house where a friend lived several years ago). Mr. B responds by refusing to return home with her.

4. Brainstorm Solutions:

- a. Mrs. B does chores different time of day so Mr. B is never alone.
- b. Mrs. B installs alarm system on outside doors.
- c. Mrs. B arranges for in-home respite/supervision of Mr. B.
- d. Mrs. B makes videotape of Mr. B's favorite television show to play at day's end.
- e. Mrs. B involves Mr. B in chores.
- 5. **Select a strategy:** Mrs. B decides to involve Mr. B in chores. Possible problems might be: finding ways Mr. B can realistically "help" or be occupied; developing communication strategies for effectively asking Mr. B to help; dealing with Mr. B's refusals (e.g., offering different task, setting chores aside for that day).

 Take Action/Evaluate Effectiveness: Mrs. B asked Mr. B to help only on afternoons when he did not seem agitated. The other days Mrs. B postponed her chores and took Mr. B on a neighborhood stroll. (Note: This solution was not on original list, but occurred to Mrs. B during week.)

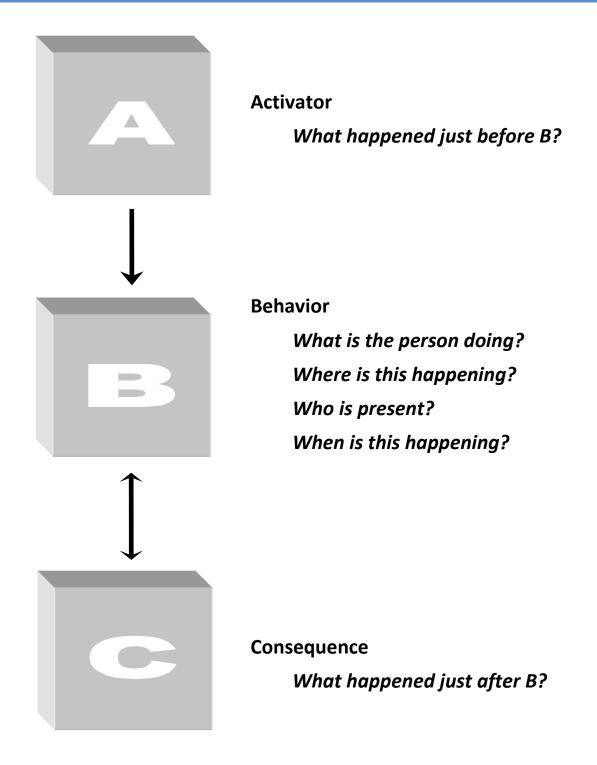


Resolution

On days Mr. B was asked to help with chores, he readily agreed. Mrs. B discovered that Mr. B particularly enjoyed sweeping the kitchen floor and polishing the dinner table while she cooked dinner. This kept him occupied and required minimal redirection by Mrs. B. On the days when there were no late afternoon conflicts between Mr. and Mrs. B, Mrs. B stated that the peace and quiet were really "reward" enough for her. Nevertheless, when their son came over to visit on the weekend, she treated herself by having coffee next door with a neighbor and good friend whose company she especially enjoys.

SESSION 2 HANDOUTS

Knowing the ABCs



Common Activators of Behavior Challenges				
Medical	Interpersonal			
Environmental	Historical			
Examples				

Medical	Interpersonal
 Infection 	 Being asked too many questions
 Pain or physical discomfort 	 Being bossed around
 Adverse medication effects 	 Impatient, critical tone of voice
 Incontinence or constipation 	 Offering "help" when it's not wanted
 Dehydration 	 Frustration at not being understood
 Fatigue or sleep deprivation 	 Being rushed
 Sensory loss 	 Being touched or held in ways that are frightening or confining
Environmental	 Verbal reasoning and logical
 Too much noise, activity, clutter, people, space 	explanations
 Unfamiliar persons, places, things 	<u>Historical</u>
 Startling movements, noise, or 	 Cultural background
touch	 Past habits and preferences
 Insufficient lighting, visual 	 Family and social routines
contrast	 Religious beliefs
 Changes in schedules and 	 Family, work, and social roles
routines	 Lifelong personality style
 Being left alone for too long 	 Education and occupation
 "Missing" objects or persons 	 Traumatic events
 Lack of orientation cues 	

A-B-C Problem Solving Plan

A	Activator: What happens before?
\downarrow	Behavior: What was the person doing?
B	Where did it happen? Who was there? When did it happen?
С	Consequence : What happened after?

Get Active: Making Change Happen!

How could you possibly change the activators?

1	
2	
3	
4	
How might you change the consequences?	R
1	
2	X
3	S
4	} <u>} </u>

Circle your best ideas to try this week!!!

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SESSION 3 HANDOUTS

A-B-C Problem Solving Plan

	Activator: What happens before?
\downarrow	Behavior: What was the person doing?
	Where did it happen? Who was there? When did it happen?
С	Consequence : What happened after?

Get Active: Making Change Happen!

How could you possibly change the activators?

1	
2	
3	
4	
How might you change the consequences?	R
1	
2	X
3	S
4	<i>} L_</i>

Circle your best ideas to try this week!!!

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SESSION 4 HANDOUTS

A-B-C Problem Solving Plan

A	Activator: What happens before?
\downarrow	Behavior: What was the person doing?
B	Where did it happen? Who was there? When did it happen?
C	Consequence : What happened after?

Get Active: Making Change Happen!

How could you possibly change the activators?

1	
2	
3	
4	<i>C</i> ²
How might you change the consequences?	R
1	
2	X
3	S
4	} <u>} </u>

Circle your best ideas to try this week!!!

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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.

	Frequency		Enjoy			
	Not at	1 to 6	7 or	Not At	Some-	Α
Activity	all	Times	more	All	what	Great
			Times			Deal
1. Being outside						
2. Shopping, buying things						
 Reading or listening to stories, magazines, newspapers 						
4. Listening to music						
5. Watching T.V.						
6. Laughing						
 Having meals with friends or family 						
8. Making or eating snacks						
9. Helping around the house						
10. Being with family						
11. Wearing favorite clothes						
12. Listening to the sounds of nature (birdsong, wind, surf)						
13. Getting/sending letters, cards						
14. Going on outings (to the park, a picnic, etc)						

	F	requenc	у		Enjoy	
Activity	Not at all	1 to 6 Times	7 or more Times	Not At All	Some- what	A Great Deal
15. Having coffee, tea, etc. with friends						
16. Being complimented						
17. Exercising (walking, dancing, etc.)						
18. Going for a ride in the car						
19. Grooming (wearing make-up, shaving, having hair cut)						
20. Recalling and discussing past events						

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Pleasant Events Brainstorm

- ☆ Looking at nature
- ☆ Meeting someone new
- ☆ Planning a trip
- ☆ Taking a walk
- ☆ Buying something
- 🕸 Singing
- ☆ Reading books or poems
- ☆ Doing a task well
- ☆ Breathing fresh air
- ☆ Being understood
- ☆ Seeing someone else happy
- ☆ Watching TV
- ☆ Thinking about something good in the future
- ☆ Finishing a task
- ☆ Laughing
- ☆ Doing a puzzle
- ☆ Remembering family events
- \Rightarrow Seeing the sunset
- ☆ Eating a snack
- ☆ Praising someone
- ☆ Talking on the phone
- ☆ Kissing and hugging family
- ☆ Praying or spiritual practice

- ☆ Being told he or she is needed
- ☆ Going to a party
- ☆ Being invited out
- ☆ Having peace and quiet
- ☆ Snuggling in a comfortable chair
- ☆ Holding hands
- ☆ Eating lunch with friends
- ☆ Watching people
- ☆ Eating a nice meal
- ☆ Helping someone else
- ☆ Solving a problem
- ☆ Combing his or her hair
- ☆ Talking with grandchildren
- ☆ Hearing about family activities
- ☆ Wearing new clothes
- ☆ Listening to the radio
- Getting letters, cards or notes
- ☆ Getting a manicure
- ☆ Hearing a joke
- ☆ Going for a walk
- ☆ Visiting with neighbors
- ☆ Arranging flowers
- ☆ Receiving a compliment
- ☆ Looking at a newspaper

Consolidated STAR-Caregivers | Page 66

- $\cancel{3}$ Having makeup applied
- ☆ Putting on hand lotion
- ☆ Getting a massage
- ☆ Taking a shower
- ☆ Taking a bath
- ☆ Being with children
- ☆ Making the bed
- Seeing or smelling a flower or a plant
- Reminiscing, talking about the old times
- ☆ Listening to music
- ☆ Cooking or baking
- ☆ Reading magazines
- ☆ Seeing old friends
- ☆ Talking about children or grandchildren
- \Rightarrow Talking on the phone
- ☆ Taking a nap
- ☆ Being with happy people
- Taking care of plants and gardens
- ☆ Hearing nature sounds
- ☆ Having visitors
- ☆ Having his or her hair cut
- st Watching the clouds in the sky
- ☆ Helping with chores

- ☆ Telling stories
- ☆ Being around animals
- ☆ Raking leaves
- ☆ Sweeping
- ☆ Having coffee or tea
- ☆ Drawing or painting
- ☆ Sewing
- ☆ Knitting or crocheting
- ☆ Going to a museum
- ☆ Riding in the car
- ☆ Hiking
- ☆ Golfing
- ☆ Playing cards
- ☆ Scrapbooking
- ☆ Going to the library
- ☆ Swimming
- ☆ Using the computer
- ☆ Taking photographs
- ☆ _____
- ☆
- $\stackrel{\sim}{\rightarrow}$
- *
- _____ ☆
- _____ ☆



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Pleasant Events Plan

Write two pleasant events (activities) that this person might enjoy:

Pleasant Event #1	Pleasant Event #2
Write how you would break each pleas	ant event into smaller parts or steps:
Ctana to complete Diagonat Frant #1.	Stans to complete Diagsant Fuent #2;
Steps to complete Pleasant Event #1:	Steps to complete Pleasant Event #2.
Steps to complete Pleasant Event #1: 1	

When will you do each of these two pleasant events (activities) during the NEXT WEEK?

	Pleasant	Event #	1
--	----------	---------	---

Pleasant Event #2

Did you do the two activities? How did it affect the person's mood?

Pleasant Event #1

Pleasant Event #2

SESSION 5 HANDOUTS

A-B-C Problem Solving Plan

A	Activator: What happens before?
\downarrow	Behavior: What was the person doing?
B \$	Where did it happen? Who was there? When did it happen?
С	Consequence : What happened after?

Get Active: Making Change Happen!

How could you possibly change the activators?

1	
2	
3	
4	 2
How might you change the consequences?	R
1	 · · · ·
2	X
3	
4	 75

Circle your best ideas to try this week!!!

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Pleasant Events Plan

Write two pleasant events (activities) that this person might enjoy:

Pleasant Event #1	Pleasant Event #2		
Write how you would break each pleas	sant event into smaller parts or steps:		
Steps to complete Pleasant Event #1:	Steps to complete Pleasant Event #2:		
1	1		
2	2		
3	3		
3	5		

When will you do each of these two pleasant events (activities) during the NEXT WEEK?

<i>Pleasant Event #1</i>

Pleasant Event #2

Did you do the two activities? How did it affect the person's mood?

Pleasant Event #1

Pleasant Event #2

SESSION 6 HANDOUTS

A-B-C Problem Solving Plan

A	Activator: What happens before?
\downarrow	Behavior: What was the person doing?
B \$	Where did it happen? Who was there? When did it happen?
C	Consequence : What happened after?

Get Active: Making Change Happen!

How could you possibly change the activators?

1	
2	
3	
4	
How might you change the consequences?	R
1	·ờ́·•
2	🏏
3	S
4	JL

Circle your best ideas to try this week!!!

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Pleasant Events Plan

Write two pleasant events (activities) that this person might enjoy:

Pleasant Event #1	Pleasant Event #2
Write how you would break each pleasa	ant event into smaller parts or steps:
Steps to complete Pleasant Event #1:	Steps to complete Pleasant Event #2:
1	1
2	2

Pleasant Event #1

Pleasant Event #2

Did you do the two activities? How did it affect the person's mood?

Pleasant Event #1

Pleasant Event #2

STAR-Caregivers	s Post-Tre	eatment	Problem Survey	
STAR-C2 ID Number	Session	ı	Session Date	
Instructions: Please think of 1 – 3 behavior challenges that you would like help with. For each problem, rate how often it occurred DURING THE PAST WEEK , and how much it bothered or upset you when it happened. Use the following scales to rate the frequency of each problem and your reaction to it. Finally, please tell us what you did the last time the problem occurred to solve it.				
Frequency Ratings: 0 = never occurred 1 = not in the past week 2 = 1 to 2 times in the past 3 = 3 to 6 times in the past 4 = daily or more often		1 = a 2 = m 3 = ve	ot at all	
	eaction □□□□□ 1 2 3 4			
Problem 2:				
	aeaction 1 2 3 4			
Problem 3:				
Frequency R	eaction 1 2 3 4			

Community Resources

- Alzheimer's Association of Oregon:
 - o Phone: 800-272-3900
 - o <u>www.alz.org/oregon</u>
- Oregon State Department of Human Services Caregiving Services::
 - Phone: 800-282-8096; TTY: 800-282-8096
 - o <u>http://www.oregon.gov/DHS/spwpd/caregiving/home.shtml</u>
- Alzheimer's Disease Education and Referral Center of the National Institute on Aging (ADEAR):
 - o <u>www.nia.nih.gov/alzheimers</u>
- National Institutes of Health (federally and privately supported clinical research):
 - o <u>www.ClinicalTrials.gov</u>
- U.S. National Library of Medicine (health news and a link list of health libraries, databases and resources):
 - o <u>www.medlineplus.gov</u>
- The Administration on Aging:
 - o <u>www.aoa.gov</u>
- American Association of Retired Persons:
 - o <u>www.aarp.org</u>