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360 Lexington Ave, New York, NY CARINGKINDNYC.ORG 646-744-2900



Understanding & Decoding Distressing Behaviors

> Stephani Shivers, MEd, OTR/L Chief Innovation Officer CaringKind

### **Our Speakers**

- Chief Innovation Officer & VP Program Development at CaringKind
- 18+ years working with individuals and families impacted by Alzheimer's and other forms of dementia
- Occupational therapist specializing in cognitive function
- 30 years leadership experience in not-for-profit organizations

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Stephani Shivers, MEd, OTR/L Chief Innovation Officer, CaringKind

### Overview: Understanding & Decoding Distressing Behaviors



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- Why do people act the way they do?
- What are "behaviors"?
- What can influence behaviors?
  - What's happening inside person?
  - What's happening outside person?
- What can be done to decrease and avoid distressing behaviors?
- Promoting well-being and meaningful engagement





### Why do people act the way they do?





### What is a 'behavior'?



### Actions, Reactions, Expressions



### Something we do (out of need or desire)



### Actions, Reactions, Expressions

# Response to something or someone

## Reaction

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### Actions, Reactions, Expressions





# What can influence behaviors?

# What's going on inside?



## What is happening INSIDE?



### What's Happening Inside? Feelings & Emotions











What do you think they are feeling? What else might they be feeling?

### What's Happening Inside? Instincts



Care, Protect

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### **Distressing / Disempowering Feelings**

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Comforting / Empowering Feelings

Feelings Wheel

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Source: Willcox, G. (1982). The Feeling Wheel A Tool for Expanding Awareness of Emotions and Increasing Spontaneity and Intimacy. Transactional Analysis Journal, 12(4), 274-276.

### What's Happening Inside? *Physical & Sensory Experiences*









### What's happening inside? Background, History







Culture

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Faith Tradition

Work Experience



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Family



Trauma

### What's happening inside? Changing Cognition





### What all is happening inside a person?

#### **Emotions & Instincts** *Physical & Sensory* Infection Happy **Poor Nutrition** Surprised Dehydration • Depression Over/Under **Emotions & Instincts** Medicated Cold, Hot, Itchy Physical & Sensory Pain History & Background Fatigue Hungry, Thirsty Changing Abilities Dizzy Overwhelmed Changing Abilities **Dementia** Type • **Dementia Stage** ٠ Language Abilities **Cognitive Abilities Physical Abilities** .

- **Explore**/Seek •
- Connect/ Relate •
- Fulfilment •
- Care

•

•

Sad

Bad

Fear

Anger Relief

Play

### History & Background

- Trauma
- Culture
- Family experience
- Work history
- Gender roles

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# What can influence behaviors?

# What's going on outside?



### What's happening outside a person?



### What's Happening Outside a Person?



Physical Space



Experience



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Appeal



Location



People & Relationships



Time

### What's Happening Outside? Environment











### What's Happening Outside? *Time of day... season...time of year...*









### What's Happening Outside? Tasks and Activities

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### Task = Abilities

### Partner provides correct level of support

### Task too complicated

### Partner over or under helps



### What's Happening Outside? Social Environment









### What's Happening Outside? *Relational Attachments*







Safe

Seen

Physical and emotional safety Feel safe and protected in relationship

Experiences, thoughts and emotions are acknowledged and validated. Enhances self-worth, value, importance

### Soothed

Being comforted, reassured, and supported when distressed

Helps to regulate emotions, use coping mechanisms

### Secure

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Sense of security, predictability, trust.

Comes from consistency, reliability, availability of relational partner



Adapted from Dan Siegel's 4 S's of Secure Attachments

What can be done to decrease and avoid distressing behaviors?



### Eden Alternative Domains of Well-Being: Promoting Quality of Life



Graphic summary created by: <u>https://abeautifulvoice.org/</u>

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The Eden Alternative Domains of Well-Being<sup>®</sup>: Revolutionizing the Experience of Home by Bringing Well-Being to Life. Copyright 2012, Rev. 2020, The Eden Alternative<sup>®</sup>. <u>https://www.edenalt.org/our-framework/</u>

### **Promote Positive Relational Attachment**



Safe

- Establish routines
- Create safe environment
- Encourage open communication about thoughts and emotions



Seen

- Practice active listening
- Give full attention, show interest, reflect back
- Validate experiences
- Engage in their enjoyed activities



### Soothed

- Respond sensitively with comfort and reassurance. Validate.
- Stay calm. Mirror calm. Model breathing, pacing, tone.
- Be consistent... as source of support.



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- Engage in positive interactions affection, play, enjoyment
- Create consistency, predictable daily routines.
- Minimize disruptions and changes.

Be kind to yourself... this is hard Get support – you have these needs too

Adapted from Dan Siegel's 4 S's of Secure Attachments

### **Responding to Distress**



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## Validate the Feeling / Emotion

Identify the emotion and confirm. Show understanding for the emotion.

- It sounds to me like you're feeling.... Is that right?
- I can understand why you're feeling...
- It makes sense that you feel...
- It makes sense that you think...

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 You are having a sad/ tough/ yucky day. • \_\_\_\_ must be difficult for you

- You have every right to feel that way
- I would feel that way too ...
- I can only imagine how \_\_\_\_\_ that must be
- It's completely normal to feel \_\_\_\_\_



### Validation

Validation: recognition or affirmation that a person, or their feelings or opinions are valid and worthwhile.

Validation IS	Validation IS NOT
Being present	Trying to fix or problem solve
Acceptance and respect	Agreement
Normalizing	Minimizing
Seeking to understand	Guessing and moving on
Listening for the underlying need	Giving advice



Safe

Seen

~



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Seen

Soothed

Secure

### Defuse & De-escalate

### Think opposite core emotions...

### Want to take power out of situation





- Take the blame....
- Apologize
  - Will you forgive me for...
- Don't argue
  - You are right.
  - Go with the flow...
    - (Sing "Let it Go" to yourself)



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CaringKind Helpline: 646-744-2900 caringkindnyc.org @caringkindnyc

### EDUCATION SEMINAR

A free learning event for individuals, families and professionals

LIVE WEBINAR

#### Tuesday <u>March 18</u>, 2025 • 6-7:15 pm EST

### Understanding Emotional Connection & Communication

Caring for someone with dementia involves navigating a landscape of emotional and communication changes. Confusion and language difficulties can quickly lead to arguments. Explanations and logical reasons provide little help.

This webinar will explore:

- Effective communication tips: Learn practical verbal and nonverbal communication tools
- Underlying emotions: Identify core emotions and discover how they impact interactions
- Building Empathy: Develop new ways to relate using empathy and validation of the other person's emotional reality.

Whether you are new to caregiving or have years of experience, this session offers valuable insights to enhance understanding, promote nurturing interactions, and strengthen relationships.



#### Speaker: Stephani Shivers, MEd, OTR/L

Stephani is the Chief Innovation Officer at CaringKind, where she leads the development of new programs and services for individuals and families impacted by dementia. With over 30 years professional experience in not -for-profit leadership and as an occupational therapist specializing in cognitive function, she is nationally recognized as a leader in community-based dementia services. Stephani is driven to 'make things better' and to improve people's quality of and engagement in life.

REGISTER LIVE or ONLINE 646-744-2900 caringkindnyc.org/education



### For More Information

### Understanding Emotional Connection & Communication

### caringkindnyc.org/ educationhub




## **Decoding Behaviors & Reactions**



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#### **DECODING REACTIONS & BEHAVIORS**

What is person doing? What is reaction/behavior? Briefly describe?

#### What Actions/Behaviors did you see? Check options:

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Verbal	Body	Physical Movements	Toward People	Toward Objects or Task
□ Yelling	Sweating	Clapping	Pushing	□ Misuse
Crying	Shivering	Tapping	Touching	Careful
Humming	Relaxed	□ Hitting	Hugging	Forceful
Laughing	Flinching	Rocking	□ Grasping	
	Breathing fast	□ Restless	□ Caressing	
Describe:				

#### What may be going on inside or outside the person to cause a reaction? Check options:

Insti D D D	ncts & Emotions Fear Anger Grief Happy		Cold, Hot, Itchy Pain Fatigue Hungry, Thirsty Dizzy	CareP	artner Approach Body Language Body Position Calm Stressed?	Physic	<i>cal Space</i> Too cluttered? Over Stimulating? Under	Locati	on Place - Familiar? Strange? Travel to/from?
	Boredom		Overwhelmed		Slower Speed		stimulating	Social	Space
	Relief,				Voice Tone		Inappropriate		Family
	Satisfaction	Backg	round, Culture		Too slow/fast?		Objects?		People
	Explore, Seek		Gender Roles		Eye Contact		Unsafe items?		Animals
	Fulfillment		Work Experience		Touch		Too much noise -		Friends?
	Connect/ Relate		Family				TV, radio		Enemies?
	Care		Faith Tradition	Activit	ty/Task		Lighting?		TV Characters
	Play		Trauma		Meaningful		Shadows?		
					Stimulating		Glare?	Time	
Physi	cal & Sensory	Chang	ning Abilities		Too Easy?		Temperature		Too Early? Too
	Health Condition		Dementia Type		Too Hard?		Inviting		Late?
	Infection		Dementia Stage		Set up		Meaningful		When tired?
	Poor Nutrition		Language		Tools		Objects?		Before/After
	Dehydration		Abilities		Lighting		Enjoyable		meal?
	Depression		Cognitive		Comfortable		Objects?		
	Over/Under		Abilities		Location		Homelike		
	Medicated		Physical Abilities		Environment		Comforting		

How can you try to change the situation? Brainstorm ideas!

#### What will you try?

## Simplify Communication



Give the person your full attention making eye contact.



Talk slowly.



Simple sentences.

Pause and wait for response.

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Give plenty of time

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Acknowledge what the person is saying.

Go along with the person's beliefs.



Use words of encouragement



## **Enhancing Communication**

An inspirational guide for people living with dementia

SERIES 1

https://the-ria.ca/resources/by-us-for-us-guides/

## Strategies for Caring Family & Friends

- Speak directly to me. Do not talk to me as though you are speaking to a child.
- Ask me what I am experiencing, how I am feeling, and validate what I am saying.
- Treat me in the same way you would want to be treated in the same situation.
- Acknowledge that you do not totally understand but that you are trying.
- Pay attention to non-verbal cues and body language, such as eyes and hands.



## Approach







## Match the task to skill level















## **Activity or Task**

- Make sure activity is Meaningful (or at least enjoyable).
- Find stimulating activities
- Break the task into parts.
- Set out the items in advance.
- Arrange the items in the order they will be used.
- Allow more than enough time.
- Label objects or places (cabinets, drawers)
- Consider environment warm, comfortable, good lighting
- Establish routines repeat the same steps daily





## Promote Joy & Resilience Find something meaningful

#### SPORTS, TRIVIA

#### **CURRENT EVENTS**





**ART, CRAFTS** 





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## COOKING, BAKING

REMINISCING

## COGNITIVE STIMULATION

PETS

HOME CHORES



MUSIC

READING

# GAMES, PUZZLES

DANCING, EXERCISE



OUTDOORS

## Meaningful Activities by Stage

Meaningful Activities by Stage							
	Early (Pace)		Moderate (Simplify)		Late (Sensory)		
Art: • •	Painting, Coloring Watercolor Clay Collage	Art: •	Simplify materials and steps for Painting, Clay, Collage, Coloring	Art: •			
Crat	its:	Crat	fts:	Crat	fts:		
•	Jewelry Making, Beading, Scrapbooking, Knitting/Crocheting	•	Simplify materials and steps. Use pony beads and shoelace string Sort collage materials Look at pictures	•	Look at scrapbook pictures while listening to music		
Boa	rd/Table Games:	Boa	rd/Table Games:	Boa	rd/Table Games:		
• • •	Cards Board Games Dice Dominos		Simplify the steps/game & provide 1:1 Board Games Checkers, Dice	•	Rolling the dice		
Coo	king/Baking:	Coo	king/Baking:	Coo	king/Baking:		
•	Follow a new recipe Share a family recipe Help with clean up		With supervision follow one step tasks Help with clean up	•	Engage the senses, watching food items, tasting, smell of food, touching vegetables fruits		
Current Events:		Cur	Current Events:		Current Events:		
•	Reading newspaper Listening to radio Watching news Engaging in discussion	•	Being mindful of upsetting news Share newspaper Engage discussions of in news stories from the past	•	Talk about your day and meaningful activities. Your joy and positive emotions will be felt		
Dan	cing:	Dan	cing:	Dan	icing:		
	Play lively music Follow dance steps	:	Play lively music Follow easy dance	•	1:1 Dancing with hands on assistance to slower music		
	rcise:		rcise:		rcise:		
	Follow an exercise video at a moderate pace Add music		Follow an exercise video at a slower pace Add music		With assistance and hand over hand help, move to a slower pace Add music		
Hou	sehold:	Hou	isehold:	Hou	isehold:		
•	Light cleaning Helping with laundry Set the table	•	napkins		Touching warm clothing out of the dryer Smell of detergent		
Mus		Mus	• •	Mus	•		
•	Chooses music Make music accessible i.e. radio with reminder for favorite station Alexa, google home		<ul> <li>Help play favorite music and talk about the past</li> </ul>		<ul> <li>Play music at certain times of day to help during bathing, dressing, meals</li> <li>Play soothing music to help with "behaviors"</li> </ul>		

Early (Pace)	Moderate (Simplify)	Late (Sensory)
Outdoors: • Gardening • Walking • Visiting gardens, parks	Outdoors: • Watering plants • Planting in soil • Picking flowers • Walking	Outdoors: Smelling flowers Listening to birds Tasting herb garden Warmth of the sun
<ul> <li>Pets:</li> <li>Caring for pet i.e feeding, giving water, brushing</li> </ul>	Pets:     Petting, brushing with     hand over hand     Discuss pets together	<ul> <li>Pets:</li> <li>Bring live pet within eyesight</li> <li>Use Stuffed animals, robotic pets</li> </ul>
Puzzles: • Crossword • Word finding • Jigsaw Puzzles	Puzzles: Large piece small number jigsaw puzzles Photo matching games Simple word finds	Puzzles: • Have them join you in a game, show pictures, discuss/reminisco about words.
Reading: Books/ Short stories Magazines Newspapers Letters	Reading: • Photography books • Visual Magazines • Short stories with large print	<ul> <li>Reading:</li> <li>Read to the client</li> <li>Choose reading materials based on client's past interests</li> </ul>
Religious/Spiritual: • Prayer books • Hymn Books • Familiar religious items	<ul> <li>Religious/Spiritual:</li> <li>Engage in religious songs</li> <li>Use religious items as visual cues &amp; discuss</li> </ul>	Religious/Spiritual:           Use religious items for visual and tactile cues           Engage in religious songs           Play sermons on tv
<ul> <li>Sports:</li> <li>Watching/listening to sports</li> <li>Reading news sports section</li> <li>Playing catch games</li> </ul>	<ul> <li>Sports:</li> <li>Sports books and photographs</li> <li>Video highlights from historic games</li> <li>Sports puzzles &amp; games</li> </ul>	Sports: • Hands on sports equipment • Smell baseball gloves; footballs
Trivia: • Familiar trivia questions	<ul> <li>Trivia:</li> <li>Trivia with pictures, music, fill in the blank</li> </ul>	Trivia: • Reminisce on favorite trivia categories
Reminiscing: • Photos, scrapbooks for recall	Reminiscing: • Pictures, scents, music for discussion	Reminiscing: • Pictures, scents, music
Watching TV/Movies: • Let choose favorites • Provide reminders for TV schedule • Engage in discussion after	Watching TV/Movies: Inform when favorite shows are on May lose interest in long shows Movie musicals	<ul> <li>Watching TV/Movies:</li> <li>Play favorite show, be not to promote anxiety or fear</li> </ul>
<ul> <li>Provide writing materials</li> </ul>	<ul> <li>Writing:</li> <li>Sign a card, stuff envelope</li> </ul>	writing:

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### EDUCATION SEMINAR

A free learning event for individuals, families and professionals

#### LIVE WEBINAR

### **Creative Connections**

Meaningful Engagement Across the Stages of Dementia

When Alzheimer's or another form of dementia progresses and a person's abilities change, finding enjoyable activities that a person can still do can be challenging. Frustrations and conflicts often arise amidst couples and families when typical activities, tasks and hobbies become more difficult.

Join us for this seminar to explore:

- Ways to engage a person in the early, middle and later stages of Alzheimer's or another dementia
- Creative and adapted activities that are meaningful and matched to a person's current abilities
- Strategies that foster connection, communication and quality of life for both the person living with dementia and their families and partners in care

#### Speaker: Olivia Cohen, MS, MT-BC, LCAT, CDP

Olivia Cohen is the Director of Early-Stage and Engagement Services at CaringKind. Olivia is a board-certified music therapist and licensed creative arts therapist with over 12 years of experience working in long-term care, healthcare, and with individuals living with Alzheimer's and dementia. Her work has been featured in publications such as The New York Times, Huffington Post, Chasing News, and Aging Today. Additionally, she has co-authored a chapter in the book "Creative Arts Therapies and the LGBTQ Community.

> TO REGISTER: 646-744-2900 caringkindnyc.org/education



## For More Information

## **Creative Connections:** Meaningful Engagement Across the Stages of Dementia

#### caringkindnyc.org/ educationhub





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Talk to a Navigator

## 646-744-2900





www.caringkindnyc.org

# Questions

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360 Lexington Ave, New York, NY CARINGKINDNYC.ORG Helpline: 646-744-2900 @caringkindnyc

## Links for reference

## Helpline: 646-744-2900

## Schedule a call with CaringKind Navigator:

https://outlook.office365.com/book/Appointments@cknyc.org/

CaringKind Website: <a href="https://caringkindnyc.org/">https://caringkindnyc.org/</a>

Education Calendar: <u>https://caringkindnyc.org/carepartnereducation/</u>

#### Professional Education Seminars: https://www.caringkindnyc.org/professionaleducation



### **The Feeling Wheel**

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The Feeling Wheel is designed to help people in learning to recognize and communicate about their feelings. It consists of an inner circle with 5 sectors and two outer concentric circles. The sectors are each labeled at the center with the name of a primary feeling: sad, mad, scared, joyful, powerful, and peaceful. The outer rings contain names of secondary feelings related to the primary ones. The wheel helps people learn how to identify, to express, to generate, and to change feelings.

Source: Willcox, G. (1982). The Feeling Wheel A Tool for Expanding Awareness of Emotion and Increasing Spontaneity and Intimacy. Transactional Analysis Journal, 12(4), 274-276

360 Lexington Avenue, 3<sup>rd</sup> Fl. New York, NY 10017 caringkindnyc.org

#### **DECODING REACTIONS & BEHAVIORS**

WHAT?	WHY	Y?	WHY?	WHY?	WHERE?	
Action	Insic	le	Outside	Outside	Outside	
BEHAVIOR	INSIDE PI	ERSON	CARE PARTNER ACTIVITY, TA APPROACH		ENVIRONMENT	
Action? Reaction? Expression? Verbal Yelling Yelling Crying Humming Laughing Body Sweating Sweating Relaxed Flinching Breathing fast Physical, Movements Clapping Hitting Restless Toward People Pushing Restless Toward People Pushing Grasping Caressing Toward Objects Misuse Careful Forceful	Instincts & Emotions Fear Anger Grief Happy Boredom Relief, Satisfaction Explore, Seek Fulfillment Connect/ Relate Care Play Physical & Sensory Health Condition Infection Poor Nutrition Dehydration Dehydration Depression Over/Under Medicated Cold, Hot, Itchy Pain Fatigue Hungry, Thirsty Dizzy Overwhelmed	Background, Culture Gender Roles Work Experience Family Faith Tradition Trauma Changing Abilities Dementia Stage Language Abilities Cognitive Abilities Physical Abilities	<ul> <li>Body Language</li> <li>Body Position</li> <li>Calm</li> <li>Stressed?</li> <li>Slower Speed</li> <li>Voice Tone</li> <li>Too slow/fast?</li> <li>Eye Contact</li> <li>Touch</li> </ul>	<ul> <li>Meaningful</li> <li>Stimulating</li> <li>Too Easy?</li> <li>Too Hard?</li> <li>Set up</li> <li>Tools</li> <li>Lighting</li> <li>Comfortable</li> <li>Location</li> <li>Environment</li> </ul>	<ul> <li>Physical Space</li> <li>Too cluttered?</li> <li>Over Stimulating? Under stimulating</li> <li>Inappropriate Objects?</li> <li>Unsafe items?</li> </ul> Sensory <ul> <li>Too much noise - TV, radio</li> <li>Lighting? Shadows? Glare?</li> <li>Temperature</li> </ul> Appeal <ul> <li>Inviting</li> <li>Meaningful Objects?</li> <li>Enjoyable Objects?</li> <li>Homelike</li> <li>Comforting</li> <li>Joy? Happy</li> </ul> Location <ul> <li>Place - Familiar? Strange?</li> <li>Travel to/from?</li> </ul> Social Space <ul> <li>Family</li> <li>People</li> <li>Animals</li> <li>Friends? Enemies?</li> <li>TV Characters</li> </ul> Time <ul> <li>Too Early? Too Late?</li> <li>When tired?</li> <li>Before/After meal?</li> </ul>	



#### **DECODING REACTIONS & BEHAVIORS**

What is person doing? What is reaction/behavior? Briefly describe?

Verbo	1	Body		Physi	cal Movements	Тоwа	rd People	Towa	rd Objects or Tasl
	Yelling		Sweating		Clapping		Pushing		Misuse
	Crying		Shivering		Tapping		Touching		Careful
	Humming		Relaxed		Hitting		Hugging		Forceful
	Laughing		Flinching		Rocking		Grasping		
			Breathing fast		Restless		Caressing		
De	scribe:								
w	hat may be go	oing o	n inside or ou	tside	the person to	o caus	e a reaction?	Chec	k options:
Insti	ncts & Emotions		Cold, Hot, Itchy	CareF	- Partner Approach	Physi	cal Space	Locat	ion
	Fear		Pain		Body Language		Too cluttered?		Place - Familiar
	Anger		Fatigue		Body Position		Over		Strange?
	Grief		Hungry, Thirsty		Calm		Stimulating?		Travel to/from?
	Нарру		Dizzy		Stressed?		Under		-
	Boredom		Overwhelmed		Slower Speed		stimulating	Social	Space
	Relief,				Voice Tone		Inappropriate		Family
	Satisfaction	Backg	round, Culture		Too slow/fast?		Objects?		People
	Explore, Seek		Gender Roles		Eye Contact		Unsafe items?		Animals
	Fulfillment		Work Experience		Touch		Too much noise -		Friends?
	Connect/ Relate		Family				TV, radio		Enemies?
	Care		Faith Tradition	Activi	ty/Task		Lighting?		TV Characters
	Play		Trauma		Meaningful		Shadows?		
					Stimulating		Glare?	Time	
Physi	cal & Sensory	Chang	ging Abilities		Too Easy?		Temperature		Too Early? Too
	Health Condition		Dementia Type		Too Hard?		Inviting		Late?
	Infection		Dementia Stage		Set up		Meaningful		When tired?
	Poor Nutrition		Language		Tools		Objects?		Before/After
	Dehydration		Abilities		Lighting		Enjoyable		meal?
	Depression		Cognitive		Comfortable		Objects?		
	Over/Under		Abilities		Location		Homelike		
	over/onder		<b>DI I I I I I</b>		Environment		Comforting		
	Medicated		Physical Abilities		Environment	_			

#### How can you try to change the situation? Brainstorm ideas!

What will you try? \_



CaringKind Helpline: 646-744-2900 helpline@caringkindnyc.org Fax: 212-697-6158

