

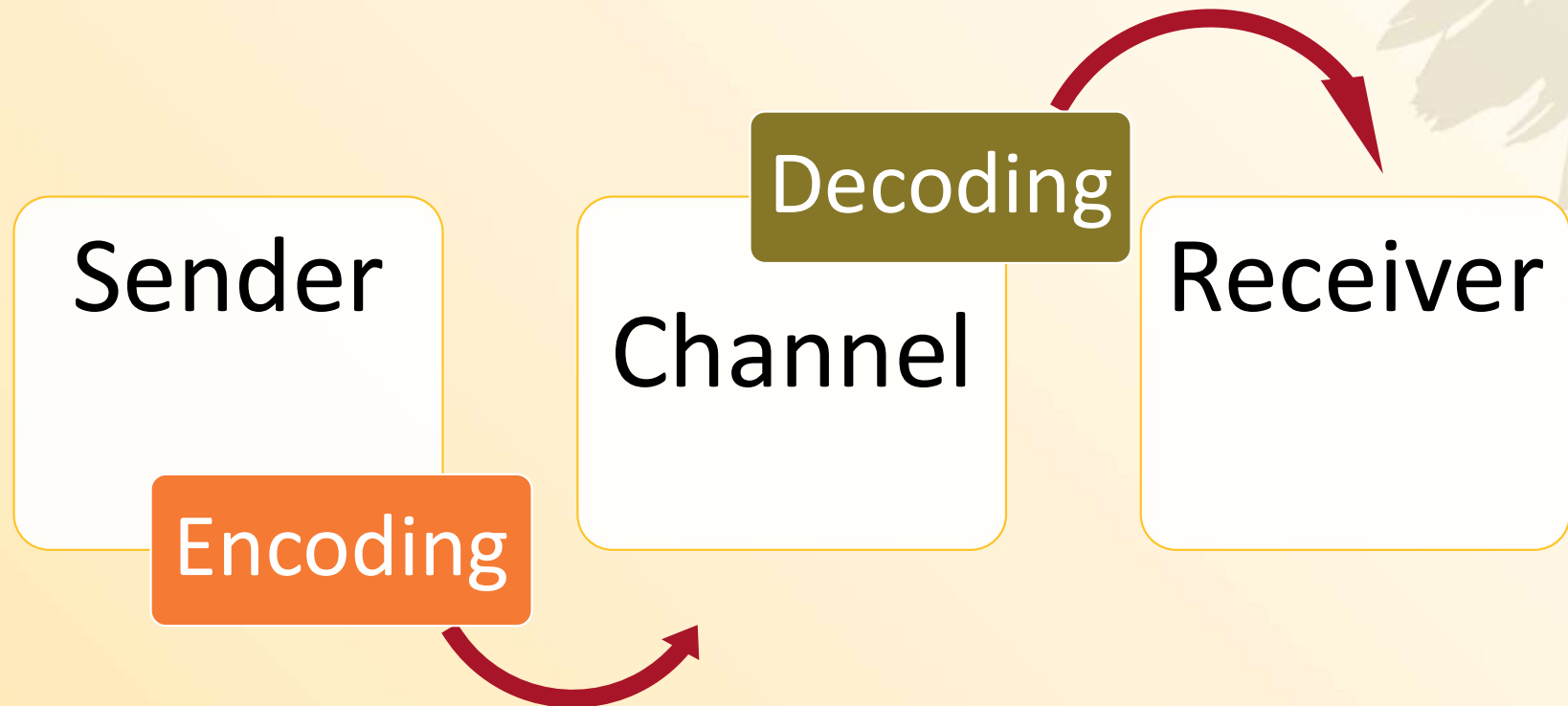
# Communication, Caregiving and Dementia

Heather Brown, M.S., Training and Development Specialist  
Johnson County Developmental Supports

# Communication is Vital to Who We Are

- Our needs, wishes and feelings
- Preserves our identity
- Maintain relationships

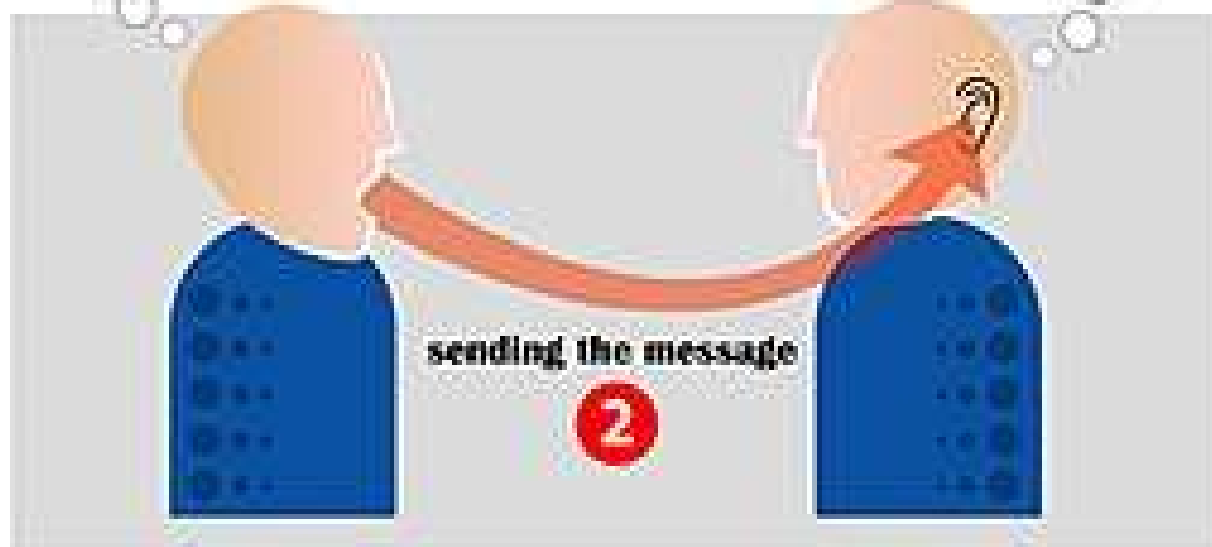
# Communication 101



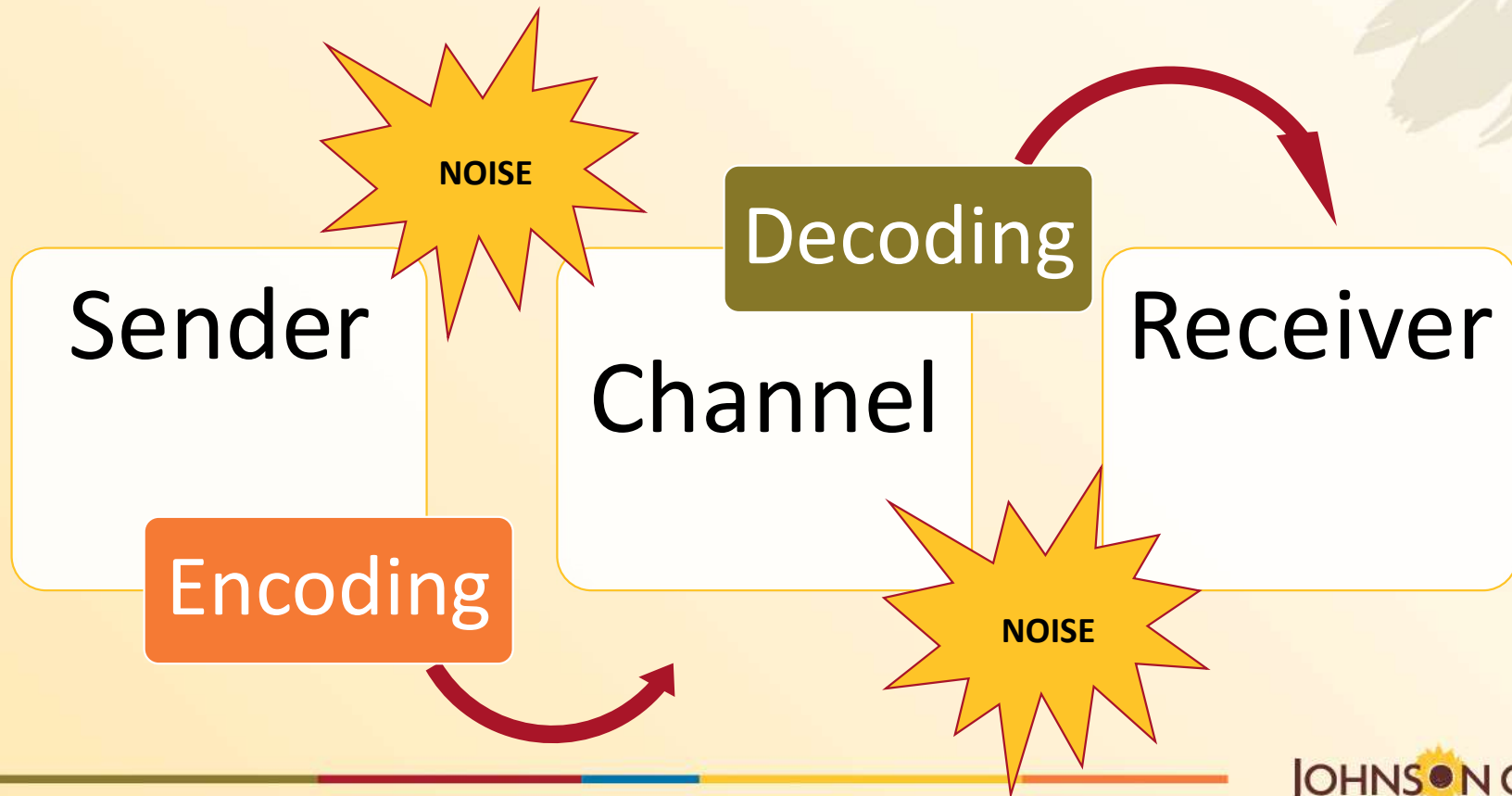
**1** codifying



**3** decodifying



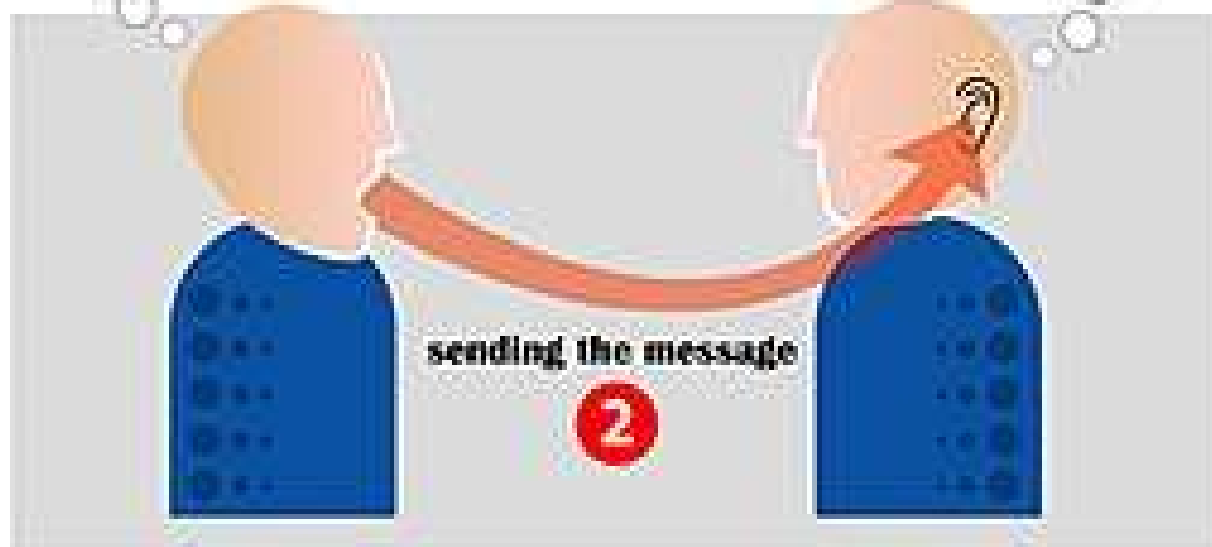
# Communication 101



**1** codifying



**3** decodifying





JOHNSON COUNTY  
KANSAS

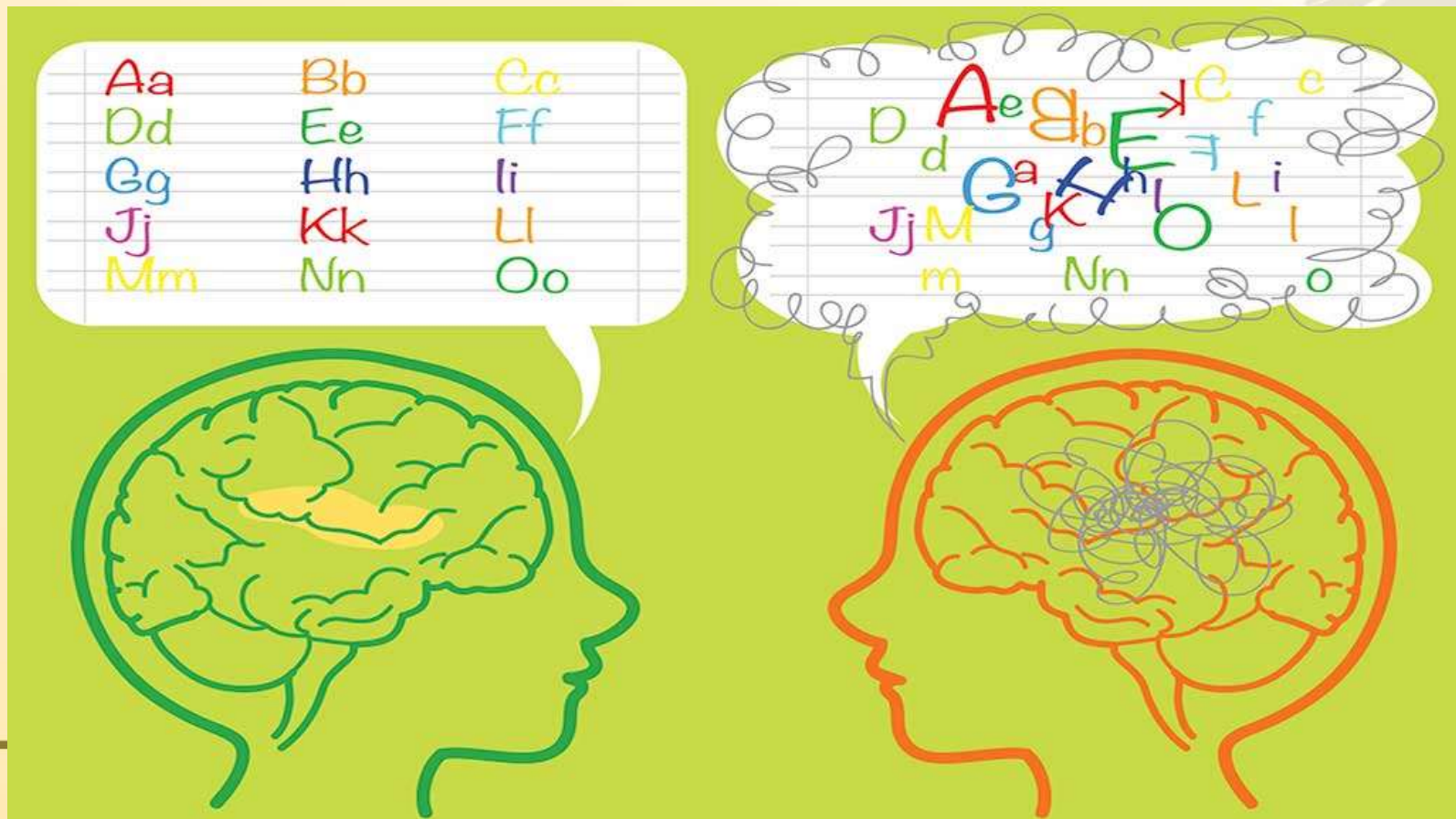
# Non-Verbal

Communication isn't just about the words we use and say, it's also:

- Gestures
- Tone of voice
- Body Language
- Facial Expressions
- Touch



# Dementia is an Information Processing Problem




# What information do you take in every day?

Type in Chat or Annotate on the Screen

# How do you get your information?

Type in Chat or Annotate on the Screen



When do you get information?  
Do you ever get it when you DON'T want it?

The information you take in and process also  
determines your behavior



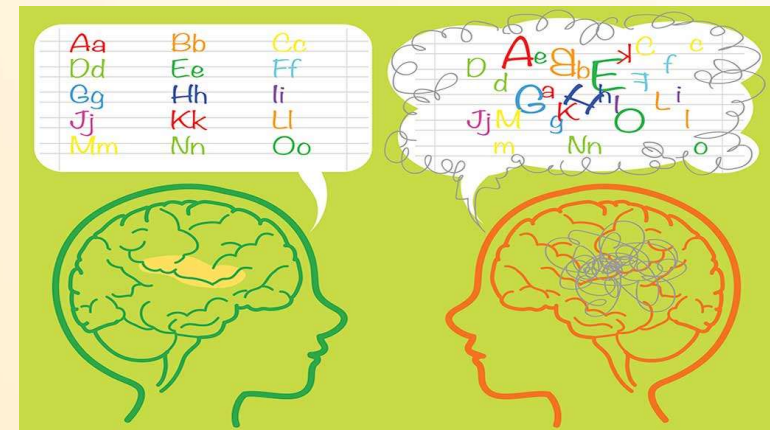
# How should you behave here?



[This Photo](#) by Unknown User has been licensed under [CC BY-SA](#)

# Dementia is an Information Processing Problem

- Sensory Issues- with all 5!
- Vestibular Sense (balance)
- Proprioceptive Sense
- Loss of time, space, location



# Proprioceptive Sense





# Proprioceptive Sense



# Receptive vs. Expressive Communication

- Expressive
  - Outward expression that comes from within
  - Words or non-verbal
- Receptive
  - I can understand you, but I can't let you know

Individuals with IDD typically have better receptive vs. expressive communication. The disparity between the two grows wider with dementia

# Non-Verbal

- As language skills are lost, non-verbal communication becomes more important
  - Caregivers must pay attention to their own non-verbal as well as verbal communication styles
  - Caregivers must pay attention to *the person's* non-verbal communication much more than they're probably used to

We need to keep communicating!

# Communication Tips

Identify Yourself  
*Every Time*

Never assume that the person remembers you

# Communication Tips (cont)

Speak *slowly, clearly, and calmly*

Loud voices can sound angry





# When *WE* get frustrated...

We talk *faster*

We breath *heavier*

Our tone gets *higher* and *louder*

We don't *reason* as well

We only see and think in *concrete* ways

We close our world with the person and ourselves.





# Communication Tips (cont)

Use *short, simple* sentences

Direct and to the point

Break tasks down to one-step directions

Give the person time to respond- 8 to 10 seconds at least!

Give them time to complete each step / task / direction before moving on to the next





# Don't Ask Complex Questions

“What do you want to drink?”  
I had milk for breakfast  
Juice sounds good  
What did she  
What's a drink?  
But I don't like the  
ask me?  
I'm am quite thirsty  
I wonder if we have red wine  
I wonder if we have milk in the fridge  
the creamer I like  
put sugar in it?  
I think I saw juice  
I love  
boxes in there earlier coffee





# Stick to “Yes” or “No”

“Would you like tea to drink?”

No.

“Would you like juice to drink?”

No.

“Would you like some coffee?”

No.

“Is water ok to drink?”

Yes.



# Communication Tips (cont)

Make sure the person is focused on you

Approach the person from the FRONT

Light touch

Eye level



Try to make eye contact if appropriate- but don't force it

Minimize distractions such as the TV, radio/music, other background noises

# Body Language

Remember- they will read into this MORE because their ability to understand words and conversation decreases.

## SMILE

Be open and relaxed

Don't stand over people- eye level, step back



# Open Vs. Closed

Both are smiling,  
but one's more  
inviting.



This is probably how we feel inside.....



But we  
can't show  
it!!!



I'm here to help.

I care about how  
you're feeling.

Our body language  
should convey a message  
of caring, interest, and  
understanding

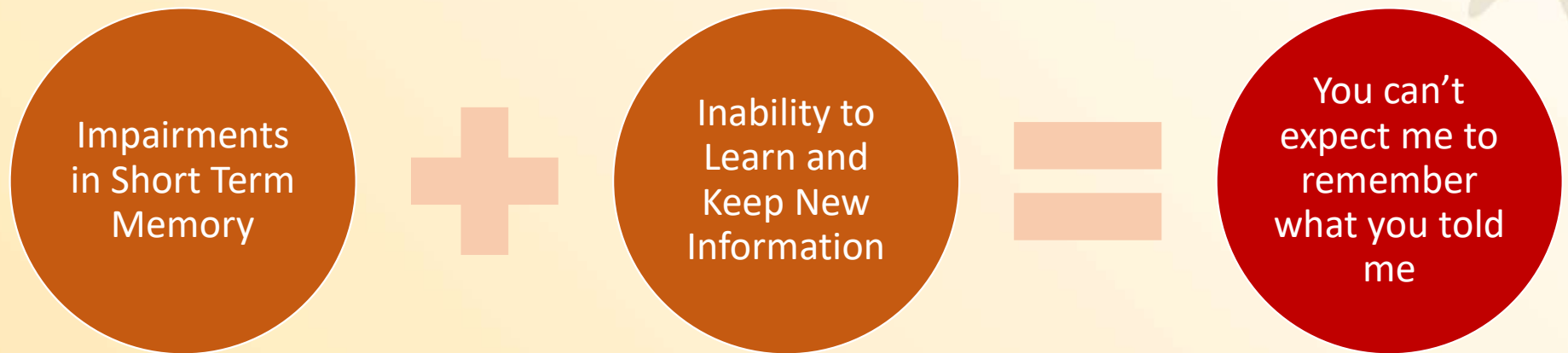
# 4 Golden Rules





# Rule #1:

## Difficult Behaviors Cannot be Changed with Words





# What *CAN* you do?

- Change your approach to the person
- Change your reaction and response to their behavior
- Change the environment





Rule #2:

Don't say "NO" and NEVER ARGUE

You can't reason with someone who has lost their ability to process thoughts in a logical and rational matter

**YOU WILL LOSE EVERYTIME**

Arguing = Frustration, Fear, Anxiety





No One Cares if You're Right.

# Rule #3: Reduce Fear and Validate Emotions

Loss of ability to express and cope with fears

Ability to self-soothe decreases significantly

Not Understanding, becoming confused, hallucinations-

These feelings and experiences can be terrifying and overwhelming, and they can't tell you how they're feeling

Focus and respond to the *emotions*, because  
THAT'S what they need you to understand

# “I’m Scared.”

It doesn’t matter *WHY* they’re scared.

But the fact that they’re scared is worth your time and attention.

When YOU experience this emotion, does it help to share it with others? That others recognize you’re feeling this way?



# Rule #4: It's THEIR Reality, and You Must Enter it

You can't bring the person out of their dementia

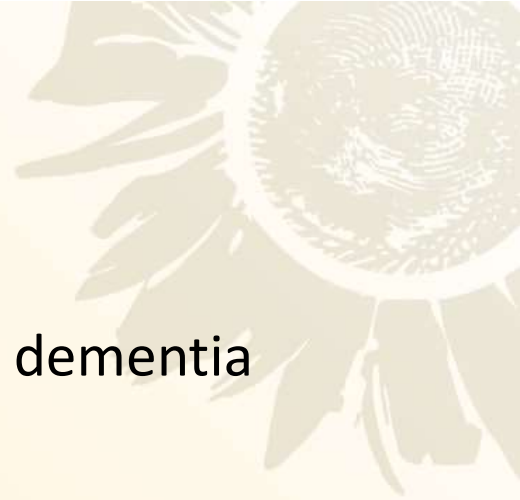
You have to step into their world, because that's where they are

Meet them there

Validate their emotions

This builds empathy, a sense of trust, reassurance, security






# Dementia Related Behaviors

- Changes in behavior can occur in all stages of a person's dementia
  - Unpredictability = stress for caregivers
- Range from Annoying > Agitated > Combative
  - Repetitive questions > pacing / yelling > hitting / spitting







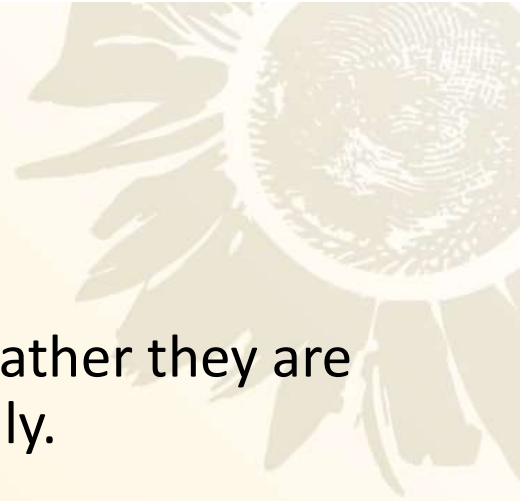
Wandering  
Repetitive questions  
Rummaging, hoarding  
Verbal outbursts – yelling, excessive vocalizations, cursing  
Physical aggressiveness – hitting, spitting, kicking  
Paranoia  
Hallucinations  
Sleep-wake disorders  
Sundowning  
Resistance to personal care  
Inappropriate sexual expression

Behaviors can seem inappropriate, childlike, or impulsive.

“The person with dementia isn’t giving you a hard time, they’re *having* a hard time.”

# Opinion: Do Behaviors Occur Out of the Blue?

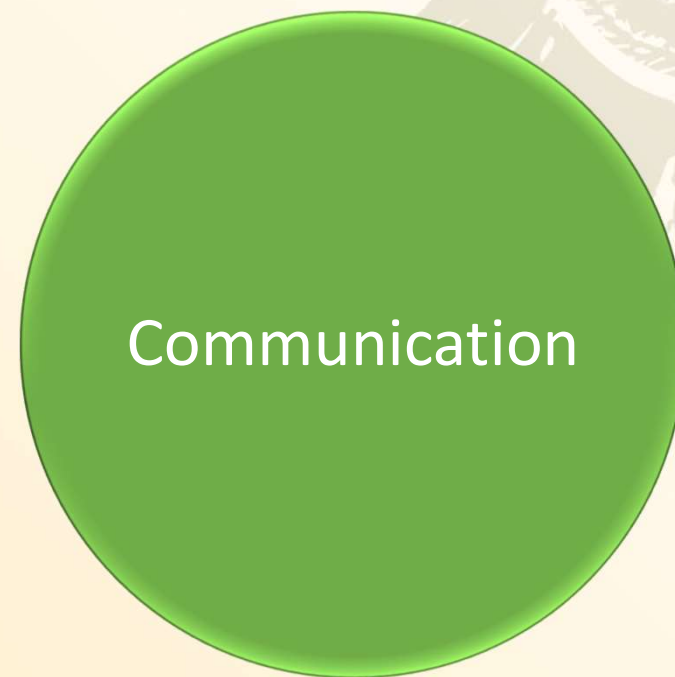
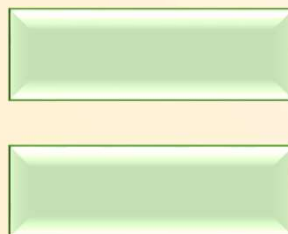




Almost ALL behaviors do NOT occur out of the blue, but rather they are triggered by something, internally or externally.

As Caregivers, it's our duty to figure out what those triggers are.





# Active vs. Passive

## Active

I know what I need or want,  
but I'm having trouble saying  
it, so I'm going to do  
something to try and get you  
to understand

## Passive

Something is wrong, but I may  
not know what it is, so I can't  
tell anyone

I begin acting differently as a  
result of what's wrong

# 3 Most Common Behavior Triggers

Caregiver Interactions

Pain

Environment



# Caregiver- YES, it's our fault sometimes

- Did I argue? Did I tell the person No?
- Was I rushing the person?
- What message was my body language sending?
- Was I overestimating what the person was capable of doing?
  - Too many steps to the task
  - Too many prompts
  - Not enough time to respond

# Trigger: Pain

- Existing medical conditions that may cause pain?
  - Arthritis, migraines, osteoporosis, GERD
- Recent change in medications?
- Temperature- too hot, too cold?
- Possible new acute illness?
  - UTI, impaction, constipation,
  - Sudden change in mental status = delirium

# Trigger: Emotional Pain

- Pain is also emotional!
- Mental Illness-related
  - Depression, anxiety
- Frustration, loss, feeling scared, overwhelmed, feeling threatened



# Remember: Validate Emotions

# Trigger: Environment

- New or unfamiliar setting, change in routine
- Change in staff
- Noise
- Lighting and Shadows
- Large number of people
- Lost- no orienting cues for way finding.

# Shadows





# Who has to change?

- We do!
- Trying to change or control behavior will be met with resistance
  - Because we're not addressing the root of the issue
- Accommodate the behavior
- Change our own behavior or the environment





# Caregiving

Beyond good Communication



# Shift in Care

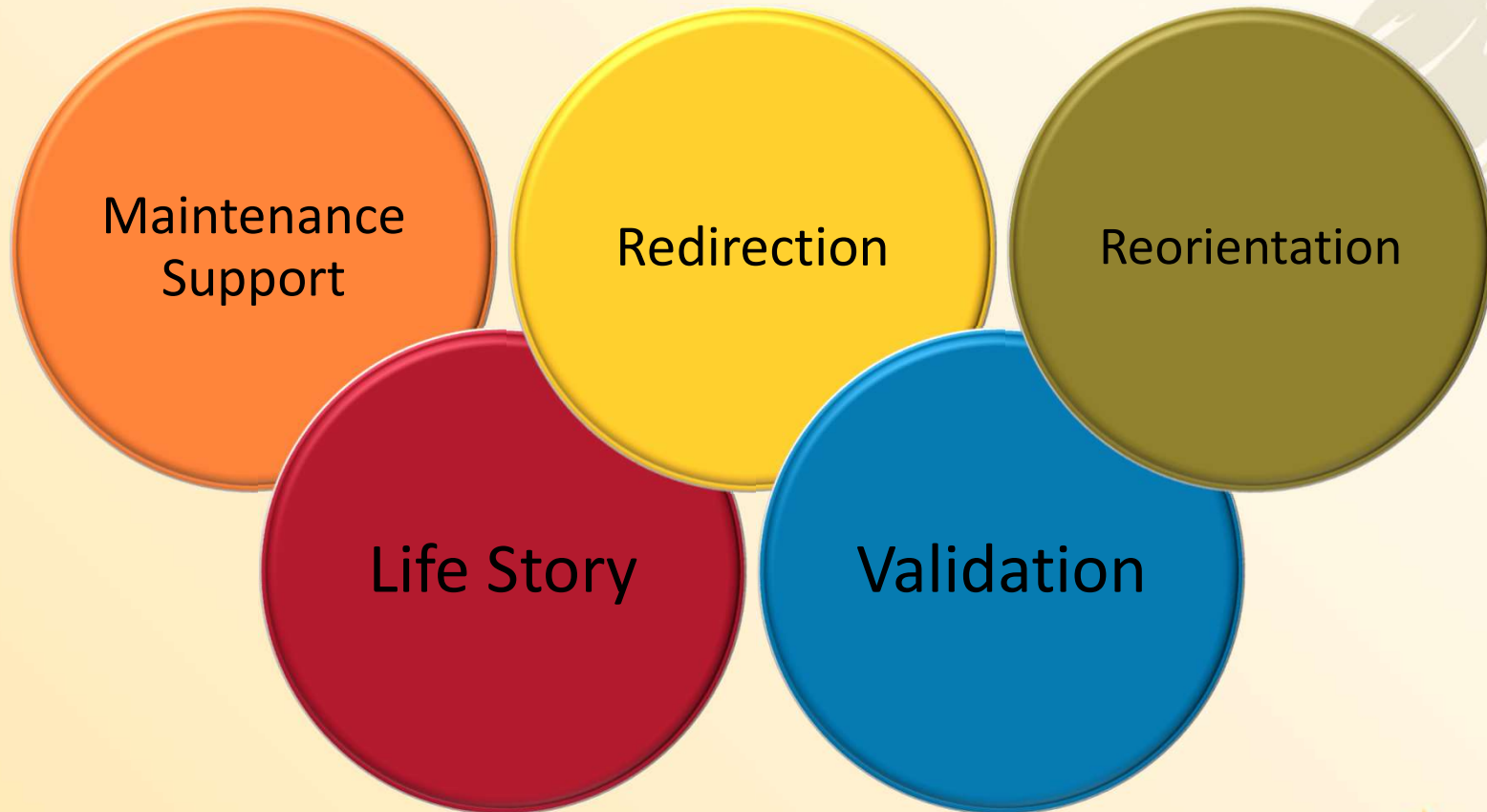
## Independence

Focus on gaining and learning skills

## Maintenance

Keeping what they have and participation

# 5 Domains of Caregiving


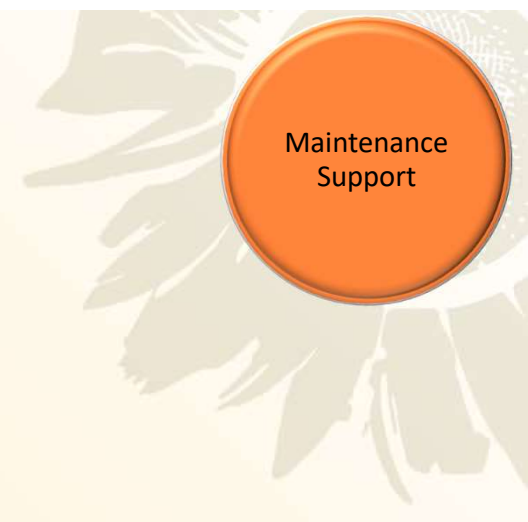


# 5 Domains of Caregiving



Maintenance  
Support

# 5 Areas of Maintenance Support



Maintenance  
Support

## Five Areas that focus on:

- Maintaining positive emotions
- Supporting remaining abilities
- Meaningful Activity
- Reduce difficult behaviors at all stages
- Appropriate for all settings

# 5 Areas of Maintenance Support

## Physical

- Reducing potential for fear and disorientation by modifying/adapting environment
- Ex. Reduce clutter, increase lighting, limit choices.

## Social

- Use of structured, failure-free activities that avoid frustration.
- Ex. Reminiscence, music, gardening

## Communication

- Increased use of body language, gestures, cueing, signs to compensate for decreased verbal skills.
- Never say “no” or argue, use redirection, enter their reality, respond to the emotion.

## Functional

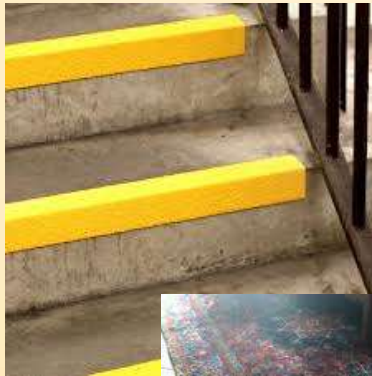
- Excess disability arises due to the person’s emotional reaction to disease.
- Avoid open ended questions, “chunking” – a series of short, simple commands

## Behavioral

- Behavior is a form of communication. To change a behavior we must change our approach.
- Analyze the behavior to find underlying trigger: pain, frustration, environment, confusion.

# Physical

- Reducing potential for fear and disorientation by modifying/adapting environment
- Ex. Reduce clutter, increase lighting, limit choices.



Contrasting elevations

Remove Rugs



Too much visual stimulation can cause anxiety and unrest

Provide limited options that still allow choices





# Physical

- Reducing potential for fear and disorientation by modifying/adapting environment
- Ex. Reduce clutter, increase lighting, limit choices.



Busy patterns can create 'movement'



Be mindful of artwork and decoration selections



# Social

- Use of structured, failure-free activities that avoid frustration.
- Ex. Reminiscence, music, gardening

## *Failure Free Activities*

- Adapted to suit needs and capabilities of the person
- Simple
- Reinforces self-esteem
- Relieves boredom and frustration
- Emphasizes and uses remaining abilities

# Social

- Use of structured, failure-free activities that avoid frustration.
- Ex. Reminiscence, music, gardening

## Activities with Social Elements

Sing-A-Longs

Pets or Animal Therapy

Interactions with Children or others that do not live with them

Sharing photos

Touch

Simply being around others

# Other Failure-Free Activities

- Bird watching
- Sitting in a park
- Porch Swings
- Painting
- Physical activities such as miming, balloons, noodles
- Going for a walk
- Reminiscing
- Listening to music

Physical	<ul style="list-style-type: none"><li>• Reducing potential for fear and disorientation by modifying/adapting environment</li><li>• Ex. Reduce clutter, increase lighting, limit choices</li></ul>
Social	<ul style="list-style-type: none"><li>• Use of structured, failure-free activities that avoid frustration.</li><li>• Ex. Reminiscence, music, gardening</li></ul>
Communication	<ul style="list-style-type: none"><li>• Increased use of body language, gestures, cueing, signs to compensate for decreased verbal skills.</li><li>• Never say "no" or argue, use redirection, enter their reality, respond to the emotion.</li></ul>
Functional	<ul style="list-style-type: none"><li>• Excess disability arises due to the person's emotional reaction to disease.</li><li>• Avoid open ended questions, "chunking" – a</li></ul>
Behavioral	<ul style="list-style-type: none"><li>• <del>Behavior of the person is the problem</del> To change a behavior we must change our approach.</li><li>• Analyze the behavior to find underlying trigger: pain, frustration, environment, confusion.</li></ul>

## Communication

- Increased use of body language, gestures, cueing, signs to compensate for decreased verbal skills.
- Never say “no” or argue, use redirection, enter their reality, respond to the emotion.

## Functional

- Excess disability arises due to the person’s emotional reaction to disease.
- Avoid open ended questions, “chunking” – a series of short, simple commands

## Behavioral

- Behavior is a form of communication. To change a behavior we must change our approach.
- Analyze the behavior to find underlying trigger: pain, frustration, environment, confusion.

# Life Story



# Everyone has a story



Life  
Story

Honor and Respect It

The story is the *essence* of the person

Must be documented over the lifespan

When the person can no longer tell their story, it will be used to inform caregiving and plan activities



# Everyone has a story



Life  
Story

To create meaningful activities, pull from their Life Story

Or help re-create it

Scrapbooks, interests, hobbies, preferences, routines, memories

Opportunities to reminisce, share, re-live

# What's your story?

What would you want people to know about YOU?

Enter here or in the Chat



Life  
Story

# Redirection

# Successful Redirection



Redirection

Used to avoid or delay outbursts or other challenging behaviors

Gentle Distraction

Suggesting a preferred activity

Always offer activities or conversation topics in a reassuring and calm tone of voice

It's not about reprimand. Avoid "No" and "Don't do that"

It may not work for others, and it may not work tomorrow.

# Helpful Tips



Redirection

- Remember- they will read (and understand) your body language FIRST
  - Smile, Relax, Warm and Welcoming
- Ask Questions
  - “Tell me about it....”

“I WANT TO SEE MY MOM!!!”

“Tell me about your mom.”

Talk about mom. What do you like to do with your mom?

Then, gently redirect attention to another activity and away from the subject.



Redirection



~~h~~ Reorientation

# Remember.....

- The goal is not to be right
- You can't bring them out of dementia, you must *enter their reality*
- As a person's most recent memories fade away, memories of years past will become their new reality.
- *It's not lying, it's respecting their reality*



Reorientation



Fading  
Memories-  
New Reality

Retirement

← TODAY

Child rearing

College

Young Adult

Childhood

Fading  
Memories-  
New Reality

*Gone*

Child rearing

← New Reality

College

Young Adult

Childhood

INTY  
NSAS

Fading  
Memories-  
New Reality

College



New Reality

Young Adult

Childhood

Fading  
Memories-  
New Reality



Young Adult



New Reality

Childhood

INTY  
NSAS

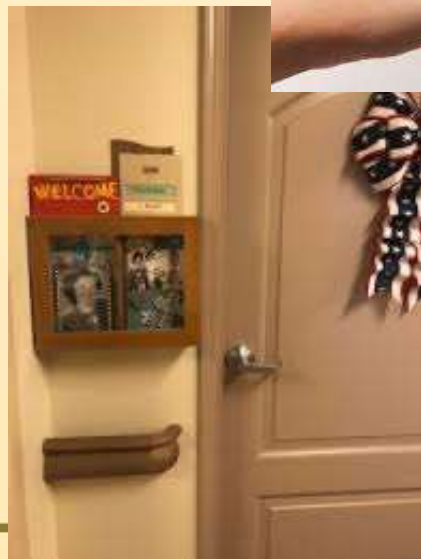
# Fading Memories- New Reality



Childhood

It IS ok to provide  
orienting /  
wayfinding cues  
in the  
environment

Reorientation



# Validation

# Review

- Focus is on emotions, *not what's causing them*
- Empathy and Understanding, Reassurance
- Acceptance of person's reality and personal truth of their experience, *regardless of their confusion*
- Can reduce stress, anxiety, agitation, challenging behaviors



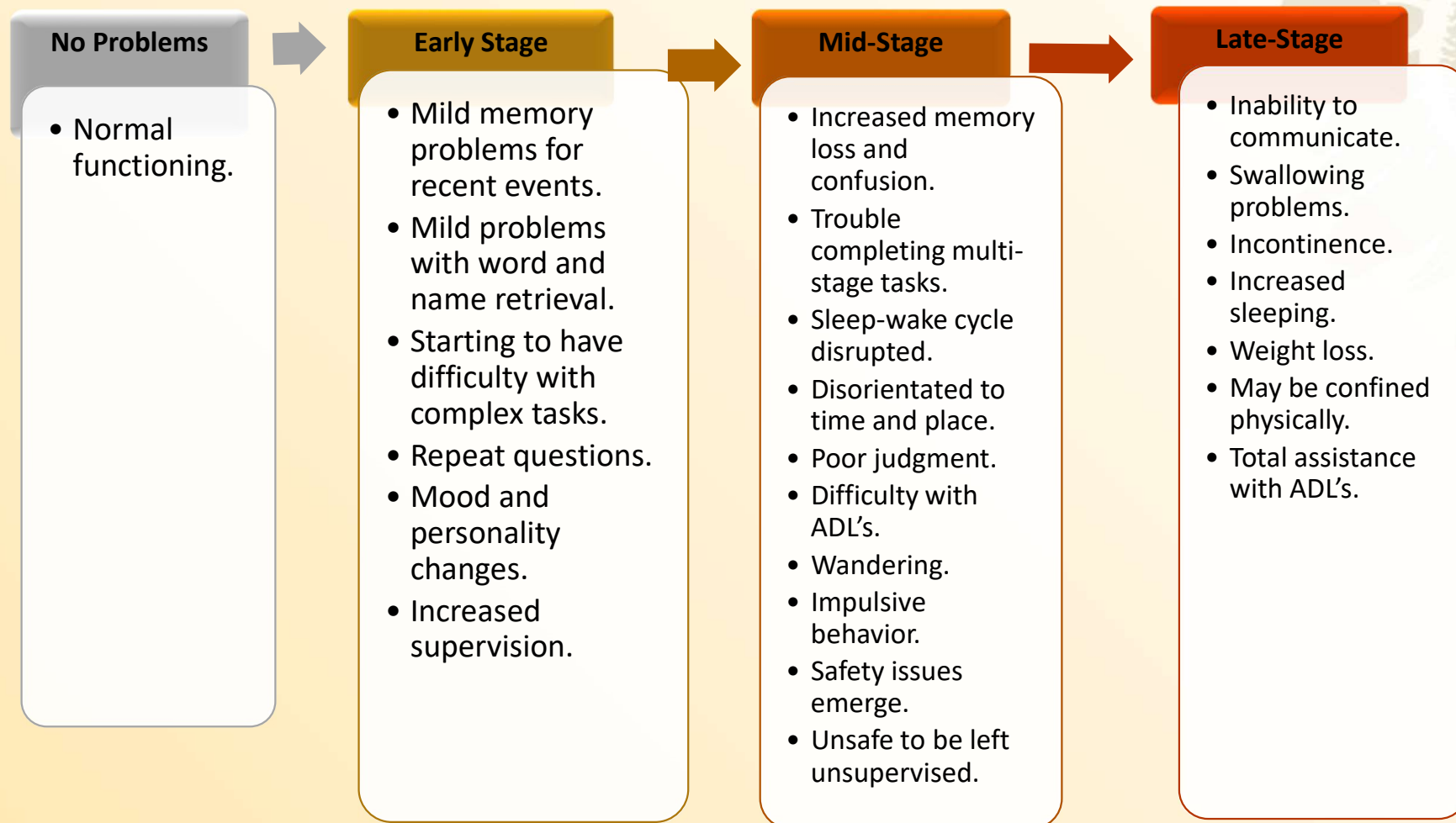
Validation



# Caregiving- Knowing the Stages of Dementia

- A Yardstick or Estimate
  - It's a general measure of the person's decline
- Used to determine appropriate supports and accommodations
  - Based on needs and abilities





# Stage-Based Considerations

## Early Stage

- Screen with NTG-EDSD, *document changes*
- Observation & reporting of functional changes to a team.
- Support functioning and maintain quality of life
- Planning

## Mid-Stage

- Modify/adapt environment to support functioning and safety
- Increase staff supervision and supports
- Maintain routine and structure as much as possible

## Late Stage

- Specialized re-training of staff including mobility, eating, and comfort care
- Increased use of adaptive equipment and procedures
- Grief support – family, staff, friends
- Hospice / Palliative Care



# Summary: Goals of Caregiving

- Maintain quality of life
- Focus on remaining abilities
- Maintain safety
- Maintain health and prevent hospitalization
- Provide meaningful activities
- Focus on emotional well-being

