



Dementia 201

Behavioral Symptoms of Dementia and Positive Interventions

Katrina Longmire, CSW
Dementia Care Specialist
Aging & Disability Resource Center of
Buffalo and Pepin Counties

Objectives

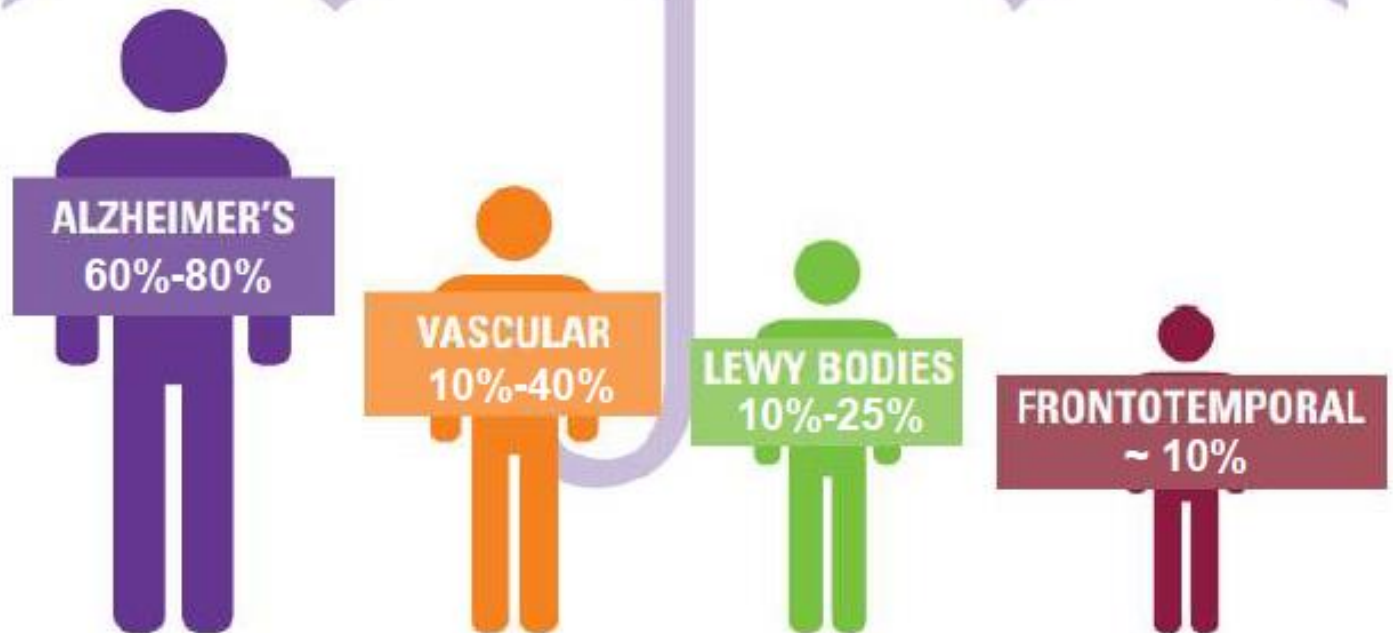
- Dementia Overview
- Caregiver Tips
- Common Behaviors
- Strategies for Communication
- DICE
- Medications

What is Dementia?

1. A loss of cognitive function significant enough to interfere with daily functioning.
2. It is a change from a previous level of functioning (decline).
3. It is a group of symptoms, some may be treatable (i.e. dehydration) and others are irreversible (i.e. Alzheimer's Disease)
4. Dementia is not a normal part of aging.

DEMENTIA

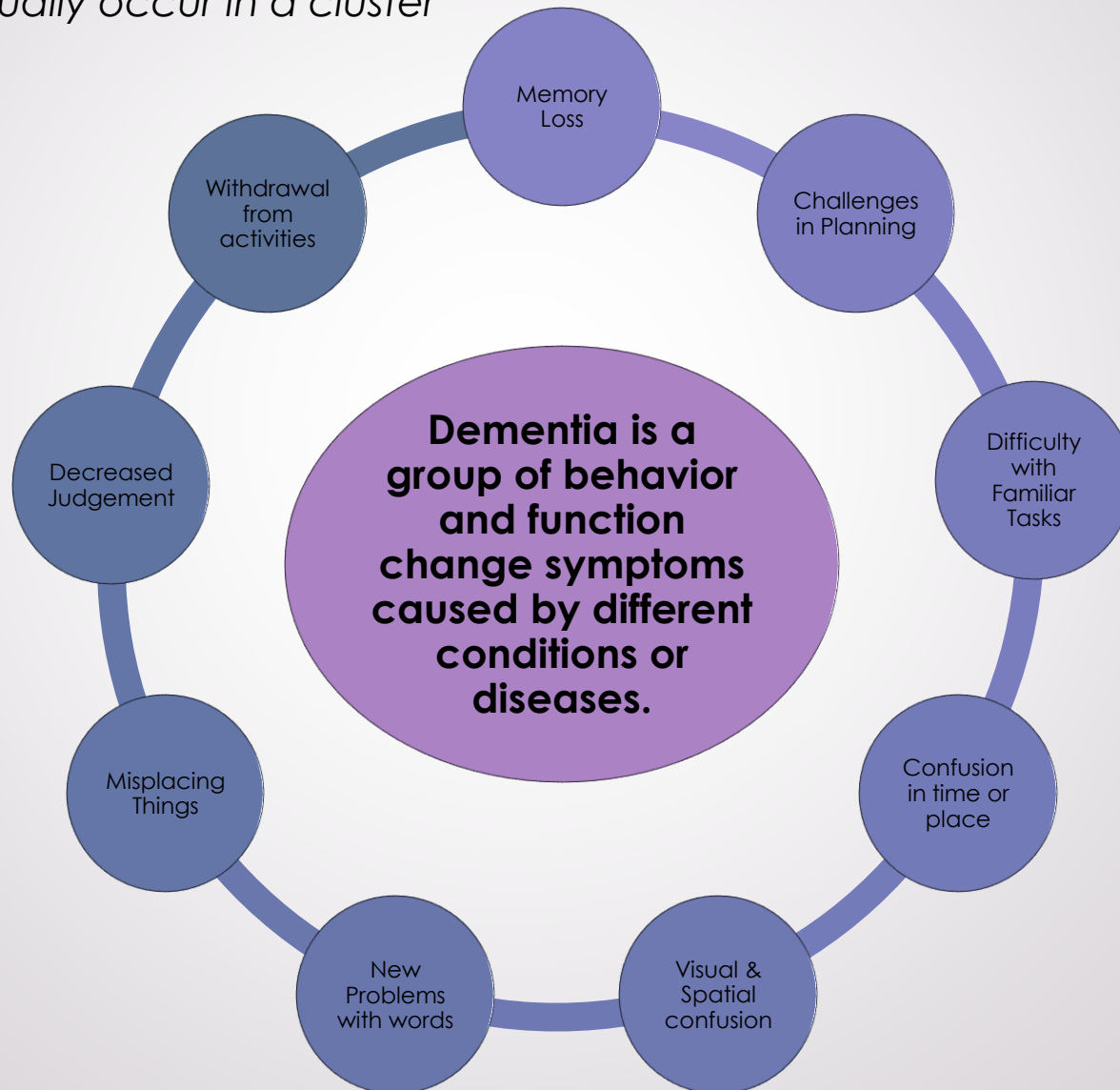
An “umbrella” term used to describe a range of symptoms associated with cognitive impairment.



Warning Signs

These problems must be notable, a change from a person's usual functioning and usually occur in a cluster

5



How dementia progresses

No Problems – normal level of functioning (for the person)

Early Stage – short term memory loss, repetitive questions, aware of their changes but may not acknowledge.

Mid-Stage – impaired ADL ability, behavioral and psychiatric symptoms, sleep changes

Late-Stage – fully dependent in ADL's, swallowing problems, incontinence



Early stage caregiver tips

- **Encourage independence but be aware that...**

1. Agitation and anxiety may arise in new situations.
2. Large tasks will need to be broken down into smaller pieces.
3. Hazardous activities should be supervised.
4. May need reminders for personal care.
5. Establishing and maintaining a regular routine is crucial.

Mid stage caregiver tips

- ▶ Flexibility, patience and humor may save the day
- ▶ The caregiver will experience increased responsibilities
- ▶ As the demands on the caregiver increase, the caregiver taking care of themselves becomes more important

Late stage caregiver tips

- ▶ Incorporate music the person with dementia enjoyed into their day if you have not already
- ▶ The feelings and emotions behind communication become much more important
- ▶ Physical interactions also become important, rubbing lotion or brushing hair as ways to communicate love and compassion

General Tips

- ▶ Do not try to reason or argue.
- ▶ Stay calm.
- ▶ Make sure you have their attention.
- ▶ Short sentences with yes/no answers.
- ▶ Loud voices can be interpreted as angry.
- ▶ Allow time, 20 seconds is not as long as we think.
- ▶ Respond to emotion, not words.
- ▶ Distract and redirect.
- ▶ Step away and try again in a few minutes.

Common Behaviors

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

Common Behaviors

- Searching for something
- Belief they need to escape from something
- Reliving the past
- Confusion in space and time.
- Orienting cues/Stop sign
- Alarms on the door
- Camouflage doors
- Provide activities
- Make sure the person carries personal identification.

Repetitive Questions

Can be stressful for caregiver but are rarely harmful.

Causes:

- ▶ Inability to retain information (short term memory).
- ▶ May be trying to express a specific concern, ask for help, or cope with frustration, anxiety or insecurity.

Strategies:

- ▶ Focus on the emotion behind the behavior.
- ▶ Stay calm.
- ▶ Provide an answer, even if you have to keep repeating.
- ▶ Distract.
- ▶ Try memory aids.

Rummaging and Hoarding

Causes:

- ▶ Unable to remember where they put something.
- ▶ Creates a sense of security and safety.
- ▶ Fear of losing an item.
- ▶ Boredom, under stimulation.

Strategies:

- ▶ Organize, but do not remove, the items.
- ▶ Make rummaging an activity, create a rummage box
- ▶ Identify the places the person hides things (pockets, drawers)
- ▶ Redirect to another activity.
- ▶ Check wastebaskets before you empty them!

Verbal Outbursts

Most common in Mid-late stage dementia.

► Causes:

- Pain, discomfort (new or sudden onset may be infection such as UTI)
- Medication interaction
- Loneliness, boredom, need something.

► Strategies:

- Physical evaluation.
- Is it something in the environment?
- Caregiver interaction?
- Distractions such as quiet music, soothing lights, rubbing hands or feet

Physical Aggression

Causes:

- Consider is this new behavior
- Pain, physical discomfort
- Biological – disinhibition, loss of emotional control
- Misunderstanding caregiver actions (esp. personal care)
- Feeling threatened.

Strategies:

- Stay calm. Try not to show fear or anxiety.
- Do not shout or initiate physical contact.
- Reassure.
- Make eye contact.
- Smile
- Distract.
- Try to identify a trigger.

Paranoia

Causes:

- Sensory deficits
- Memory loss
- Unfamiliar environment
- Misperception of environment

Strategies:

- Help them look for lost item, then distract to another activity.
- Respond to the feeling behind the behavior and reassure the person.
- Distraction
- Keep a log.
- Medication may be helpful in some instances.

Hallucinations

Causes:

- ▶ Vision, hearing impairments.
- ▶ Lewy body dementia symptom
- ▶ Change in medications.

Strategies:

- ▶ Ignore if harmless
- ▶ Don't argue
- ▶ Check hearing aid batteries
- ▶ Detect cause and remove if possible



Sleep Wake Disorders

Causes:

- Sundowning
- Pain
- Hunger
- Side effects of medications
- Disruption of circadian cycle due to brain damage.
- Dietary: caffeine, sugar

Strategies:

- Increase daytime activity
- Quiet, calm evening hours
- Is bedroom comfortable?
- Treat potential pain.
- Maintain bedtime and waking routine.
- Light snack before bed.
- Avoid upsetting activities late in the day

Sleep Wake Disorders

Sundowning – An increase in confusion and agitation that traditionally occurs in late afternoon

Causes:

- ▶ Not completely understood
- ▶ Changes in circadian rhythm
- ▶ Fatigue is a common trigger
- ▶ Lack of activity

Strategies:

- ▶ Stick to a schedule and routine
- ▶ Turn lights on before it gets dark and close curtains.
- ▶ Provide distracting activity
- ▶ Minimize stress, quiet music
- ▶ Large meal at lunch instead of dinner
- ▶ Keep a journal

Resistance to Personal Care

Causes:

- ▶ Short term memory loss.
- ▶ Embarrassment, modesty concerns
- ▶ Sensory changes
- ▶ Pain or discomfort

Strategies:

- ▶ Stick to familiar routine.
- ▶ Respect modesty.
- ▶ Set the stage. Be sure room is warm enough and enough contrast to easily see.
- ▶ Use dry shampoo for hair washing.
- ▶ Towel or bed bath as alternative.

Sexual Behavior

Causes:

- Caused by the disease – reduced inhibitions.
- Uncomfortable clothing – too hot, too tight.
- Pain – UTI, vaginitis, constipation.
- Mistake caregiver for partner.

Strategies:

- Comfortable clothing.
- Distract, redirect.
- Keep a journal to determine triggers.
- Evidence to support pharmacologic interventions is limited.

Whose problem is it?

Is this behavior just a problem for me?

- Ignore it (mismatched clothes)

Or.....

Does this behavior have the potential for harm to either the individual or to another?

Who needs to change?

- Accommodate, don't control the behavior.
- We can change our response to the person/behavior or we can change the physical environment.
- The person with dementia no longer has the ability to change.

Communication Strategies

- Communicating is vital to a person's sense of identity and well as to preserving their quality of life
- Communication is more than verbal.
 - It is also gestures, facial expressions and touch.
- Nonverbal communication becomes more important as disease progresses and as language skills diminish and are lost.

Communication Approaches

- ▶ Validation
- ▶ Reassurance
- ▶ Redirection
- ▶ Orientation
- ▶ Essence of the Person

Validation Approach

- ▶ Focuses on **empathy and understanding**.
- ▶ Acceptance of the reality and personal truth of a person's experience, no matter how confused
- ▶ Can **reduce stress, agitation, and need for medication to manage behaviors**
- ▶ Emotions have more validity than the logic that leads to them.

What does Validation look like?

John (agitated):
“Someone stole my book!”

Instinct: persuade John his book is misplaced but not lost

Better response: “I'd be upset too, if that happened to me. I'll help you look for it.”





Sally (determined):

“I want to go home!”

Instinct: reassure Sally she is home

Better response: “I understand you want to go home, you must be homesick. I remember when I went off to college how much I missed home.”

Apologize

- ▶ Taking responsibility (even when not responsible) allows for the person with dementia to feel heard and validated
- ▶ Can stop defensiveness
- ▶ Can help move the brain forward
- ▶ It's OK for the caregiver to apologize for things they have not done.
 - ▶ I'm sorry, I must have moved your wallet and forgot to tell you. I'll help you find it.

Reassurance

- Naturally comforting
- Reduces anxiety
- Switches the focus of the brain



“I would like to look into that for you.”

“I am going to see about that.”

“We will fix this.”

Let's practice...

PERSON WITH DEMENTIA	CAREGIVER
1. "I cant find my purse"	?
2. "That's not my car in the garage"	?
3. "There are people breaking into my home."	?
4. "Do you know when my son will be home?"	?
5. "I need to get out of here. This is not my home!"	?

PERSON WITH DEMENTIA

CAREGIVER

1. "I cant find my purse"

I'm going to help you look for it

2. "That's not my car in the garage"

How strange, I will look into this for you.

3. "There are people breaking into my home."

Oh my goodness, we can't have that! I am going to make sure everything is locked up!

4. "Do you know when my son will be home?"

I'm not sure but I will find out for you.

5. "I need to get out of here. This is not my home!"

I will help you get back home (then redirect)
I see they're serving lunch, why don't we eat first and then get you back home?

Redirection

- Distract AND Divert
- Redirected with gentle distraction or by suggesting a desired activity such as music, walking or looking at pictures.
- Providing food, drink, or rest can be a redirection.
- Smile, use a reassuring tone.
- Be creative and have a mental list of redirections

Example



Susan [agitated]: I need to get to work. I'm going to miss my bus!

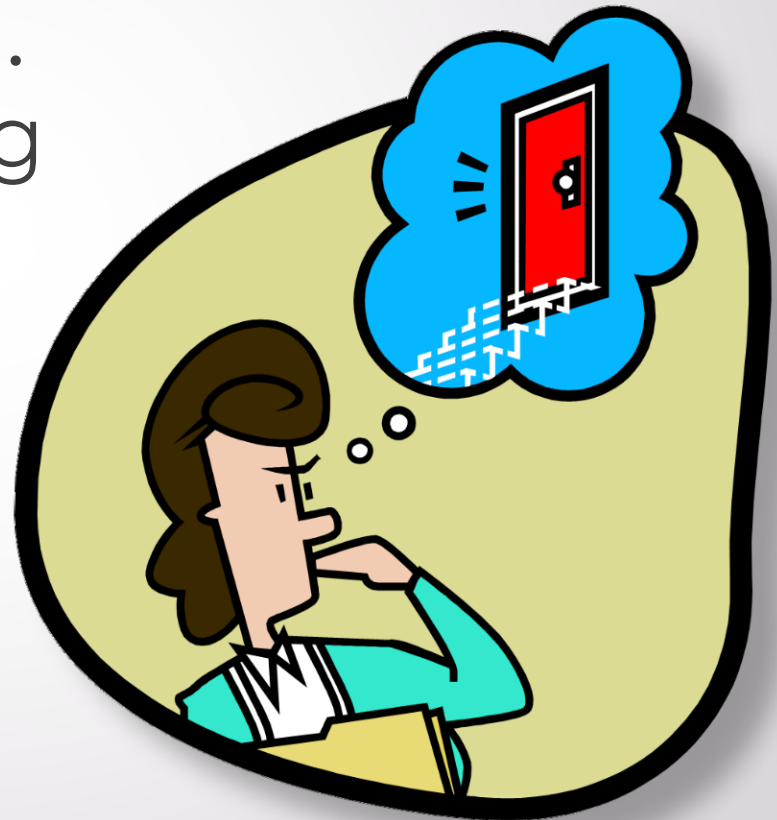
John: Okay, Sue, but I just made breakfast. How about you eat with me first and then I'll drive you to the bus stop. You'll make the bus **and** get a good meal that way.

Redirection: John did not have to remind her she no longer works. If Susan asks about work again after breakfast, John can be ready for another redirection

Let's practice....

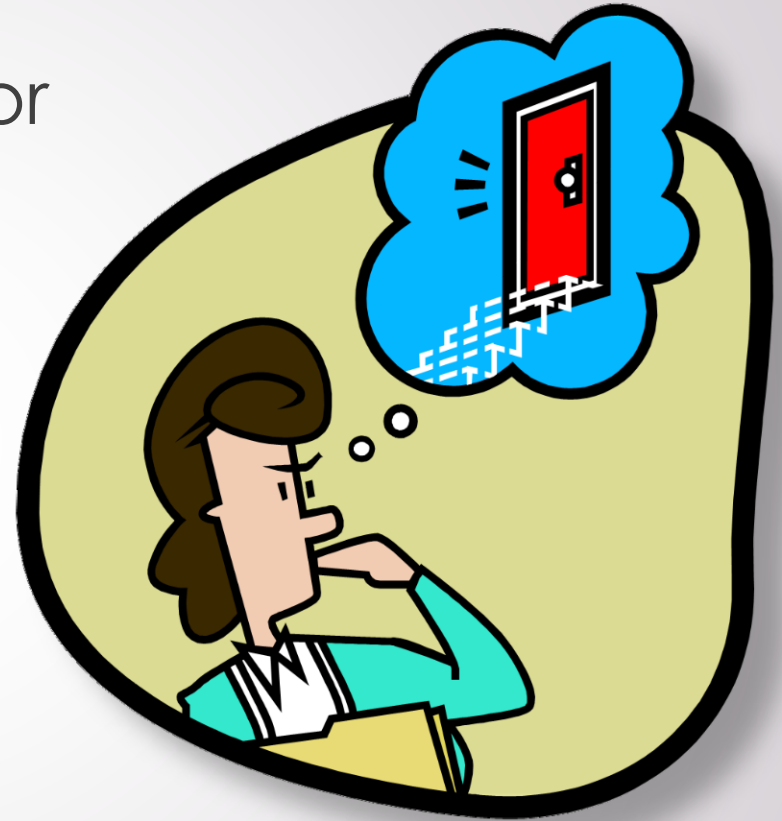
Helen (agitated): I
want to go home.
My mom is waiting
for me!

Response: ???



Helen (agitated): I want to go home. My mom is waiting for me!

Response: You're right, we should be on our way. It's nice to have a snack before hitting the road though, would you like a cookie or a piece of fruit?



Just go with it...

Example:

“What time is my mother coming?” (You know Ken’s mother died 20 years ago.)

Which response is better:

- a. *“Your mother is dead, Ken. Your sister will pick you up at 4:00.”*
- b. *“She’ll be here in a little while. Let’s get a dish of ice cream while we wait.”*

Response:

- a. *“Your mother is dead, Ken. Your sister will pick you up at 4:00.”* This response can cause sorrow, agitation and reoccurring grief with no benefit to the person with dementia.
- b. *“She’ll be here in a little while. Let’s get a dish of ice cream while we wait.”* Response reassures feeling of safety or security while causing no harm to the person with dementia.

Everyone has a life story that needs to be honored and respected.





Essence of the Person

- The person's story is their essence and understanding their story helps in caregiving.
- When they can no longer tell their story, pictures, scrapbooks can help tell their story.
- Caregivers who understand the essence of the person is able to better care for the individual (i.e. There is a Catholic Mass on television, lets watch together)

Putting it all together

Essence of the Person



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graph TD; A[Essence of the Person] --> B[Validate]; B --> C[Reassure]; C --> D[Redirect]; D --> E[Just go with it...]
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Validate

Reassure

Redirect

Just go with it...

Communication Strategies

1.

Difficult behaviors cannot be changed with increased expectations.

- Change:
 - Your approach to the person
 - Your reaction to the behavior
 - The environment

2.
Refrain from
using “no”
and NEVER
argue!

- Reasoning is no longer possible
- Arguing will encourage frustration, fear, and anger.
- Feelings are more important than facts.

3.
**It's their
reality and
you must
enter it.**

- Validation:
 - Builds empathy and creates a sense of trust and security that reduces anxiety.
 - Enter their reality and reminisce with them.
 - Match their emotions.

4.

**Reduce fear by
acknowledging
underlying
emotions.**

- Loss of ability to express and cope with fears.
- Inability to “self-soothe” when fears become overwhelming.
- Respond to their emotion and offer reassurance.

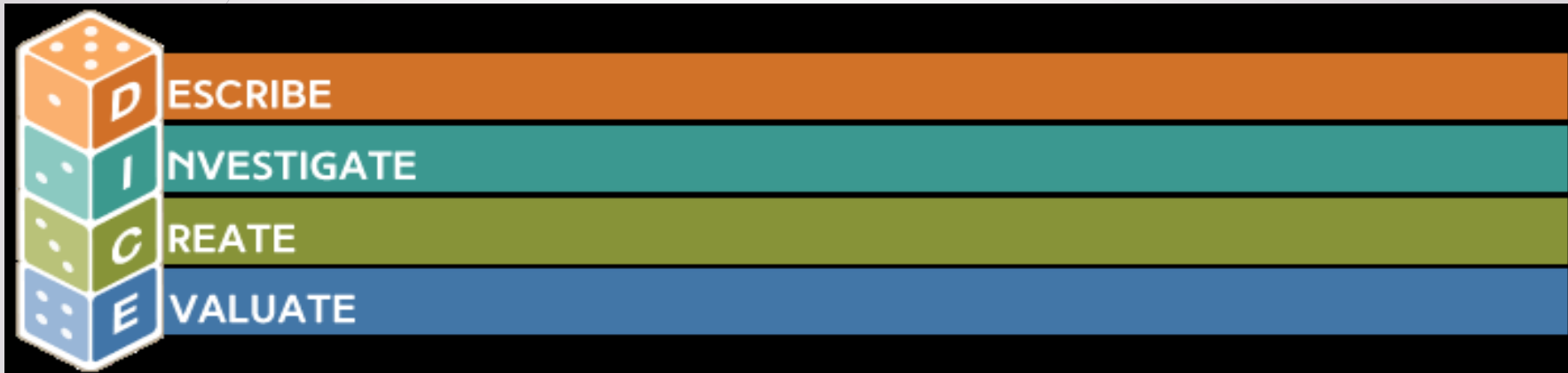
Tools for Change

The DICE Approach looks at ways to modify interactions and environments to decrease behaviors

Considers the PATIENT (person with dementia) CAREGIVER and ENVIRONMENT

Goal is to eliminate psychotropic medications when possible.

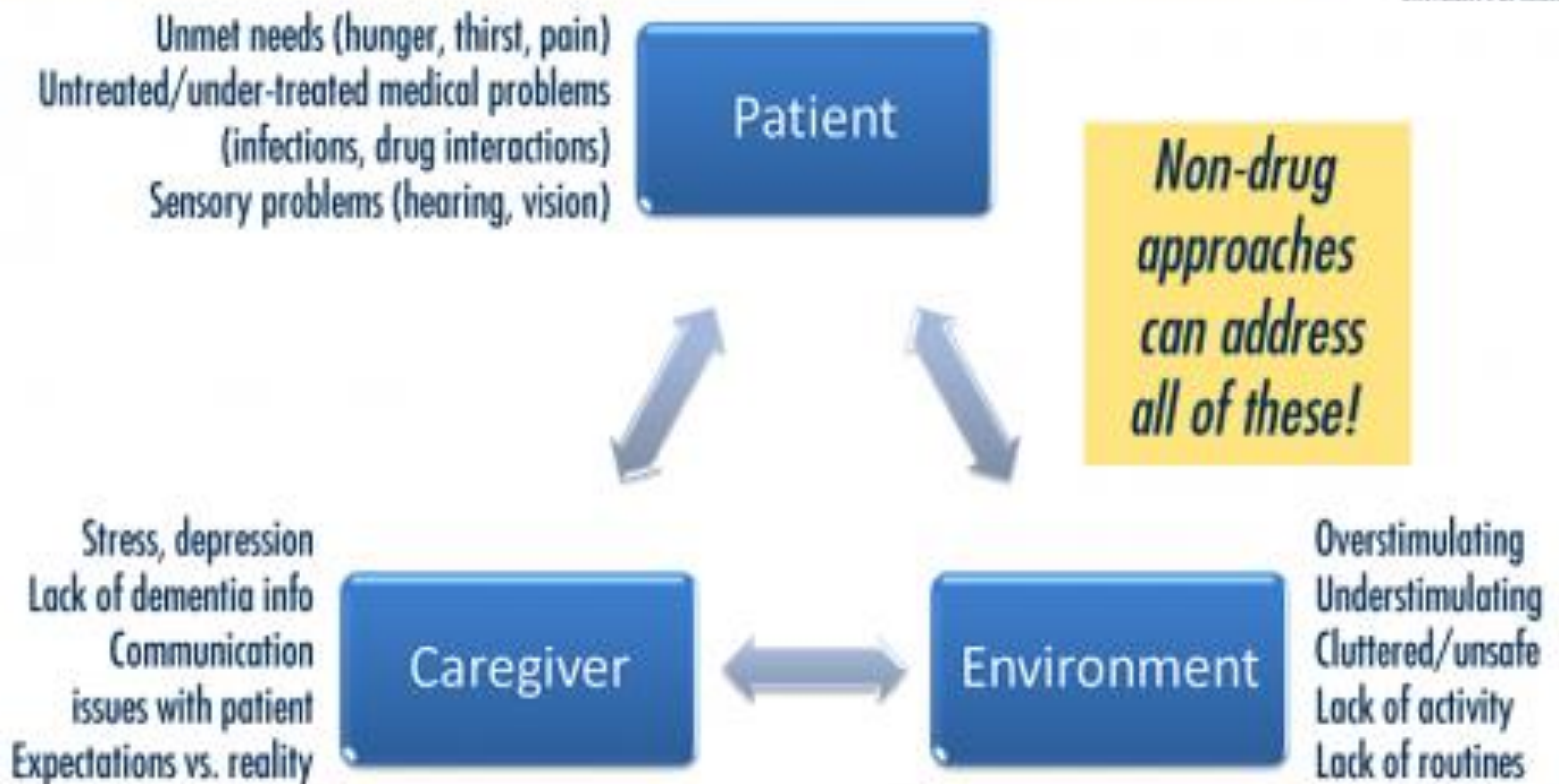
The Four Steps of DICE



- Describe situation completely to understand the behavior.
- Investigate to determine possible causes.
- Create a plan for intervention.
- Evaluate the success of the plan.

The DICE ApproachTM

What can cause behavior problems in dementia?



Person with Dementia Factors

- Psychiatric problems, personality issues from earlier in life
- Acute medical problems
- Sensory Changes
- Unmet needs



Environmental Factors

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

52



Caregiver Factors

Is it something I did?

Attitude – relaxed or anxious?

Body language – tense?

Tone of voice – cheerful or demanding?

Facial expression – smiling?

Medications and Dementia

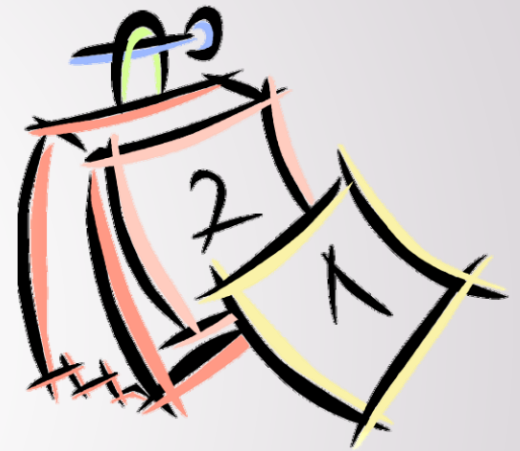


Psychotropic medications are only used when there is a concern of:

- ▶ Harm or risk of harm including significant distress for the person with dementia
- ▶ Behavior is not allowing completion of needed medical intervention or a full investigation or assessment of the person with dementia
- ▶ There is serious depression, psychosis or aggression with risk of harm
- ▶ Always evaluate the medication fully to determine adverse effects, continues risk requiring medication or effectiveness in alleviating the behavior

Remember....

*What works today may not work
tomorrow!*



*If you've met one person with dementia,
you've met one person with dementia.*



Questions?

Please reach out with any questions you may have!

Katrina Longmire, CSW

Dementia Care Specialist

Cell: 715-279-7870

Email: katrinal@co.pepin.wi.us



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Thank you!