Stage-Based Strategies

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What's Ahead

For all 3 stages (early, middle, late) we will discuss:

- Features and presentations of symptoms and behaviors
- Support needs
- Strategies and interventions

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Early Stage

Across Stages, the goal is always to:

- Protect the person from injury
- Maintain independence as long as possible
- Focus on what the person can still do
- Provide physical and mental activities the person can do
- Always support the person's dignity and self-esteem

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Maintain the Essence of Each Person

- We all have an “essence”
- Life events, preferences, experiences shape who we are
- We call this our “Life Story”

- Gather documentation and information about the person’s life span
- Use their Life Story for interactions, activities, and supports

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We want to gather information now (or before now) so it’s not too late
Use Life Story when person can no longer communicate or tell us about themselves
Use Life Story to reminisce/remember

Entering Early Stage

Recognize the Early Symptoms:

- Recurrent memory problems (not just forgetting)
- Confusion
- Loss of focus
- Disorientation
- Change in habits

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Normal Aging vs. Alzheimer's or Dementia

Typical Age-Related Changes	Signs of Alzheimer's or Dementia
Making a bad decision once in a while	Poor judgement and decision making
Missing a monthly payment	Inability to manage a budget
Forgetting which day it is (but remembering later)	Losing track of the date or the season
Sometimes forgetting which word to use	Difficulty having or following a conversation
Losing things from time to time	Misplacing things unable to retrace steps to find them

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Early-Stage Characteristics

Language Difficulties:

Especially finding words

Short term memory loss

Learned skills begin to fluctuate from day to day

Difficulty learning, retrieving new information

Disorientation to place and time, navigating familiar places

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Early-Stage Behaviors

- Typically involves a change in behaviors or personality traits

Examples:

- Lack of interest, enthusiasm, or concern
- Lack of pleasure
- Withdrawal
- Irritable or easily upset
- Suspicion, paranoia
- Decreased Verbalizations or loss of language skills

More Frequent
More Intense
Lasts Longer
OR Brand New

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It's a change from the norm.
NEW behaviors, or the same behavior becomes more frequent/longer/more intense

Early-Stage Progression

- Difficulty performing tasks
- Getting lost or misdirected
- Confusion in familiar situations
- Personality Changes
- Changes with gait/walking
- New Seizures
- Recalling recent events
- Recognizing places or people

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Early-Stage Progression

- Trouble finding words
- Problems planning and carrying out tasks or plans
- Trouble exercising judgement such as emergencies
- Controlling emotions
- Decline in personal care- grooming, bathing
- Social withdrawal

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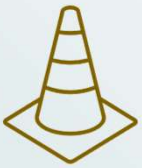
Activities of Daily Living







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Eating

- Try one food at a time
- Use contrasting dish colors vs. food colors
- Allow extra time to eat

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Bathing / Using the Bathroom

- Warmth of room
- Lighting
- Preferred staff
- Patterns in flooring, curtains, tiles
- Gentle/soothing sounds or music
- Increase prompts for using the bathroom
- Reduce frequency of showers
- Don’t argue!

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Getting Dressed

- Clothing should be easy on/off and comfortable
- 1-2 choices
- May need physical prompting
- Pay attention to textures, materials, fabric patterns

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Safety

- Identify potential hazards
  - Rugs/flooring, doors/cabinets, bed, room
- Address concerns promptly
- Monitor and document

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Transportation Challenges

- May see frequent refusals to get in or out of vehicle / bus

Sensory issues may be to blame:

- Smells, loud noises, personal space
- Discomfort with seats or bumpy ride
- Pain with mobility
- Dark interiors can be disorienting

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Changing Your Supports

- Keep activities familiar and follow established routines
- Structure the environment and adapt activities for safety
- Change how you provide prompts and directions
  - Visual aids, gestures, tactile prompts, shorten verbalizations
  - Demonstrate what you want them to do
  - Visual Field
- Maintain skills to the extent possible
  - Hand-over-hand assistance
- Adaptive / medical equipment

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Health, Wellness, and Advocacy

- Movement, activity level
- Hydration and nutrition
- Monitor chronic health conditions closely
- Pay attention to sudden changes in behavior
  - Acute Illness
  - Pain or discomfort (including gastrointestinal)
  - Infections (UTI, respiratory)
- NTG screening tool
- Differential Diagnosis

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Communication and Documentation

- Develop a process for communication between all support providers
- Document and share information about:
  - Sleep
  - Fatigue
  - Agitation
  - Discomfort/pain
  - What is comforting / what works
  - Activities that are distracting or too stimulating
  - Observed behaviors
  - Any and all concerns

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Summary: Early-Stage

- Changes are often subtle
- Changes are needed in the way that supports are provided
- Gather information about the person's life story
- Establish and maintain good routines, including communication with all support providers

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Middle-Stage

Mid-Stage Characteristics

- Significant loss in abilities and profound memory impairment/loss
- Disorientation to time and space
- Confusion and frustration
- Severe changes in personality
- Refusals to participate in previously preferred activities
- Refusals with transportation

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Mid-Stage Characteristics

- Decline in judgement and decision making
- Speech is hard to understand
- Increased difficulty with language- expressive AND receptive

Physical changes:

- Incontinence
- Swallowing
- Mobility
- Seizures- new or increased

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Consider:

- Increased need for 1:1 care, especially with ADLs
- Modify routines and environments to meet changing needs
- Assess current and future placement and support needs
- Discuss Advanced Directives, Guardianship
- Caregiver Burnout

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Key Practices

- Maintain Skills
- Keep routines, provide a stable environment
- Use of Life Story
- Reassurance and Validation
- Physical Health
- Don’t argue!

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Mid-Stage Behaviors

- Hoarding
- Swearing
- Repetition
- Paranoia/Suspicion
- Apathy
- Withdrawal
- Anger
- Inappropriate sexual behavior
- Agitation
- Physical Aggression
- Verbal Aggression
- OCD Behaviors
- Wandering
- Resistance to support

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There's a difference…

Nuisance Behaviors

Do NOT pose a safety issue, but require staff to be alert and pay attention

Compromising Behaviors

DO pose a safety issue and require special attention and careful planning for support

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- Rummaging
- Hiding
- Hoarding
- Shadowing
- Repetitive activities
- Pica (eating non-food items)

Nuisance Behaviors

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Compromising Behaviors

- Agitation
- Combativeness
- Unpredictable or extreme emotional responses
- Suspiciousness
- Delusions, Hallucinations
- Sundowning
- Wandering

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Behaviors related to Mental Health

- Anxiety
- Euphoria / Dysphoria
- Apathy
- Disinhibition
- Sleep disturbances
- Wandering
- Emotional lability
- Delusions
- Hallucinations
- Agitation
- Aggression
- Depression
- Irritability

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Possible Causes of Disruptive Behavior

- Adverse drug reactions
- Pain or discomfort
- Physical illness
- Loss of physical abilities
- Underlying infection
- Depression
- Environment

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Wandering / Elopement

- Searching for something
- Escaping from something
- Disorientation

Consider:

- Relationships with neighbors- call if alone!
- Search no more than 15 minutes. Keep updated photo and health information available
- Rural areas- Game Warden

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Considerations

- GPS devices
- ID jewelry
- Relationships with neighbors- call if alone!
- Search no more than 15 minutes. Keep updated photo and health information available
- Rural areas- Game Warden

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Supports

- Orienting cues both inside and out
- Camouflaging doors
- Distractions
- Safe places to wander
- Door/window alarms
- Life Story

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Disrupted Sleep-Wake Cycle

- Rule out physical causes such as pain or discomfort, medications, unmet needs

Consider:

- Short naps during the day
- Dark and quiet bedroom
- Use red or amber night-lights
- Limit screen time on devices before bed, reduce blue light

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Sundowning

- Increased confusion, restlessness, and agitation in late afternoon or early evening
- Can also cause suspicion, disorientation, and hallucinations
- Can become worse after a move or change in routine

Consider:

- Closing curtains early to avoid reflections and shadows
- Calming music
- Quiet time in the afternoon

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Incontinence

Causes can include:

- Unable to react quickly enough
- Unable to communicate
- Can't find the bathroom or toilet
- Unable to understand prompts
- Unable to undress
- Embarrassed to get help

Do not rely on the person to tell you they need to go- use a schedule!

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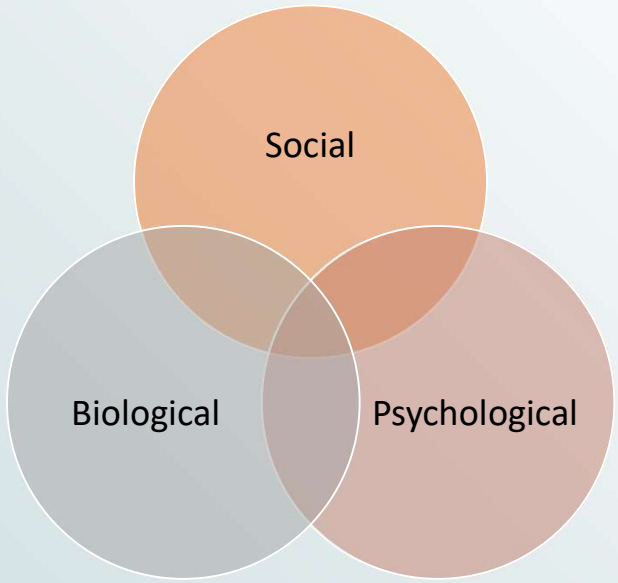
Agitation



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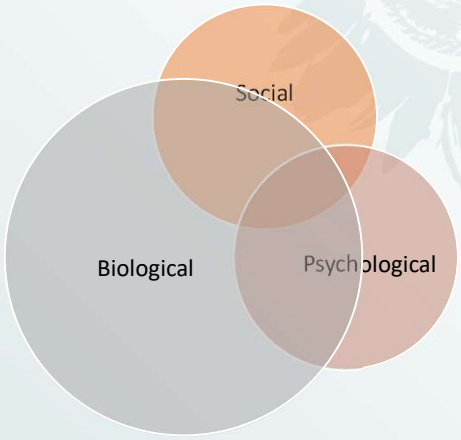
Agitation- Biological

- Pain / Discomfort
- Constipation, Thirst
- Sitting too long
- Illness
- Side effects to medications
- Over-stimulating environment
- Misperceptions and Misunderstandings
- Disinhibition / emotional reactivity



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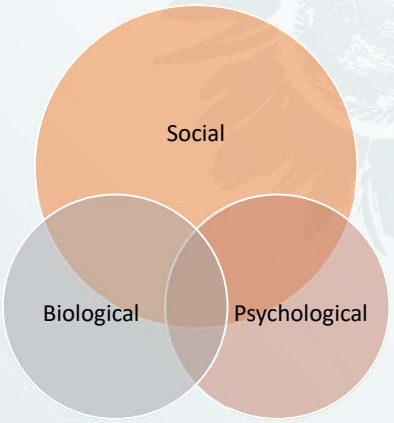
Agitation- Social

- Lonely
- Lack of social contact
- Boredom/inactivity
- Sensory deprivation
- Different approaches by staff
- Change in routine
- Not liking or trusting certain staff



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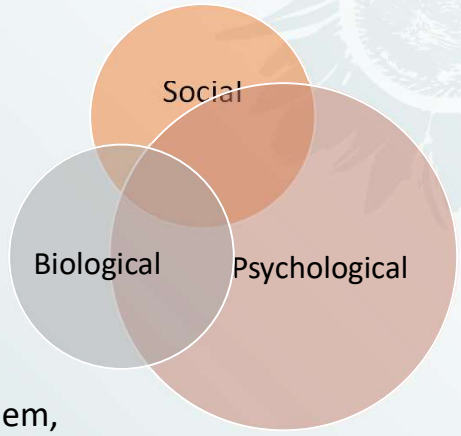
Agitation- Psychological

- Depression
- Poor interactions with staff
- Frustration with tasks / activities
- Feel threatened by environment
- Frightened by unfamiliarity
- Difficulty interpreting the world around them, experiencing a different reality from others



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Health and Wellness

- Encourage movement and physical activity, with periods of rest
- Health snacks and fluids within eye-site
- Safe walking paths/areas

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Delirium- rapid changes are usually a result of delirium
Delirium is rapid and fast change in cognition and mental state

Health and Wellness

- Monitor health conditions closely- increase in chronic health condition symptoms during mid-stage
- Monitor incontinence, accidents, gait changes, weight loss, falls
- Delirium
  - Acute Illness
  - Pain/discomfort, especially with constipation
  - UTI or respiratory infections

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Delirium- rapid changes are usually a result of delirium
Delirium is rapid and fast change in cognition and mental state

Providing Support

- Visual range: 14-18 inches from eye-level
- Reduce distractions and clutter
- Nurture relationships with family AND peers
- Promote joy and fun, keep things positive

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Providing Support

- Keep things “failure free”
- Break tasks down into one-step direction or actions
- Short simple sentences
- Use verbal and hands-on cuing
- Use of gestures and demonstration

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Failure Free Activities

- Painting
- Coloring
- Tactile activities
- Music and Dance
- Rhythm and drumming / percussion
- Movement
- Gardening

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Summary: Middle-Stage

- Most challenging behavioral changes occur during this stage
- Previously observed changes continue to decline
- Requires more 1:1 support especially with ADLs
- Use of life story to promote failure-free activities
- Plan ahead
- Don’t argue!

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Late-Stage

Characteristics

- Increasing frailty
- Weight loss
- Communication is severely impaired
- Intense support needs
- Chewing and swallowing difficulties
- Sever memory loss
  - Familiar faces
  - Their own reflection

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Characteristics

- Unable to find their way around familiar places
- Unable to identify everyday objects
- May believe they are living in a time from their past
- Increased difficulty with walking, or can no longer walk
- Loss of previously learned skills and interests

- CAN still appreciate and respond to stimuli such as music, scent, touch

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Consider the Context of the Person's Lifetime

- Each stage of loss should always be considered in the context of the person's abilities throughout their life
- It's not a loss or change if the person has always had difficulty with it, such as communication, eating, personal care, etc.

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“Regular” Care

- Active throughout the day
  - Work, home, social life
- Working towards independence and achieving goals
  - Learning new tasks
  - Acquiring new skills
- Community Participation
  - Shopping
  - Recreational and social activities

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Shifting Support Needs

- Supports shift towards comfort, dignity, and reducing distress
- Active days transition to relaxing days
  - Activity level is determined by the person and their tolerance or desire
- Learning activities transition to maintaining and participation to the greatest extent possible
- Community participation is reduced

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Staying Engaged

- Sense of Taste, touch, smell, hearing remain present
- People are still able to appreciate or respond to stimuli. Use these remaining senses to communicate and to provide sensory activities
- Continue to talk to people, even if they are unable to respond
- Refrain from talking about the person in front of them, as if they do not understand or aren't there

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Activities that match energy levels
Smell- herbs, different foods, flowers, incense
Touch- hand massages, textures- clothing, objects, hot and cold
Taste- sweet tastes, different tastes in succession
Hearing- listening to music, ambient sounds such as rain. Outside noises- birds
Talking- important because they can still hear!!

Staying Engaged

- Focus on activities that produce joy, comfort, being in the moment
- Continue to encourage and foster relationships with family, friends, roommates
  - Enjoying music together
  - Reminiscing by telling stories of memories, past events
  - Provide warm blankets
  - Being in nature, watching or listening to birds at the feeder
  - Provide a variety of fluids at varying temperatures
  - Sit in the sun
  - Scent sensory activities such as smelling flowers, herbs or spices, other scents

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Remember, our goals is to keep people happy and distress-free
Family members may need help figuring out how to spend time with their loved one

Shifting Support Needs

DSPs must shift their attention to:

- Pushing Fluids
- Maintaining nutrition
- Monitoring vital signs
- Observing and reporting physical changes
  - Urine, bowel movements
  - Swelling, fever, pain and discomfort
  - Appetite, swallowing
  - Weight loss
- Reading non-verbal communication

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The shift is towards more medical-related observations and supports
Non-verbal becomes the focus, because the person cannot communicate any other way
- Eyebrows frown, lips pout- these are actions that we all do sub-consciously, especially if we are in pain

Why the shift?

- Towards end of life, people will:
  - Stop communicating verbally
  - Lose mobility
  - Become incontinent
  - Experience decreased stamina and tolerance
  - Lose time and space
  - Lose the ability to perform tasks previously learned
- Re-focus attention and efforts based on what the person is experiencing

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Difficult Behaviors

- These declines may come with an increase in troublesome behaviors
- Funnel these behaviors through a lens of communication
- Behavior is communication! Some may be healthy, while others may require our time and attention to keep the person comfortable and decrease their emotional stress

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Remember that our response and approach may be different than what we would use for someone who does not have dementia.
We are not trying to teach replacement behaviors and coping skills at this point, our focus needs to be on addressing the underlying issue at hand
Coping skills decrease with dementia and end of life

Late-Stage Behavior

Rocking motions, repetitive movements, repeating the same word or sound

- Is the person otherwise calm?
- Is the person tense?

- Consider physical needs, comfort and well-being, pain, constipation, hunger, thirst

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Hallucinations and Delusions

- A very common occurrence
- Hallucinations can be frightening or pleasant
- Can include hallucinations with all 5 senses
- Delusions can be frustration for both the person and staff

Best Supports:

- Don’t argue!
- Distract, divert attention elsewhere
- Just go with it

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Restlessness, Pacing, Wandering, Hand-fidgeting

- May indicate a need for more physical activities or tasks
- Plan light physical activities such as walking, light movement activities, household tasks or ADLs
- Consider a rocking chair

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Rummage Boxes

- Items related to their past
- Pictures
- Multiple colors and textures
- Yarn
- Safe objects / tools

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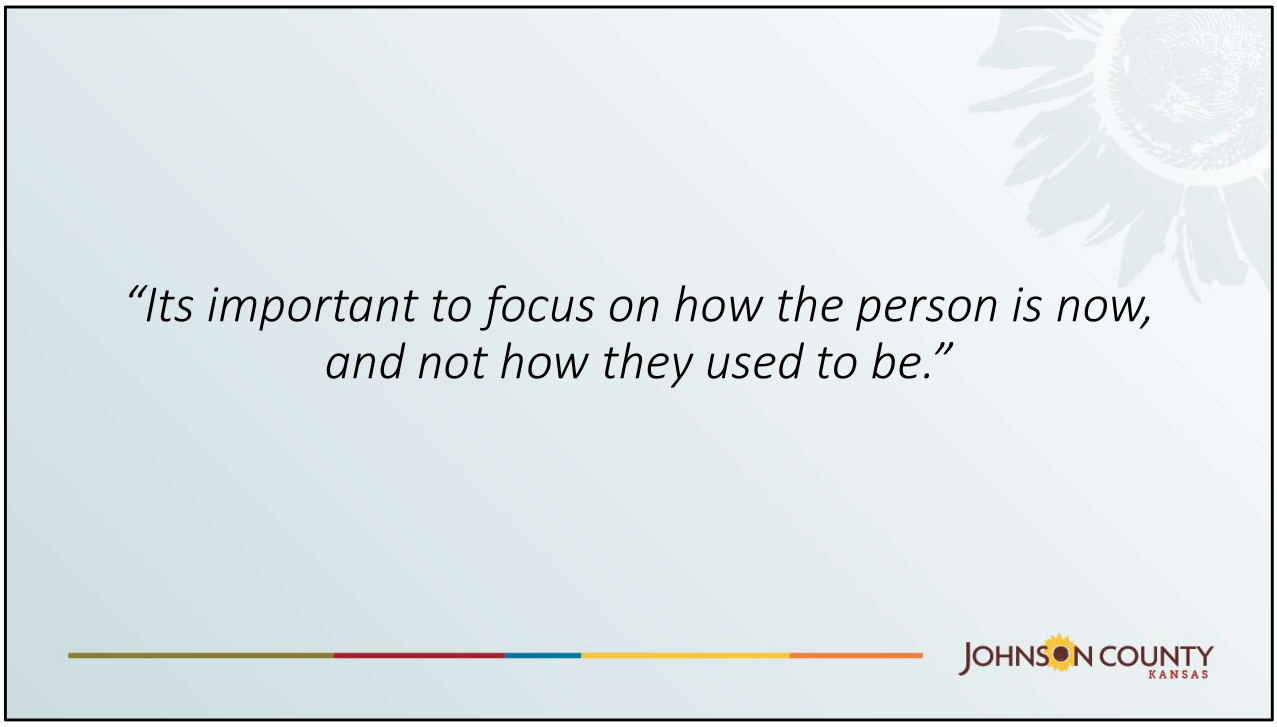

When we only focus on loss, it brings frustration, grief, and may cause us to hold the person to higher standards than what they are currently capable of

Considerations and Planning

- Plan for the transition home.
- When will we need additional supports for the person, and what will that look like?
- What criteria will indicate that it's time for this transition?
  - Transportation or Transition Issues
  - Decreased stamina that results in a lack of active participation in day supports
  - Significant health changes that require more personalized attention and care
  - Increase in troublesome behaviors in specific environments

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Planning Guide- Questions for the person and their family

- What do you expect the person to be doing, or what do you want them to continue doing as he or she ages?
- What supports are currently in place, and will any additional supports be needed to achieve this?
- What are your concerns about the future as the person ages?

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Planning Guide- Questions for the person and their family

- What do you anticipate will change in the future, and what are some resources in planning for those changes?
- How will you communicate to others what strategies and supports have worked in the past, particularly if they will be beneficial in the future?

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What's the difference between Hospice and Palliative Care?

- Both provide comfort care
- Palliative care is usually sought at diagnosis and at the same time as treatment
- Hospice is usually sought after treatment is stopped and the person will not survive the disease or illness

- Both require a physician's referral

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Qualifying Factors

- *Reisberg's Functional Assessment Staging (FAST) scale is often used to determine hospice eligibility for persons with dementia.*
  - Bowel and bladder incontinence
  - Vocabulary of one word or less.
  - Dependent for all activities of daily living.
  - In addition, they need to have had a complication of their illness (aspiration pneumonia, sepsis, pyelonephritis, stage 3 or 4 pressure ulcers, persistent fever, or significant weight loss).

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Get the Assessment

- Even if you're uncertain that the person will qualify for Hospice or Palliative Care, it doesn't hurt to have an assessment done!
- Hospice will do an intake assessment to determine the person's eligibility, and will refer them to palliative care if hospice care is not an option
- Bring all pertinent documentation and data to show as many qualifying factors as you can

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Hospice or Palliative Care

- Often, hospice or palliative care is underutilized!
- These services provide care that greatly supplements the work of the people providing supports
  - Bathing Support
  - Pain management
  - Personalized medical care and treatment plans
  - Services such as counseling, grief support, chaplain, pet and art therapies
  - 24-hour access to care and concerns
- These supports reduce the pressure and stress on the people providing care

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Death Anxiety

- Described as a 'negative emotional reaction provoked by the anticipation of a state in which the self does not exist' accompanied by feelings of fear or dread
- Fear of unknown
- Attitude towards care
- Avoidance as a defense mechanism

- Death Anxiety is reduced with training and education programs

(https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3565229/)

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Experiencing this can often lead one to contemplate their own mortality
Inexperience increases fear and worry
Fear of the unknown- afterlife, what happens when you die
Attitudes towards care are affected by death anxiety, which often causes disengagement and avoidance

Valuable Information

- *Physical* changes the person will experience as they die, and how to continue to support the person
- Cultural Beliefs
- Expectations and protocols when the person actually passes
- Explain hospice process
- Grief / Anticipatory Grief

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Physical-
swelling, fever, “death rattle”
Stops accepting food/drink/meds
“air hunger”

Cultural-
their own, the person/family, and those of others

Expectations and protocols-
Who do I call, and when?
Can family stay in the home with the person?
Any local regulatory issues
DNRs- what does that mean for me as a DSP?
-advocating for better policies

Hospice-
Learn their protocols and how they can support the person and the DSPs / family members
They are the best resource for providing support and education!
Comfort Kits
Grief- Educating DSPs that this is a normal process for them to go through.

Anticipatory Grief- mourning the loss of someone before they're gone

Summary: Late-Stage

- Supports shift when the person enters late-stage and end of life to comfort care and reducing emotional distress
- Difficult behaviors are still communication
- Hospice / Palliative care is underutilized, and provides a wide variety of services to support the person as well as the DSP
- Educating and supporting DSPs / other caregivers can reduce stress and anxiety

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What questions can I answer for you?

THANK YOU!

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