

End of Life Care: What you need to know

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Objectives

- Supporting people vs. supporting people at end of life
- Active treatment and activities
- Reading a person's behavior
- Planning
- Hospice and Palliative Care
- Supporting DSPs



“Regular” Care

- Keeping people active throughout their day
 - Work, home, social life
- Working towards independence or achieving goals
 - Learning new tasks
 - Acquiring new skills
- Community Participation
 - Shopping
 - Recreational and Social activities



Changes

- When someone is approaching end of life, we need to shift our supports in a different direction, focusing on comfort, dignity, and reducing emotional 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 greatest extent possible
- Community participation reduces



Active Treatment and Activities

- 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





Active Treatment and Activities

- 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



Active Treatment and Providing Care

- 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 to determine support needs





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
- These changes require us to re-focus our attention and re-focus our efforts in a new way, based on the changes the person is experiencing



Difficult Behaviors

- These declines may come with an increase in troublesome behaviors
- DSPs must funnel these behaviors through a lens of non-verbal communication in order to understand what is trying to be communicated by the person
- 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






Behaviors

- Rocking back and forth
 - Are they calm, or tense?
- Hallucinations or delusions
 - Distract / Divert, DON'T ARGUE
- Restlessness, pacing or wandering
 - May need more physical activity. Scheduled times, rockers or swings
- Excessive restlessness with hands
 - Rummage / Fidget boxes or quilts









*“Its important to focus on how the person is now,
and not how they used to be.”*



Considerations and Planning

- At some point, it will be better for the person to transition to home supports vs. day supports outside of the home
- Teams should plan this transition in advance
 - 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
- When will we need additional supports for the person, and what will that look like?

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?

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?

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 it is clear that the person will not survive the disease or illness
- Both require a physician's referral

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).



Qualifying Factors (cont.)

- Reisberg's Functional Assessment Staging (FAST) scale has 7 stages, with the last stage listed as follows:

“People in this stage have essentially no ability to speak or communicate. They require assistance with most activities (e.g., using the toilet, eating). They often lose psychomotor skills, for example, the ability to walk. Average duration: 2.5 years”

Full Reisberg Scale included in conference handouts



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



Hospice or Palliative Care

- Often, hospice or palliative care is underutilized!
- These services provide care that greatly supplements the work of the DSPs
 - 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
- This support reduces the pressure and stress on the DSPs providing care



Ethical Considerations

- Religious, spiritual, and other values are different amongst DSPs, supervisors, family members, and the person
- Any regulatory and legal issues
 - DPOAs, local and state regulations or laws, guardianship
 - DNRs
- Family dynamics and conflict





Supporting DSPs

- “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/>)

Educating DSPs

- *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

When the person is passing in the home

- DSPs need other people to be *physically present* during the active dying process, *as well as after the person passes*
 - Supervisors
 - Additional DSPs or co-workers to share the experience with
 - Hospice providers (experts)
- They shouldn't be alone!
- Support the person dying, others in the home, family members, and other co-workers



Support the grieving process

- DSPs will grieve, and it's important that they go through the grieving process
 - Filling or cleaning out bedrooms
- Offer time away. Really.
- Group grief sessions
- Celebrations of life
- Helping others grieve (peers, roommates)



Helping Others

- Don't let fear of saying or doing the wrong thing stop you from reaching out
- But, do avoid:
 - Talking about "It's God's plan"
 - "Look at what you have to be thankful for"
 - "They're in a better place now"
 - "It's time to move forward"
 - "You should..." or "You will..."
 - Judging their well-being by their outward appearance

Helping Others

- Acknowledge the person who has passed, and what has happened- don't avoid it
- Let them know you're there to listen
- Offer to help in practical ways
- Know that the grieving process is unique to everyone, including length of time

Take Away Points

- Our supports shift when the person enters end of life, to comfort care and reducing emotional distress
- Hospice / Palliative care is underutilized, and provides a wide variety of services to support the person as well as the DSP
- Educating DSPs on end of life care can reduce stress and anxiety
- It must be a priority to support the grieving process for DSPs



What questions can I answer for you?

THANK YOU!

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