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Supporting Changing Needs Through the End of Life for Adults with Disabilities in Residential Settings



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Everyone changes with aging, often in invisible ways. You may be surprised to learn that beginning at age 25, there is a slow decline in speed, reasoning, spatial skills, and memory (Salthouse, 2009). At the age of 30, there is a 3-8% loss of muscle mass per decade (Volpi, 2004). By the age of 65, a person has lost approximately 20% of their muscle mass. Our senses, including smell, hearing, and vision, begin to decline around the age of 50. This aging process is accelerated in individuals with disabilities. This extends to a heightened vulnerability to several serious conditions.

Individuals with developmental and intellectual disabilities (IDD) experience age-related health conditions earlier than the general population and also experience higher rates of chronic health conditions. For example, the prevalence of Alzheimer's disease in individuals with Down syndrome is 90% (Forte, 2021). To put this in perspective, in the general population, the prevalence rate of Alzheimer's disease is approximately 10%. This vulnerability can have a detrimental impact on quality of life (Garcia-Dominguez et al., 2020). Currently, there are approximately 640,000 people with developmental disabilities over the age of 60 in the United States. This is expected to more than double by the year 2030 (Heller & Sorenson, 2013). Hence, the service delivery world needs to prepare for the challenges of serving those with developmental disabilities as they age. There is also the consideration of where and how to support individuals as they age. Most individuals, including those with IDD, want to age within their homes and communities.

Early Identification of Need

Long-term planning should begin as early as possible in adulthood. While identifying someone's future needs is not always possible, there are factors we can take into consideration early, such as the person's current diagnosis and what type of prognosis is generally expected with that diagnosis, as well as the person's family medical history. These types of considerations can assist providers and families in determining the best living arrangement needs early.

When this is not possible, discussions about future medical needs should occur during the early stages of the medical and behavioral changes that occur with aging or other health-related conditions. For example, when a person first starts showing symptoms of memory issues, early decisions related to environmental needs can be made. Some areas to consider are whether the person can stay in their current home with some renovations for accessibility or whether they will need an alternate living arrangement to accommodate their changes in physical mobility. While these conversations can be challenging, it is important that they occur prior to the person experiencing an urgent need in a crisis context.

Another set of considerations is necessary to consider when a person receives a terminal diagnosis, such as Alzheimer's disease or terminal cancer. For example, the team can consider whether or not hospice care will be explored in the later stages of illness. Having these conversations ahead of time with the person, family members, and caregivers makes the process much easier and less stressful to put in place when the time comes. It is challenging for loved ones to make those types of decisions without much notice, and when there is an opportunity to avoid that, we should. It can be easiest to address these issues regularly and when an urgent decision is not required.

Staff Training

Caring for individuals with IDD across the lifespan requires compassionate caregivers and dedicated professionals. Collaborating with experts in healthcare, physical therapy, occupational therapy, speech-language pathology, and palliative care/hospice is necessary to maximize each individual's goals for aging well, maintaining a high quality of life, and dying with dignity. As changes occur to an individual's functional status, caregivers should have access to robust training and education. Trainings, including practice, discussion, and follow-up, allows the caregiver to best support an individual to age with dignity and respect. Caregivers can then recognize future changes in status and reach out for support. Areas of training needs often include topics such as how to provide care due to changes in functional status, which can include mobility changes, ability to eat independently, diet texture changes, and communication changes. Throughout this process, there is a continued need for interdisciplinary collaboration from all therapists and practitioners involved in the person's care. Training should be developed by these team members and then trained by the person's primary caregivers. Often, in residential settings, direct support professionals carry out complex care plans daily that require frequent follow-up, training, and revisions.

Supporting Family Needs

An important aspect of end of life care includes having available support and familiar people, such as families and friends, who continue to be part of the individuals' lives. When End of Life Care begins, the teams should continue to encourage visitation and communication with their loved ones. Depending on the current care needs of the individual, this may be in the home visits or visits to their family's home if the environment supports this. Alternative communication methods for families that live further away include phone calls or video conference calls to be able to see and support their loved ones during this time of transition. Some family members may not know what will comfort the individual at this time. The National Institute on Aging (2018) has recommendations that can be shared with families, including providing physical contact, setting a comfortable mood, asking the person receiving end of life care if they have any preferences, and also just being present during the time together.

As the needs of the individual change, open and frequent communication helps the families understand the progression while also preparing them for any changes that may be seen during their visits. Care needs can change in a short period of time, and even families that visit daily could see a difference from one day to the next. Education on the progression of illness, while also being transparent that each person experiences this progression differently, can equip the family with the understanding of these changes. Families that do not live within a proximity that allows them to visit frequently during this time may value frequent communication from the care team.

Maximizing Quality of Life

When an individual is diagnosed with a terminal illness or begins end of life care, the care team should evaluate how the quality of life can be increased through their daily interactions and ensure that meaningful opportunities are provided. Through open communication with the individual's medical care team, these options can be assessed for appropriateness and decided with the best interest of the individual in mind. For those that have the skills to communicate, these wishes may be explicitly shared with the care team. For others, considerations may be made based on the knowledge of likes and interests prior to end of life care, beginning with speaking with those who know the individual the best, such as family or friends.

Supporting Peers and Staff

Individuals who live in provider residential settings create bonds with those they have lived with or participated in various activities during the time they were together. Providing education to their peers about changes and the progression of life can assist with understanding how age and illness can impact someone. This sensitive topic should be discussed at a level that can be understood and evaluated by the individual's care team on the benefits of seeing someone who is at the end of life stage. If appropriate, a visit to see their peers during this end of life stage can provide an opportunity to share memories they had together. It may also help the individual to create some memory books or other concrete reminders of the shared time and memorable experiences.

Support Post-Passing

When End of Life care ends due to the passing of an individual, there are various steps teams can take to continue their support. Team members who have been involved with communicating with the family members may consider the family's wishes for continued communication. Many individuals' family members are involved throughout the overall time spent in a long-term living setting and grow relationships with those who provide this care. Communication with the family post-life will vary based on the wishes of the family. Sharing with the family the impact that the individual made on the team, as well as the memories made, provides a sense of comfort. When the family shares the details of services or gatherings to remember the individual, the team should make every effort to be there to continue to support the family during this difficult time. This may include members of the team who managed the care and support staff who provided care to the individual.

Once the services are arranged, communication with the family will also include conversations about their wishes regarding the individual's belongings. This communication will assist the family and team to arrange a time to come together and ensure that all items the family would like to have to remember their loved ones can be available. This time may vary depending on the setting, but sharing the available time with the family can provide an opportunity for family members to discuss how to best arrange this process.

Case Review

Jackson, an individual with Downs Syndrome, began to show some differences in his typical everyday behaviors and was observed to be forgetting common people or skills he previously knew. When these changes were identified by the team, they completed an assessment that showed signs of dementia. Through medical follow-up with his primary care doctor and neurologist, Jackson was diagnosed with dementia. At this time, Jackson had been living in a home that had multiple flights of stairs and a large layout. Due to the perceived risk of his progressing dementia, the team met and was able to identify a home that had a layout that better suited the long-term needs for Jackson. Communication with the individual's external team and family occurred to share the proposed change early on to ensure that all questions could be answered before any major changes were observed for the individual. This early transition to a new home allowed Jackson to learn the layout and bond with staff who worked in this new setting.

As Jackson's dementia progressed, there was a decrease in cognition, memory, and ambulatory needs. Family and friends were no longer easily recognized. The setting of the home was arranged for open movement, without obstructions, to ensure that it was familiar to Jackson early on during his diagnosis. Jackson began to sleep through much of his day, leading to retirement from his day program setting. Frequent changes to his care were communicated to his family, as well as the staff. Some of these changes occurred quickly, while others were maintained for longer periods of time. As his care needs increased, his diagnosis and current health status now required hospice care.

The team met to review some opportunities to provide an increased quality of life during this time of change for him. Jackson was an avid Philadelphia sports fan. His favorite hockey team was having an upcoming game near his home. The team reviewed this opportunity to see a game with his family, as well as the medical personnel overseeing Hospice Care recommendations. After all considerations were reviewed, his support staff were able to bring him to see one last game from box seats. Although there were times when Jackson was not able to express himself as he had in the past, there were multiple instances of large grins and celebratory motions. He was able to experience this with peers he had grown to know over the years, and it appeared to have had a positive impact on his life. Photos of this experience were shared with his family so they could share the joy it brought to their loved ones.

As time progressed, Jackson's diagnoses increased, and his care needs increased. This individual, once independent in most aspects of his life, now depended on full physical care throughout his day. As this transition occurred, the bond between him and his care staff continued to grow. His family increased their visits to see him as often as time would allow. The team continued to share the care needs changes with the family to keep them informed of changes, and this communication continued until the individual passed peacefully with staff by his side.

After Jackson's passing, many members of his team joined the family at a local service. Memories of time spent together were shared by all who grew a bond with Jackson over the years. After the service, the Director of the Jackson's Residential home spoke with the family about their wishes for his belongings. Since the family had traveled from different areas, they decided to come the next day to see which items they would like to remember him by. The family wanted to donate the medical equipment that could be passed to others who needed it, as their own lives changed as they aged.

Summary

Planning for end-of-life care is never easy and is always fraught with anticipated grief. Yet, these realities must be faced for all lives, including those of individuals with disabilities. Much can be done to ease the transition to the end of life by ensuring that the individual, their family members, their peers, and their caregivers are helped throughout the process. It is important to prioritize quality of life and comfort at all stages of an individual's life and, increasingly, when age and medical conditions warrant changes in care. Contact with the individual who is approaching the end of life can enhance coping for the individual and for family members, caregivers, and peers. Sharing memories and mementos of times together can be important in the later stages of life and after the individual's passing. Acknowledging the loss is important, as is the preservation of the memory of the individual and their impact on others.