



## Hospice Case Study: ALS (Amyotrophic Lateral Sclerosis)

For patients with ALS/Lou Gehrig's Disease, our hospice provides customized plans of care and palliation for optimal outcomes, with focus on clinical interventions for patient comfort, education and support for caregivers, and hospitalization reduction.

Mr. D was a 67-year-old man diagnosed with bulbar amyotrophic lateral sclerosis (ALS). Prior to his official diagnosis and admission to hospice, Mr. D had been experiencing mild cognitive changes, difficulty swallowing, and periodic slurred speech. Initial diagnostic work led his practitioners to suspect his complaints to be suggestive of dementia; however, onset of excessive drooling and complete loss of speech resulted in his diagnosis of bulbar ALS. Even after diagnosis, loss of mobility was one of the final symptoms experienced. Mr. D had no other co-morbidities and until his symptoms began, he had been healthy and worked full-time.

Mr. D married his high school sweetheart and joined the Navy upon graduation, serving in the military a large portion of his life. He had two adult children, one of which had died tragically just months before his diagnosis. The combination of Mr. D's sudden onset and quickly developing symptoms, combined with the recent loss of his daughter, made Mr. D's care difficult for his family and the hospice staff.

Mr. D was persistent in his attempts to eat and drink, despite almost daily progression of swallowing difficulties. He had a Living Will in which he had requested no artificial nutrition or hydration. One of his favorite past times was cooking, and he continued to create meals, tasting along the way, which led to multiple choking episodes and eventually two episodes of aspiration pneumonia requiring antibiotic intervention. His desire to eat and drink, coupled with his inability to speak and progressing cognitive changes, made it difficult for staff to educate him on the potential complications of his choices. Use of assistive technology, communication boards, and gesturing were unsuccessful.

Mr. D's behavioral changes were increasingly problematic. Prior to his diagnosis, he had been experiencing cognitive changes, primarily extreme forgetfulness. This appeared to be progressing into periods of complete confusion. Due to his inability to speak and utilize assistive communication devices, it was difficult to ascertain to what extent, but his actions indicated significant issues. He became prone to turning on the stove or oven and walking away, placing objects in unusual places such as the T.V. remote in the back of the commode tank, and attempting to grab the wheel of the car while his son was driving. He also began to develop behaviors such as removing his clothing in front of guests, urinating in inappropriate places, becoming physically assertive with his family: all things reported to be very out of the "norm" for him. Despite these actions believed to be the result of his declining cognitive status, he would also stand in front of a picture of his daughter and weep.

Within four months of admission, Mr. D's mobility waned resulting in bed-bound status. A hospice aide attended to his personal care. Initial visits were three times per week, but increased to daily. Mr. D would wake repeatedly throughout the night despite medicinal interventions to address his insomnia. A volunteer was initiated to sit with Mr. D for short periods to allow the family time to rest or complete other necessary activities. Throughout the course of Mr. D's care, the social worker and chaplain provided visits to support the family with Mr. D's diagnosis and decline, as well as attempt to address the grief associated with the loss of the daughter.

Mr. D died peacefully at home with his wife holding his hand. Without the efforts of the hospice team and Mr. D's attending physician, this would not have been possible. Mrs. D and her son are currently receiving bereavement counseling, including the initiation of a community-based counselor to assist with complicated grief issues.

### Our Care Matters

- Mr. D's hospice care occurred in the home, where he lived with his wife and son.
- His individualized plan of care was adjusted for insomnia and increased assistance with ADLs.
- Social Work and Chaplain resources assisted the patient and family with complicated grief from a previous family loss and Mr. D's unexpected diagnosis.
- Volunteer services were initiated to assist the family with caregiver fatigue.

### When Life Matters Most

- Clinical interventions were adjusted specific to the patient needs for comfort for improved outcomes.
- Multiple communication methodologies were introduced to assist with the patient's education during cognitive decline, including assistive technology.
- Though care was challenging due to the patient's cognitive decline and persistent grief issues in the family, hospice services made it possible for Mr. D to remain in his home until his passing.
- Grief counseling and support will continue for the family.

Contact us to begin the hospice conversation or to address specific questions regarding hospice care for patients with ALS. We Are Here.