

Nikos P., 43 years old, was diagnosed with ALS. He could not speak or swallow and was placed on a BiPAP machine to assist his breathing. His wife and children were devastated.

Amyotrophic lateral sclerosis (ALS) *A father's special wish*

Background:

Nikos P. owned and operated a well-known restaurant for 17 years. A bright, cheerful man in his early 40s, he took great pride in his homemade Greek food. Many people in town knew him personally, and he considered them family. One morning, Nikos noticed a change in the sound of his voice and over the following few days, had increased difficulty projecting his voice.

Nikos first passed it off as a cold, but 2 weeks later, he began to experience difficulty swallowing. His family physician performed routine tests; the diagnosis was a mild stroke. Nikos underwent speech language pathology but lost his ability to speak and swallow within a 7-month period. As his weight dropped, he used a feeding tube to maintain nutrition. He became depressed and developed feelings of hopelessness. His wife and two children were devastated, particularly his daughter, Sophie, who was engaged to be married and dreamed of having her father walk her down the aisle.

Within 10 months after his first symptoms, Nikos experienced difficulty breathing. His family physician referred him to a clinic that specialized in amyotrophic lateral sclerosis (ALS), better known as Lou Gehrig's disease. At 43, he was diagnosed with the disease. The physician and staff explained that because of his diaphragm muscle weakness and the progressive nature of the disease, he would need to make a decision about ventilator life-support in the near future. He went home with a BiPAP machine to assist him in breathing. The clinic's social worker contacted BAYADA Home Health Care, known for their expertise in empowering people with catastrophic illnesses to return safely to their homes and families.

Challenge:

Maureen K., a rehabilitation registered nurse and clinical manager for BAYADA, visited Nikos and his wife, Anna, the following day at home. Anna was frantic and needed answers. Could she safely care for her husband at home? Did BAYADA care for patients on ventilators? Was it wise to choose a ventilator to extend her husband's life? Should they see an attorney for a living will?

"I sensed the family's concern and wanted to give them some control over the situation," Maureen said. "I explained that BAYADA safely cares for clients on ventilators at home and trains their families to provide ventilator care."

To set goals for Nikos, Maureen asked the following questions:

- What were Anna and Nikos' thoughts about quality of life?
- Did the family have any particular goals they wanted to achieve?
- Did they have health insurance to cover nursing care?
- Would Anna consider being her husband's family caregiver?
- Could they modify their home to support a progressive illness?

Two weeks later, Nikos was rushed to the hospital in respiratory failure. He made the decision to use a ventilator to extend his life because he wanted to be present for his daughter's wedding two years away. His wish became the number-one priority that directed his care.

“I sensed the family’s concern and wanted to give them some control over the situation. I explained that BAYADA safely cares for clients on ventilators at home and trains their families to provide care for their loved ones.”

– **Maureen K.**, CRRN
BAYADA Clinical Manager

Goals attained:

- The local BAYADA office, faced with only 3 days to provide nursing staff for 24 hours a day, contacted other BAYADA offices in the surrounding counties for assistance.
- Nikos’ primary care physician, in conjunction with the physician from the ALS clinic, agreed to follow his care at home.
- A respiratory company placed Nikos on a home ventilator. His wife and two adult children were trained to operate the ventilator and other respiratory equipment.
- A medical equipment company delivered the hospital bed, special mattress, and a wheelchair that Maureen set up in the family’s former dining room, which was converted to his care area.
- Maureen had the respiratory therapist provide two equipment training sessions for the nurses who would be caring for Nikos.
- Physical and occupational therapy visits were set up for the second day Nikos would be home.
- Maureen called the utility companies and the local police and fire department to notify them that Nikos was dependent on a ventilator in case of an emergency. A generator was donated by the fire department.
- An ambulance transport brought Nikos home as planned on the third day.

Outcomes:

After 3 weeks of 24-hour nursing care, the insurance authorization changed to 16 hours a day. By then, Anna had learned how to care for Nikos and took over in the evenings.

Through the ALS clinic, Nikos received an augmentative communication device: a computer with an on-screen keyboard and special software called Words Plus. Nikos had never used a computer before, and his BAYADA Nurses worked with him every day until he could operate it. He used an adapted mouse to select letters to form the words he wanted to speak, and the computer spoke the words for him. He was delighted with the computer and was able to choose the restaurant menus each day. This helped to allay his depression.

Over the next year and a half, Nikos’ medical condition declined to paralysis from his neck to his feet. A lift was ordered to transfer him out of bed into his wheelchair. He found it hard to rest at night because of cramping and twitching in his lower legs that didn’t respond to medication. His BAYADA care team often performed range-of-motion and stretching exercises to relieve him. It was becoming more difficult for Anna to provide his care in the evening without assistance. By now, the wedding was a month away, and Nikos was determined to be there.

Anna said, “When I saw my husband all dressed up in his wheelchair coming down the aisle with my beautiful daughter, it made all the struggles worthwhile. There wasn’t a dry eye in the church. I was so joyful and proud of our family. I cherish that memory. My family is so thankful for all the nurses who helped make it possible.”