

CASE STUDIES

Keeping a Client With MS as Independent as Possible

Background: Jack W. is a 44-year old Seattle-area man with multiple sclerosis. During the 25 years he's lived with the disease, he has experienced progressive changes in his health; however, up until seven years ago when he went into a manual wheelchair, he was able to live independently. More recently, he has needed light assistance from friends and caregivers for some activities of daily living. In May of 2004, he was hospitalized with pneumonia. During the hospitalization he contracted a series of infections that significantly lengthened his stay. At the same time, he received an implantable baclofen pump to help control increased muscle tone. Consequently, Jack spent nearly six months recovering in both a hospital and a skilled nursing facility. He was referred to Gentiva Rehab Without Walls' Seattle location in the fall of 2004 when he was finally discharged home.

Rehabilitation Needs: The overriding goal of Jack's work with Gentiva Rehab Without Walls was to help him become as independent as possible so he could remain in his home. "I wanted to get my life back and get back to work," says Jack, who to this point had continued to work full time as an accountant for an aerospace technology company.

"In many ways, this was a trial to see if Jack could live at home—something everyone on the Gentiva Rehab Without Walls team really wanted for him—because the other option was to live in a skilled nursing facility," says Martha Traas, OT, who helped

coordinate Jack's case. "We had several challenges we needed to overcome in order for this to happen." She outlines them as:

- **Relearning fine motor skills.** "As a result of the infused medication, Jack experienced a decrease in muscle tone that affected his function. He also had sensation loss in his fingers. In a sense, he had to learn how to do many activities of daily living all over again."

- **Decreasing dependence on caregivers.** "At the outset, we started with 24-hour caregivers. In addition, Jack needed two caregivers for shower transfers. He'd always need assistance in the mornings and evenings, but we needed to make it more manageable for one person to provide Jack's care."

- **Safety issues.** "One of our biggest concerns was keeping him safe in the home so he could be alone and independent for long periods of time."

The Rehabilitation Process:

Gentiva Rehab Without Walls' Seattle location put together a multi-disciplinary clinical treatment team to work with Jack, consisting of a clinical coordinator, physical therapist, occupational therapist, nurse, rehab specialist and a psychosocial counselor. Initially, the team worked at a fairly intense level, 18 to 20 hours a week, but tapered off as he began meeting his goals. All treatment goals were developed with input from Jack, his family, the clinical members of the team and his primary physician. Goals revolved around the identified challenges above as well as demonstrating adjustment to the disability (on the part of both Jack and his family).



Here's how they addressed those challenges:

Physical issues: Both the physical therapist and the occupational therapist worked with Jack on learning different kinds of transfers. They also developed an upper and lower extremity exercise program that addressed range of motion and strengthening.

Activities of daily living: With the help of the team, Jack identified areas where he felt he needed assistance and others where he was independent. "He was very realistic on what he could and couldn't do and what he wanted to work on," explains Traas. "For example, he had no interest in cooking because he has an arrangement with a neighbor, but he was clear about wanting to do self-catherizations and medication administration."

Working with caregivers: In taking the steps to cut back from 24-hour care, the team helped Jack problem solve and prioritize caregiver duties for the mornings and evenings. Jack then went through the interviewing and training process as an active participant. He hired a caregiver, developed a backup plan and established a daily routine.

Adaptive equipment. Team members helped Jack obtain modifications in his bathroom for transfers and showering, as well as a sliding board for bed transfers. They also worked with him to obtain authorization from his insurance company for a power wheelchair and helped him learn how to use it when it arrived.

Safety at home: Traas investigated technology with Jack to make him safe at home, including trying out Bluetooth and several kinds of cordless and cell phones to find one with a touchpad that worked best with his impaired finger function. She also worked on getting a wireless doorbell installed next to his bedside table that connected to his downstairs neighbor's apartment to use in case of emergency. "We also did trials to determine how many hours he could stay at home alone—starting in two hour intervals and mov-

ing quickly up to five to six," says Traas.

Independence in the community: Outings included a trip to the local electronics store to test technology, a meal at a restaurant, practicing entering and exiting his building in the new wheelchair, and a trip back to his office to prepare for return to work.

Emotional issues: Ironically, says Jack, it was his family who benefitted most from meeting the psychosocial counselor. "I think because I live with MS everyday I am more aware of the realities of my condition and the gradual changes occurring in my body and with my level of independence. After this last hospitalization, my mother felt overwhelmed and had a hard time with it all. Talking with someone who heard her pain and addressed it from a rehabilitation perspective really made a difference for her."

Recovery and Results: By the end of the six weeks of treatment with Gentiva Rehab Without Walls, Jack improved his functional ability, learned new methods of self-care and required minimal assistance from caregivers. Instead of 24-hour care, he has a caregiver come to his home for an hour and a half in the morning to help him prepare for the day and then again in the evening to prepare for bed. He has returned to work three days a week, and during the day cares for himself independently. He is able to remain at home alone for long periods of time. Before Jack was discharged, Traas reviewed additional adaptations—as well as adaptive equipment catalogs and online resources—that Jack could access if his condition changed.

"I needed a new base level of what I could and couldn't do," says Jack. "Gentiva Rehab Without Walls helped me find it and be as functional as I could be at the new level. The team listened well and took into account my overall condition as well as the day-to-day fluctuations. I feel the treatment helped me accomplish my goals: returning to work, staying as independent as possible, and most of all, remaining in my own home."

**Names of patients and family members have been changed to protect their privacy.*