

CASE STUDIES

The Role of *Family* in home- and community-based rehabilitation

Background: When 30-year-old Southern California resident Wendy L.* didn't show up for work one day in the fall of 2002, friends tracked her down in her apartment, where she lay on her bed unresponsive. Tests revealed a grade 2 subarachnoid hemorrhage with blood in the Sylvian fissures and an aneurysm which required repair; she later underwent a skull repair and cranioplasty. After a long hospital stay followed by a transfer to acute rehabilitation, Wendy was discharged to her parents' home in early March 2003, where she began treatment with Rehab Without Walls®.

Rehabilitation Needs: At the pre-admission screening, Wendy's case coordinator, Beverly Workmon, Director of Clinical Management at Rehab Without Walls/Greater Los Angeles, found Wendy to have significant physical and cognitive impairments as a result of her acquired brain injury. This included bowel and bladder incontinence, impaired balance that placed her at high risk for falls, limited mobility in her left arm, an inability to perform activities of daily living independently, moderate speech impairment, inattentiveness and difficulty with problem-solving.



Workmon coordinated a treatment team consisting of a physical therapist, occupational therapist and speech therapist, and together with Wendy's family set the following functional goals:

- Supervised ambulation with improved quality of gait, balance and endurance.
- Supervised for bowel and bladder continence.
- Increased attention for functional activities to allow participation in individual and group activities for two to four hours daily.
- Transition to programs providing purposeful day activities (based on information provided by the treatment team).

The Rehabilitation Process: The linchpin in Wendy's treatment was her sister Ruth, who took over the management of Wendy's care even though she worked full time and lived in the Bay Area with her husband and small child. "My parents don't speak English," she explains, "so I became my sister's legal guardian." She also became her sister's fiercest advocate.

"Ruth was one of the most amazing family members I've ever seen," comments Workmon. "She could write the book on how to advocate and

manage a family member's resources." Workmon points out the specific things that Ruth did that really made a difference in her sister's treatment. "First, even though it was an incredibly difficult time in her family's life, and everyone was still reeling from shock, Ruth plunged in. She read everything she could get her hands on. She asked questions. She talked with people. She fought in a very positive way for the best care possible for her sister, often initiating conferences with insurance case managers. Second, she didn't try to micromanage the process, striking a perfect balance between pushing the family agenda and trusting the professional staff's experience and judgment. Third, she got involved in the functional aspects of rehabilitation and was able to give us input on how to tailor rehabilitation to her sister's interests—in this case, playing piano and badminton. And fourth, Ruth communicated well. On weekdays, she'd stay in touch via phone and e-mail; on the weekends when she flew down to be with her sister, she was always available to confer with the treatment team."

Workmon points out that this level of family involvement can only benefit the client, and that the Rehab Without Walls staff encourages it. "We make the family members a part of the treatment team," she explains. "Not only do they give us insight into what the client's life was like before the injury or illness, but because clients spend the majority of their time with their families, the families need to understand treatment, goals and the

rehabilitation process. We believe that rehabilitation continues long after we've left the home. The more the family understands, the more they can help the client, and the better and more durable the outcomes."

Recovery and Results: At the end of nearly three months of treatment, Wendy met her functional goals and is continuing to improve. She now attends outpatient physical therapy. Ruth attributes much of her sister's progress to Rehab Without Walls. "I knew that my sister would never be the same person again," says Ruth, "but I wanted her to be able to communicate her emotions. I wanted her to be able to watch movies, to laugh and cry, and to walk. But most of all, I wanted her to be able to look into peoples' eyes again and focus. The Rehab Without Walls team understood this; I only wish every brain-injured patient could have access to a program like this."

Workmon, however, gives credits to Ruth and the family. "Ruth was extraordinary, but she's not an isolated case—rather, she's a good example of families we often work with; the kind of family that can make a difference."

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