

alternatives

beyond home and community: whole person rehabilitation

Gentiva Rehab Without Walls refers to the type of rehabilitation we offer as home- and community-based because these are the settings in which treatment can occur, but actually this label isn't entirely accurate. In reality, Gentiva Rehab Without Walls provides a more encompassing kind of treatment—something we like to call whole person rehabilitation.

What does this mean? In essence, it means that we provide treatment wherever life happens: home, community, school, workplace. But more importantly, we look at obtaining meaningful results that allow the client to live as independently as possible with a high quality of life. It is not enough for the client to be able to walk unassisted. For example, we want to be sure that a client can walk through the neighborhood every night after dinner with his spouse the way they used to—if that is important to them. That a mother not only regains muscle strength and range of motion, but once again is able to carry her child in her arms. Or that a client not only restores cognitive skills, but is able to use them purposefully at work or school.

In order to create these real-life, meaningful results, we know we need to treat more than the client's physical symptoms. We need to understand the core of his or her life, work with the family and support systems, connect with community resources, tap into the client's internal motivation, recognize emotional issues that may impede progress, identify subtle barriers and find innovative ways to remove them, and help clients embrace their recovery within the context of who they now are and what they are capable of doing.

To best illustrate how this approach works, we've zeroed in on a single case at the Gentiva Rehab Without Walls Michigan location and spoken with several treatment team members, including the client's family. By focusing on all the details, the big picture—our whole person approach to rehabilitation—becomes even clearer.

The Client and Family Situation

A few years ago, 20-year-old Michigan State University student Sam Howell was the top biochemical student in the world. In fact, during his freshman year, he was invited to assist a Harvard University professor in a research project on lymphomatoid papulosis. Less than a month after his return to Michigan, however, he was in a such a severe motor vehicle accident that his parents were told that he had just a 2% chance of survival. Sam spent two and a half months in a coma, emerging from it severely impaired—unable to speak, walk or care for himself. Sam's family rallied around him, determined that not only would he recover, but that he would once again lead a full life that tapped into his considerable intellectual gifts.



Looking for the Right Team

Sam's mother Maureen, an ICU nurse, contacted 25 different healthcare facilities and agencies looking for the right rehabilitation team for her son. "I wanted people who were comfortable and experienced with head injuries. It was key for Sam to undergo rehabilitation at home because of his reduced stamina due to pituitary failure with secondary adrenal gland insufficiency," explains Maureen. "As soon as I met with Gentiva Rehab Without Walls, I knew it was the right fit." With Gentiva Rehab Without Walls, the family began assembling the treatment team. Maureen left her job to serve

Sam with his physical therapist and clinical coordinator Steven Mandley.

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NIH recommendations for TBI closely match Gentiva Rehab Without Walls' pioneering approach

How do you find the most effective treatment for traumatic brain injury (TBI) and still keep costs under control? That was one of the questions addressed in the last NIH Consensus Development Conference on Rehabilitation of Persons with Traumatic Brain Injury (TBI). The 16-member panel representing the fields of neuropsychology, neurology, psychiatry, behavioral medicine, family medicine, pediatrics, physical medicine and rehabilitation, speech and hearing, occupational therapy, nursing, epidemiology and biostatistics, then made recommendations for best practices. The panel also noted that the average lifetime cost of care per person with severe TBI was between \$600,000 to \$1.9 million—and growing.

Several of the NIH recommendations regarding rehabilitation practices for people with TBI:

- Rehabilitation services should be matched to the needs, strengths and capacities of each person with TBI and modified as those needs change over time.
- Rehabilitation programs for persons with moderate or severe TBI should be interdisciplinary and comprehensive.
- Rehabilitation of persons with TBI should include cognitive and behavioral assessment and intervention.

- Persons with TBI and their families should have the opportunity to play an integral role in the planning and design of their individualized rehabilitation programs and associated research endeavors.
- Community-based, non-medical services should be components of the extended care and rehabilitation available to persons with TBI.
- Families and significant others provide support for many people with TBI. To do so effectively, they themselves should receive support.
- Specialized, interdisciplinary, and comprehensive treatment programs are necessary to address the particular medical, rehabilitation, social, family and educational needs of young and school-age children with TBI.

These recommendations remarkably mirror the principles of Gentiva Rehab Without Walls—even though we have been delivering non-facility based, or community-based therapy, in line with their recommendations for more than 12 years (five years before these recommendations were made).

In a nutshell, Gentiva Rehab Without Walls' non-facility based, interdisciplinary program for TBI takes place in the home and community and supports people with TBI “wherever life happens” by achieving functional outcomes. This includes the support of family members and significant others who support the person with TBI because they have a significant impact on long-term outcomes. As a result, outcomes are durable and clients experience long-lasting gains and an improved quality of life. ●

Source: Rehabilitation of Persons with Traumatic Brain Injury. NIH Consensus Statement 1998 Oct. 26-28; 16 (1): 1-41.

Health Observances

Gentiva Rehab Without Walls salutes the dedicated healthcare professionals who contribute to the rehabilitation community.

September

National Rehabilitation Awareness Celebration: Sept. 17 to 23

October

National Physical Therapy Month

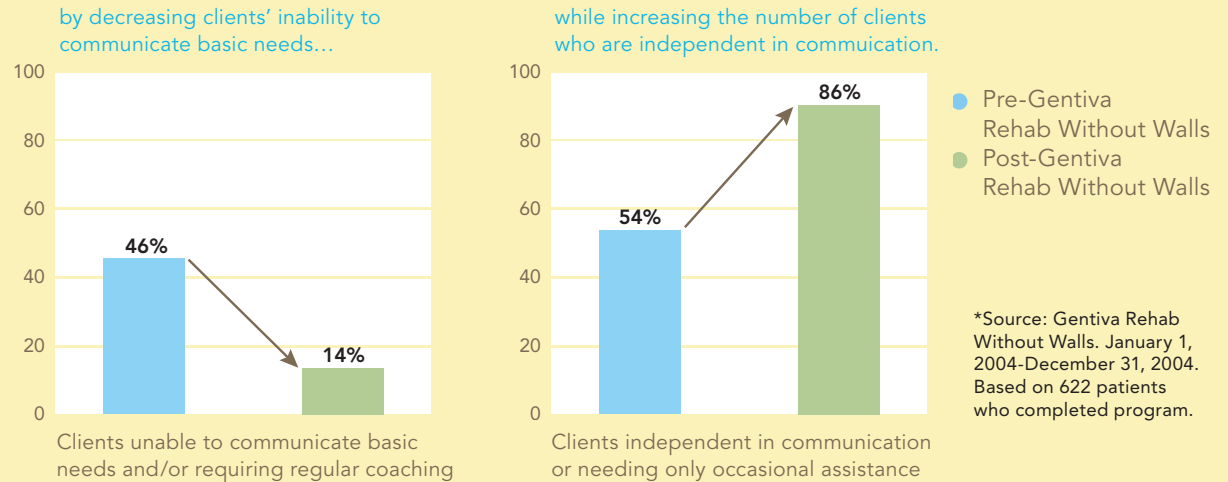
National Brain Injury Awareness Month

Case Management Week: Oct. 8 to 14

November

National Family Caregivers Month

Gentiva Rehab Without Walls improves clients' ability to communicate:



where are they
NOW?

creating a new normal

checking in on client outcomes post-discharge

Back in October of 2002, Ken Sinclair, a flight attendant instructor for Mesa Airlines, sustained a stroke. Not only was he paralyzed on his right side, but he had also lost the ability to speak. He went through an 11-month course of rehabilitation with Gentiva Rehab Without Walls, and with the team's help, along with the support of his wife, Mae Levine Sinclair, he was able to create what's known as the "new normal."

Clients may not be able to have the exact same life as they had before, but they still can have a quality of life that encompasses their interests and involves maximum functionality and independence.

"Ken was a very high achiever and was into everything. He had his own radio show, he made his own shirts, he loved traveling, jazz, cooking and writing," says Mae. "There was a point where we wondered if he'd ever be able to return to the things he loved and

create a new life that in some way resembled the one he had before the stroke."

As everyone who goes through Gentiva Rehab Without Walls home and community rehabilitation learns, clients may not be able to have the exact same life as they had before, but they still can have a quality of life that encompasses their interests and involves maximum functionality and independence. Ken was no exception.

Within a year, he was able to speak, walk, drive and return to work. Although he was unable to go back to his previous highly demanding job, his employer created a position for him better suited to his skills. He now works four hours a day, five days a week filling in on office work and performing odd jobs around the airplane hanger. Ken also has become the "soup guy," his wife explains, exercising his cooking skills to feed his co-workers. In fact, says Mae, "Ken's supervisor tells me that Ken is an inspiration to them everyday."

Ken's hobbies continue to be eclectic and far-reaching. He has become computer savvy, and spends much of his free time researching history and staying in touch with wide-ranging friends via the internet. Sewing has been difficult because he only has limited use of his right hand but he's been investigating getting a student to help him with his projects. There are the occasional bad periods where depression hits, says Mae, but "the Gentiva Rehab Without Walls team helped me understand that this was a part of his life now and I have learned to accept it."

Overall, she adds, the rehabilitation team was "phenomenal." In particular, she admired how they set functional goals and helped Ken work toward them systematically. "They were clearly focused on the direction in which he needed to go. I watched them continue to try different ideas and techniques in order to achieve the goals. I credit their hard work and inspiration for where Ken is today." ●

back to school: lessons for client and team alike

Every case Gentiva Rehab Without Walls handles is full of lessons—often life changing—for clients and their families. However, as every clinical team member has found out, learning is a two-way street. Many times clients teach our therapists a thing or two. In this particular case, the entire treatment team got a lesson in respecting a client's goals—however unrealistic they may appear—and never underestimating a client's will power (especially if she is a 13-year-old girl on a mission).

Background: In October 2003, on the way to a birthday party in Orange County, California, the SUV in which 13-year-old Emily R.* was riding was hit by a drunk driver. The vehicle rolled three times. Emily's head and arms smashed through the passenger window. Two other passengers were killed. Due to severe brain swelling, Emily experienced a non-induced deep coma for two months, spending a total of nearly five months in the hospital. By March 2004, she was discharged home and admitted to Gentiva Rehab Without Walls for home and community rehabilitation.

Rehabilitation Needs: Overall, Emily had decreased physical mobility, cognitive deficits and poor endurance. She required 24 hour supervision and a wheelchair, although she could take a few steps with maximum assistance. Her trunk control and posture were poor. She had significant problems with memory and problems with speech, including speaking too softly. After the initial assessment, a Gentiva Rehab Without Walls interdisciplinary team was assembled, including a physical therapist, occupational therapist, speech therapist, social worker and a clinical coordinator, to set goals and recommend a course of rehabilitation. Emily made it very clear, however, that her number-one goal was to return to school immediately. There was also her 8th grade class graduation party at a water park followed by the class trip to Washington, D.C., that she was determined to attend.

"These clearly were non-negotiable goals," says Clinical Coordinator Norma Caloca. "Normally, we would plan a slower re-entry built on small, obtainable successes. One of our concerns was that returning to school too quickly would be discouraging which, in turn, would actually impede her long-term progress.

Another concern was that Emily's disabilities would alienate her from her friends. We were flat out wrong. Little did we know how much support she had at home and at school. She was a good student, popular and very social. She loved school, and the teachers, administrators and other students loved her right back."

The Rehabilitation Process: "The first thing I did was to contact the school to arrange to be present for all the IEP [Individual Education Program] meetings. I also contacted the Special Education department, worked with Emily's mom, Sharon, who was extraordinarily pro-active, and talked with anyone and everyone who was involved in her care," says Caloca. "We arranged to have an attendant assist Emily when she first went back who could also help with the OT and PT. I also worked with the school to modify her schedule so that all her classes would be on the first floor for easier access." On the home front, Emily's father turned the garage into a gym for her physical and occupational therapy. There, the therapists worked with her on strength, balance and range of motion—all things she'd need for the trip to Washington—and trained her parents to assist her. They practiced going up and down stairs because that's what she'd have to contend with on the tour bus. They also practiced transfers from her wheelchair to airplane seat. With accommodations and planning that trip went off without a hitch and, according to Emily, "I was able to pretty much do everything the other kids did."

To prepare for the water park trip, the therapists took her to the community pool and the neighborhood park slide, where they coached her on body positioning, posture and safety. "It was true community reintegration," says Caloca. And to help her return to one of the activities she enjoyed with friends—shopping—the speech therapist would take her to the mall, have her sit in front of the water fountain and practice speaking to her friends above the sound. On the same trips, the PT or OT would have her practice walking, reaching for items and asking for directions.

Recovery and Results: Emily graduated with her class, and then turned her focus to starting high school in the fall. "We stayed with her for the transition to high school," says Caloca, "because, among other



things, Emily was determined to not be using a wheel chair by the time she started. However, the school is on a hill with a pretty significant slope, so we had our work cut out for us.”

Emily went for summer classes, so during this time Gentiva Rehab Without Walls was able to work with her and her assistant, who followed for safety. Sure enough, on the first day of high school, Emily walked through the doors using just a walker for support. In fact, the walker was purchased after the PT and OT did extensive research to find one that would work on steep hills.

Today, Emily is a sophomore, carrying a full course load. She now walks independently with a cane and is planning for college and overseas study. “I still have to have a lot of therapy—three times a week—but things are so much better,” says Emily. “After the accident, I was so weak I had to relearn every physical thing. All I wanted to do was be back to school and be with my friends.” With the help of Gentiva Rehab Without Walls, mission accomplished.

Lessons Learned: “For us,” says Caloca, “we learned so much from Emily and her family: Not to doubt people’s will and their goals. How important family support can be in achieving them. And what determination and focus can do—despite the odds.” For Emily, it was about being supported and taken seriously. “The treatment team really got the fact that I was a teenager. They knew what would embarrass me in public and they took my likes, dislikes and social concerns into account. They understood what was important to me, and made that a part of my treatment. That helped me stay motivated and meet my goals.” ●

** name has been changed in accordance with HIPAA regulations*

How Gentiva Rehab Without Walls Facilitates Return to School

The way in which Emily’s Gentiva Rehab Without Walls team handled her school re-entry, while faster than usual, was actually fairly typical. Because Individual Education Programs are mandated by law to be available in every school district, the Gentiva Rehab Without Walls representative—often a speech language pathologist or psychologist—will work with the designated person or department—sometimes Special Education, other times the counseling office—to put together a re-entry plan for the student. There are multiple advantages of having the Gentiva Rehab Without Walls team member working in this capacity, including the first-hand knowledge of the clients’ strengths and deficits and the ability to set functional goals that directly relate to skills needed for school.

Some of the ways in which Gentiva Rehab Without Walls can help smooth the return to school and ensure a more successful re-entry include:

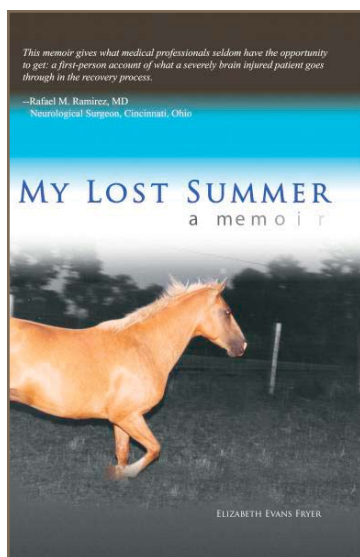
- Safety assessments of the school building, campus and environment that can identify and remove possible barriers for the client
- Arranging for adaptive equipment when needed
- Connecting with community resources, including transportation alternatives
- Teaching of compensatory techniques
- Re-aligning functional goals and incorporating new exercises and processes into therapy as the client’s needs change
- Day-to-day support; in some cases, the Gentiva Rehab Without Walls team member will accompany the student to school for a period of time until the adjustment is complete.
- Liaison with parents, teachers, principal and other staff
- Ongoing advocacy for the client.

My Lost Summer, A Memoir by Elizabeth Evans Fryer

Reviewed by Peggy Irons, RN, Gentiva Rehab Without Walls, Las Vegas,

Specialty Accounts Representative (SAR)

It was Fourth of July weekend 1983 and Libby Fryer was just 13. Little did she know that one misstep would change her life forever, but it did when her favorite



horse tumbled and fell on her. Her memoir, *My Lost Summer*, chronicles her recovery from a coma and brain injury and the affect this has had on her life now 22 years later.

At the time of the accident, her family was initially told that she had a concussion; yet, as the days went on, it was clear that her diagnosis was much worse and came with dire complications and touch-and-go implications. Despite

it all, her family, steadfast in the belief that she would recover fully, held a bedside vigil for months. Libby tells the story of her accident and recovery both from memory and with the help of a notebook kept daily by her grandmother.

As a healthcare professional, I found validation in Libby's story of things I have always practiced and believed to be true about comatose patients. For instance, Libby recalled words that were said about her when she was unable to respond. Several times she heard the staff talking about her condition in her presence. Then, of course, there are the little details that make this story so endearing: her account of the embarrassment she felt over having to be "potty trained." It reminded me that even with all she was going through, she was still a 13-year old, and in the dramatic 13-year-old mind there was no greater humiliation.

Libby Evans now leads a "normal average life" and wrote the book to

share her experience with others who may be undergoing a similar ordeal. Throughout the book, I was struck by the love and support of her family. I found her story to be a valid account of the dynamics between the medicine and the family love and support that heals severely injured patients. The story that Libby tells could be a great tool for families going through a similar experience—as well as an inspiration and confirmation for health care professionals who treat these patients on a daily basis. ●

rehabilitation terms defined:

- **Barriers**
- With Gentiva Rehab Without Walls, we often talk about eliminating the barriers—or walls—to recovery. This refers to anything that may impede progress: physical disabilities, emotional issues, cognitive problems, home design impediments, workplace regulations, and so on. Our team is trained to advocate for our clients in all aspects of their lives because we know that the sooner barriers are removed, the quicker and more complete the recovery may be. We can work on everything from arranging transportation alternatives, medical adaptive equipment and government assistance to supporting legislation and forging community links. Without barriers, true rehabilitation can occur.

resources

Useful web sites for rehabilitation professionals

www.biausa.org • Brain Injury Association of America

www.nashia.org • National Association of State Head Injury Administrators (many key TBI folks belong to this)

www.spinalcord.org • National Spinal Cord Injury Association

<http://tbindc.org/registry> • TBI National Data Center

www.strokeassociation.org • American Stroke Association

Throughout the entire treatment process, therapists and family members teamed up to reinforce the teaching from the individual disciplines.

as the 24-hour RN. She also, with the agreement of their insurance company, brought on their own speech language pathologist, Randi Michael, SLP, from a local facility, because her skills best matched Sam's needs. "That was not a problem," says Clinical Coordinator Steven Mandley, who also served as PT on the case, "because what's best for the client is what's best for us."

Understanding the Client's Unique Qualities

From their first meeting with the family, the treatment team members realized that they were not dealing with an ordinary head injury client. "Typically, there is some, if not significant, cognitive impairment," says Rachel Barrett, the team's occupational therapist, "but in Sam's case, his intellect had not been affected at all. Here we had a client and family that were highly educated and highly motivated. We had to adjust our approach and techniques to reflect this."

As the team got to know Sam, they began to understand how much his personality could impact treatment. "He was very strong willed, competitive and goal oriented. At age two and a half, he had taught himself to read. Plus, with his scientific background, he had a strong sense of perseverance, and an understanding that you need to take baby steps to get to the bigger goal," Barrett says. "So we co-opted this idea, and framed his treatment in those terms."

In addition, she adds, "there was so much love in that house. This, in turn, supported the treatment tremendously. The family was always open to trying something new. They came at a problem from all angles, they always followed through on treatment exercises and techniques, and they contributed their own skills to the rehabilitation process." For example, Sam's two sisters, both teachers, set up a handwriting program for him. All the adult family members, including brothers-in-law, received training by the Gentiva Rehab Without Walls team so they could help with assists. And one of the brothers-in-law, a carpenter, built practice stairs and a custom standing frame so Sam could stand longer with less assistance.

Setting Goals

Sam's mandate was to be independent, which included returning to school, sports and his research activities. The challenge was finding ways to bridge the gap between Sam's intellectual acuity and extreme motivation and his physical deficits without letting him become discouraged with the pace of progress. "He initially used a spellboard the first few months so he could communicate while the speech therapist worked with him on his vocalization," says Mandley. "We also let him learn through experience, which helped him deal with his frustration in not reaching goals sooner. For example, he knew how much he was practicing and thought he could do more with less assistance, so we let him try. When he lost his balance, Sam had the necessary proof to understand that he did indeed need more assistance. We framed as much as we could scientifically and empirically because that made sense to him."

Regaining speech was one of the key goals, and the trickiest to reach because even when Sam was speaking, understanding him was difficult. "This was due to extreme muscle weakness, including poor jaw control and impaired range of motion with the tongue," explains Speech Language Pathologist Randi Michael. "We later discovered he had velopharyngeal insufficiency, which basically meant that it took extraordinary respiratory effort to speak because the muscles didn't close off on certain sounds and he would lose air out of his nose." Some of Sam's doctors strongly advised that he get a computerized voice machine, but his parents disagreed entirely. Michael implemented an oral motor home exercise program and re-taught Sam each sound (phoneme), one phoneme at a time. This technique worked remarkably well and at present, Sam's family can understand his speech 90% to 95% of the time.

There were also problems with swallowing. In response, Michael obtained certification in Vital Stim therapy, which uses small electrical currents to stimulate the muscles responsible for swallowing, and is used in conjunction with therapists who help patients "re-educate" their muscles. She also taught him compensatory safe swallow strategies. Again, progress has been remarkable, and Sam can currently attain his nutritional needs via oral intake of mechanical soft solids and nectar thick liquids.

Co-Treatments Are Key

Throughout the entire treatment process, therapists and family members teamed up to reinforce the teaching from the individual disciplines. For example, the speech therapist taught the PT what to listen for and what to correct while Sam was speaking during his exercise sessions. As a reinforcement to both teachings, the PT would write down all the steps of an exercise and ask Sam to verbalize them. During initial gait training sessions, the PT worked with Sam's leg coordination while the OT addressed proper trunk alignment and body dynamics. Speech therapy would be conducted while Sam was standing so he could also practice proper posture. Family members would review speech exercises with Sam in the car, and so on. "The team effort is so important," says Barrett, "because we work off of each other to ensure that nothing slips through the cracks. If one of us misses something, the other will catch it. We also continually brainstorm together to find new solutions to problems as they emerge."

Looking at Subtle but Important Interventions

High on the list of priorities for Sam, his family and the team, was to minimize the appearance of disability. Not out of vanity, but because it was important that people see Sam and his intellect first—not his deficits. "This was a key piece for Sam to return to his world," says Michael, "and an important part of his quality of life. We didn't want to settle for 'just good enough.' It wasn't good enough that he could just speak; we wanted him

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to speak articulately so that everyone could clearly understand him. It wasn't good enough that he could move, we wanted him to move without tics or distracting mannerisms." Adds Barrett, "We're looking at the quality of his movement and how it transfers to the big picture. We continually ask ourselves 'how normal does he look in public?'"

Another Gentiva Rehab Without Walls priority is the emotional stability of the family. In this case, the family was extraordinary but the stress of dealing with their medically fragile son and the day-to-day challenges of his treatment took its toll. The team brought a psychologist on board so the family could learn new coping skills. "Supporting the client and family during these times cannot be underestimated," says Mandley. "The stresses on them can be crushing, and the usual ways in which they deal with a crisis may simply not be enough. The family's ability to support the client can be the foundation for rehabilitation."

Driving Each Part Toward the Whole

In this case, progress has continued on an upward trajectory, with no plateaus. More typically, clients will reach their goals and start to plateau. At that point, the rehabilitative gains become minimal and the team begins to taper treatment toward discharge. Sam, however, has continued to achieve functional goals and move on to new ones, so the team has remained in place. "We've followed the lead of Sam and his family and have not set restrictions or limitations on him—despite the poor prognosis his doctors offered. There's no reason why he can't go back to school and become gainfully employed," says Michael. "Each of us both together and apart is doing everything we can to make that happen." ●

About Gentiva Rehab Without Walls

With a focus on functional goals and measurable, durable outcomes, Gentiva Rehab Without Walls® provides comprehensive rehabilitation in the setting that we've found most effective: the client's home and community. Using an interdisciplinary clinical treatment team developed to meet the specific needs of each client, we help clients return to life as quickly, fully and independently as possible equipped with the functional skills necessary to participate in practical, daily activities at home, school and the workplace—often at a significant cost savings. For more information or to make a referral, please call 1-866-734-2296 or visit us at www.gentiva.com/rww

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alternatives