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Local program fills in the gaps for Multiple Sclerosis patients.

Dec 30, 2004

By Brendan Garvey



Helping Hands: Terri Nash (left) received a service dog, Mabel, with the help of Andrea Dowdall (right) from the Quality of Life Project. *Jane Morba*

Terri Nash has lived with Multiple Sclerosis for the past 35 years of her life. Now in her 50's, she has undergone the slow and painful deterioration that all MS patients eventually experience, losing function in her limbs (including, in Nash's case, her legs) and of her smaller muscles, making speech difficult and, in time, impossible.

MS erodes the connections between a person's brain and body. And the disease severs a person's connection to the outside world.

"You have to be tolerant," Nash says, "of yourself, of the people that you meet. With the wheelchair, people don't look at you."

Though her room contains some necessary medical equipment, her house feels comfortable, like a home should, and Nash seems far from a suffering medical patient.

"I enjoy bringing a light into someone else's life," she says, "even though they might look at me as if I'm under a dark cloud."

Her optimism is what prompted her to become the first client of the Quality of Life Project, a pilot social program founded by local psychologist Lotte Marcus. The program attempts to raise awareness about the disease and treat it in all its day-to-day manifestations: physical, psychological and emotional.

Few sources exist in the public to inform people about MS. This, added to the medical world's inability to pin down the facts about the disease, limits efforts to confront and cope with it.

MS is incurable and without a known cause. It occurs more frequently in women, and doctors suspect there is a slight predisposition to the disease among a patient's family members. Some symptoms can be prevented and

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[12-30-04]

Local program fills in the gaps for Multiple Sclerosis patients.

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contained through physical therapy and medicine. Nash, who loved riding horses and hiking, continues to exercise and pays strict attention to her body.

"If someone came along with a miracle cure," she says, "a magic bullet, then I want my body to be strong enough to be a test subject."

Through recently obtained grant money, the Quality of Life Project has provided Nash with the help of Andrea Dowdall, a social worker.

What we're trying to do is provide a safety net for these people," says Dowdall, a warm and cheerfully intense woman, "because right now it is broken."

The Central Coast has no unified clinic that deals exclusively with the different needs of MS patients. Instead, they have to negotiate with a large network of numerous organizations in order to, for example, get a ride to a support group—or even to find that support group in the first place. Marcus and her associates understood that the bureaucratic isolation that patients felt added to their emotional and physical isolation.

The dilemma of helping an incurable patient remain positive and interested in life drew Marcus into working more and more with MS patients.

"The young doctors I [trained] would ask me what they can do with these people who can't be cured," she says. Marcus, a Carmel resident for the past 50 years, started receiving MS patients who needed help with depression and anxiety. The isolation and dread that, in Marcus' analysis, remains the underlying and clinical psychological problem in MS patients, couldn't be treated without a more broad involvement in their lives.

Looking into charities that focus on MS, Marcus discovered large and unworkable bureaucratic organizations that can fund clinics and emergency response groups, but can't improve the daily lives of MS patients. The Monterey Bay Area sees very little of the money collected from residents for charities like the National Multiple Sclerosis Society.

The Quality of Life Program is run primarily by people directly affected by MS. The only paid worker on the small, all local and grass-roots organization is Dowdall.

"I feel [QLP] deals more with the person," Nash says about the program, "the mental and physical person."

Dowdall and Marcus set up a network of doctors, psychologists, caretakers and family members to help protect and support each MS patient.

"Lotte, with her bulldog passion keeps this thing going," Nash says, "because there's such a need for it."

Without the safety net that the QLP set up for Nash, she could have ended up in an institution, removed from her home where she feels safe and comfortable. Of particular importance to Nash, the QLP helped her find her service dog, Mabel. Beyond giving Nash a constant interactive companion, Mabel helps her in daily life, picking things up off the floor and opening doors for her master.

"She's an icebreaker," says Nash. "Many people are very afraid to approach a person in the wheelchair. That's one of the things I try to bridge. They see [Mabel] and they'll talk to me."

To find out more about the MS Quality of Life Project, or to donate, call 625-7127 or e-mail msqlp@sbcglobal.net.

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