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An indomitable spirit

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Saturday, August 5 Gary Rosen sat in a recliner in his living room on a Wednesday in June, waiting to have his teeth cleaned.

His wife Mary was in Bennington at work. His kids Penn and Eliza were at school; his oldest Lela was off for the first day of her summer job. But Rosen was not home alone.

On the other side of the house, Bette Abrams, a friend of the family, was doing research on the Internet for him. In the kitchen, a caregiver named Barbara Prusik was tidying up. Betty and Corky Elwell, two more friends, had been there all morning.

In the living room, Brooke Finnell, another friend and a dentist, was clearing a space beside Rosen. She carefully moved the metal pole where his feeding tube rested and adjusted the machine that sometimes helps him breathe. She placed her own chair next to his.

She walked across the room to his CD player and asked Rosen what he'd like to listen to. His preference was already queued up: a new album he produced with his children. Brooke only needed to find the right track.

"Number five," Rosen said, but the words were squeezed and slurred and hard to understand. He tried again, and once more, and Brooke got it. She pressed play, and Lela's soprano spread over a warm piano. Rosen smiled his enormous smile, and Brooke had to smile too.

Wind in the willows is whispering low. Still is the meadow which dreams in the sun.

Rosen looked out the window. The grass was dew-coated, the leafy trees were sodden. It had been raining all week. But all the green under a gloomy sky made the world outside look sad and sweet.

Blue overhead and green your bed. Sleep little people to lullaby. Lullaby.

Brooke picked up her slim, steel instruments and sat down. Rosen tipped his neck back, moving some of the only muscles he can still control. He closed his eyes and Lela's song filled the room.

Rosen, 59, has been to childrens' music what Elvis was to rock 'n roll. He performed almost constantly for more than 30 years, playing venues as great as the White House and Fenway Park and as small as the Brattleboro Commons. He's been on television, radio and recorded five solo albums, including one just released this month, plus dozens of others with various musical partners.

Two summers ago, Rosen was diagnosed with amyotrophic lateral sclerosis, a neurological disease known by its initials, ALS, or as Lou Gehrig's Disease. ALS destroys the brain's ability to control the body. Patients eventually become paralyzed and lose their ability to speak, while their mind remains unaffected. There is no cure.

Rosen kept touring for some months after his diagnosis, but mostly he's been in Brattleboro, the place he's called home since 1974. For much of the last year, he's been homebound, with a gradual loss of movement. He can no longer use his limbs or eat, and his speech is limited, but he is still lightning quick with a joke and his beaming smile still communicates a million nuanced feelings and thoughts.

Rosen's difficulties with ALS have not been his, or his family's alone to bear. Nearly every day, for the last year, has been like that Wednesday in June: filled with a near constant stream of friends doubling as personal caregivers, errand-runners, secretaries, gardeners, snow-shovelers, lunch-makers, dentists who pay home visits, and sometimes just companions to Rosen, his children, or Mary, his wife.

When the Rosens went public with Rosen's diagnosis, a flood of friends and some relative strangers from the community contacted the family and offered to help, anyway they could.

"It was overwhelming," Mary Rosen said. "The kindness."

It was also demanding a response. So the Rosens, with the help of their close friends Bonnie and Stephen Stearns, threw a sort of party, inviting as many people as they could remember that had volunteered their support.

At the gathering, they laid it out for everybody: the brutal reality of the disease, what kind of help they needed from people. And they asked each person to think if they really wanted to, and really could, commit.

Just about everyone there signed on. And since then, they've created a unique and highly organized system of helping the family.

"We've pieced what the family needed together," Bonnie Stearns said, "all through the community."

Stearns is now the keeper of the schedule. At all times she carries a thick, dog-eared datebook that shows when Mary, a dietician, has to work, when the younger kids, Penn, 17, and Eliza, 14, need to get somewhere, and Stearns makes sure there's a friend available to fill in those gaps. When Rosen has an appointment -- or more importantly, a Red Sox game to attend -- she makes sure there are enough people at the house to lift him into a wheelchair, into the van the family travels in these days. She rounds up enough people to help when the family returns, too.

Professional assistance can't be there all the time, and it was important to the Rosens' friends to not overextend the family, who are also carrying the emotional weight of the disease.

"Health care services offered through the system are about measured outcomes," says Noree Ennis, a friend and volunteer. "That leaves a lot of gaps. People here have really stepped in to fill that gap. For them, it's about a relationship, and wanting to share a burden."

In the Rosens' kitchen, Betty Elwell is packing a lunch for Lela, about to turn 19, who is working this summer at Yellow Barn Music Festival. In the living room, her husband Corky, is reading the day's newspaper aloud to Rosen.

Mary, ready to head to work, stops to talk with Betty about the kids' schedule that day, and Betty passes on a few phone messages she took while Mary was upstairs.

After Mary leaves, Betty joined Corky and Rosen and the three chat about the local politics and the fate of the River Garden. Rosen slowly tells them about a plan he hatched with some friends, to turn the downtown space into a comedy club. He tells them, half-seriously, that he wants to recruit Windham County resident Whoopi Goldberg for support.

"Whoopi's Cushion." That would be Rosen's name for the comedy club.

It takes several tries from Rosen and several guesses from Corky and Betty to keep the conversation moving, but no one seems to mind. Sometimes he spells out words, because it's easier that way.

"T-R-O-L-L-S."

"That's what he calls us," Betty says, affectionately. "His trolls."

When the Rosens and Bonnie and Stephen Stearns held that meeting last April with friends who wanted to volunteer, they did it with guidance from Compassionate Care, a

nonprofit ALS support group based on Cape Cod. The organization emphasizes the nonmedical needs of patients, and it serves both patients and their caregivers. Its founder and director, Ron Hoffman, has helped more than 300 families deal with what he describes as the "ALS journey."

The disease is a hard one, he says. Most patients are told that within three to five years after diagnosis, they will die of complications from the disease. But it can go on for an indefinite amount of time, Hoffman said, and the way it manifests is different for everybody.

"You really don't have a clue about what awaits you," he said.

But what makes ALS especially difficult is that it's a "family disease." That everybody close to the patient also deals with its symptoms.

"My wish," Hoffman says, "is that more families would take the journey like the Rosens have, with support like they have from the community. It's an amazing thing and it doesn't happen enough. Many people are very much alone with the struggle."

This week, on the hottest day the year, four stout-looking men crowded into the Rosens' kitchen in their bathing suits. Betty Chamberlain, another friend and volunteer, recruited them for the afternoon with a goal of getting Rosen, for the first time this summer, in the sparkling pool in his backyard. She couldn't have picked a better afternoon.

Rosen sat in his cumbersome electric wheelchair with a radiant grin. His daughter Lela put sunglasses on his face and a Red Sox hat on his head. She took the wheelchair's controls and led her father through the back porch, down a ramp and onto the poolside deck. Gary was parked at the shallow end, with a slightly dubious expression.

The men -- most of them who are also friends and volunteers -- crowded around. One took Rosen's slippers off, one foot at a time, and carefully collapsed the footholds. The four of them looked at each other and decided it was time: with help from Gary's son Penn, they hoisted Gary from chair and into a canvas harness.

In the pool, his daughter Eliza steadied an inflatable float. The plan, apparently, was to put Gary and the harness, on top. Slowly.

"Ooooh," he groaned, when his legs touched the water.

Eliza clung to the float, once her father was tucked in. She looked at him sweetly, and with a free hand splashed a little water on his chest.

Everyone stood around, applauding the great idea and the success of executing it.

It was humid and the sun was blazing, so everyone with a bathing suit on, also jumped in. For a moment, Gary floated a few feet by himself. He tipped his head back and looked up at the sky. His eyes were closed and he was smiling.

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