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## **Local doctor with quadriplegia strives for independence**

By Sula Pettibon, writer for *The Herald*

Cardiologist Tom Johnson of Rock Hill once used his hands to perform delicate procedures on his heart patients.

But since being paralyzed in a car accident almost five months ago, picking up a piece of popcorn has been one of his greatest triumphs.

Life is dramatically different for Johnson, who lost the use of his legs and much of his arms during the accident Thanksgiving weekend when he lost control of his Jeep Cherokee on a Florida interstate.

But the 42-year-old doctor isn't bitter. He just wants be independent again.

"This doesn't affect who I am," he said recently when interviewed at a rehabilitation hospital in Atlanta. "There is nothing to be mad about. It happened for a reason. I've got to make the best of it."

At his side is Michelle, 35, his wife of three years and a physical therapist who is his caregiver and biggest supporter.

"I couldn't do this without her," Johnson said. "This has been equally hard for her. The amount of care required is incredible."

His recovery has required four months of therapy at the Shepherd Center, which specializes in spinal cord injuries. They lived in an efficiency apartment provided by the hospital since mid-February when Johnson became an outpatient.

They're home now until mid-May, when he'll return to the hospital for a few weeks.

"It feels good to be home," Johnson said. "This gives me a chance to see what the problems are so we can go back and say, 'Can we work on this?'"

Come summer, he plans to be back at work at the Sanger Clinic in Rock Hill. He won't be able to perform procedures but will see patients and read echocardiograms at the four-doctor practice.

Johnson has the use of his biceps, the muscles on the front of the upper arm; but little use of his triceps, the muscles underneath. At first, he couldn't use his hands. Now he can control his wrists and has movement in his thumbs and a few fingers. He also has some feeling in his right foot and leg.

It could be six years or more before his recovery reaches a plateau.

"Progress is so infinitesimally small," he said. "I've gained patience, that's for sure. There's no way to survive without it."

Couple inseparable since accident

He and Michelle have been inseparable since Nov. 30 when, coming home from seeing family in Florida, traffic came to a halt on Interstate 75. Johnson swerved to avoid hitting the car in front of them. They flipped several times, landing upright. Both were wearing seatbelts. Their 11-year-old Doberman pinscher was thrown from the car and killed.

They still remember tumbling and the noise.

Johnson wasn't bleeding but couldn't feel his legs, and his arms felt funny, he said. He was flown by helicopter to Orlando Regional Medical Center, where neurosurgeons fused his neck bones to prevent further damage.

At first, Johnson had trouble breathing and could not cough. Now, he has low blood pressure problems and often is chilled. It's part of his body's adjustment.

At the Shepherd Center, he learned to use a wheelchair and feed himself. He sticks the fork in his fingerless glove and can grip a plastic bottle if it's not full. He's learning to play tennis with the racket taped to his hand. He's also played hockey and rugby. This summer, he plans to learn to water ski again.

He balances with his shoulders and no longer needs to be strapped into his wheelchair. His appetite has improved and exercise is developing his back muscles. He's lost 30 pounds because of muscle atrophy.

At the hospital, Johnson started his day at 6:30 a.m. with a shower and breakfast bar before heading to eight hours of therapy. Exhausted, he'd often fall asleep before dark.

The day is longer for Michelle. She stays up later at night to turn him. Even when they sleep in on Sundays, she sticks to their early-morning routine before drifting back to sleep.

"It's not like you can forget about it for a little while," she said.

Johnson's therapy included physical and occupational therapy and electric stimulation of muscles for strength.

The 100-bed hospital, which also serves people with brain injuries and multiple sclerosis, helps patients continue the activities they participated in before their

injuries. Therapy is tailored to their abilities and interests, like Johnson's love for tennis.

"The whole goal is to get you prepared for home," he said.

The private, non-profit center is among the few to offer animal-assisted and recreational therapy and to teach patients how to use voice-activated technology. Not covered by insurance, these special therapies are paid for by private donations and are free to patients.

The recreational therapy was a lifesaver, Michelle said.

The staff took them out to dinner and the movies and to the airport to see what it's like to board a plane in a wheelchair. They went on a six-family camping trip.

"Everybody is amazing," Johnson said. "It's nice when you roll into the gym and someone says, 'You look so much better than last week.' It makes all the difference in the world."

Therapists even went to his apartment to show him how to use a shower chair.

"You check your shame at the door," he said. "I've been naked around everybody in this place."

The couple also has met former patients through the center's peer program. Johnson's been inspired by one man who's been in a wheelchair 22 years, competes in marathons and has 2-year-old twin daughters.

Like his friend, Johnson wants his wheelchair to become invisible.

"They lead lives normally," he said. "There is a way of making it work for you."

### Big decisions

For the Johnsons, a big decision has been to get a manual wheelchair instead of an electrically-powered chair, which is bigger and heavier. They found the power chair awkward to use, especially in restaurants, where the table had to be raised for the chair.

"I didn't want the extra barrier," Johnson said.

The manual chair also is cheaper. A power chair can cost \$20,000, plus \$50,000 for a special van to accommodate it. They ordered a manual chair with power-assist wheels that cost \$9,000.

Insurance has picked up most of their bills, although it won't pay for some items like a shower chair. They have no idea how much this ordeal will cost in the end, Michelle said, noting he'll continue therapy in Rock Hill.

Here at home, they're getting used to life outside the center, where they were surrounded by people like them and served by merchants used to seeing customers roll in.

"At home, he'll be an oddball," said Michelle. "It will take some adjusting for the whole community."

It may not take as long as they think.

Doctors, staff and patients at the Sanger Clinic can't wait to see him again, said Dr. Nat Edwards. They plan to install voice-activated software for Johnson's computer and will be ready when he is.

"So many patients ask about him," Edwards said. "He wants to be seeing patients, and the patients definitely want to see him."

The Johnsons know acceptance of his injury may be easier for them than for their friends and families. His sons, ages 11 and 9, from a previous marriage, took it hard at first but are adjusting, Johnson said.

"As Tom gets stronger, it will get easier on them," Michelle said. "Tom's attitude from the beginning has been not to feel sorry for himself."

Their families have been a godsend. His family lives in Atlanta and provided meals and companionship. Michelle's mother from Florida stayed with them over Christmas. Her brother and his sons spent their spring break modifying the Johnsons' home.

They installed a lift outside, removed some wall-to-wall carpet, adapted the bedroom closet and created a roll-in shower in the bathroom. They may lower an island in the kitchen.

The couple also bought a new car - a Volvo station wagon. Michelle noted more than once how safe it is.

But the car and the house aren't the only things that have changed since the accident. "We don't do anything we did before," she said.

Gone are his 60-hour weeks and impromptu tennis with a friend. He misses driving; she misses their dog. But he's getting better and appreciates the support from the Rock Hill community, including the hundreds of cards he received.

"I have a different outlook on life," Johnson said. "My family, my kids, my wife are infinitely more important than anything else. You'll never be the same."