

Diagnosis ALS

ALS affects the patient and the family

TONY PALERMO

THIS WEEK

Tasma "Tammy" Breton sits in her electric wheelchair, but her hands are nowhere near the controls. Instead, they disappear under a large, blue blanket that covers the lower part of her body.

An intravenous pole stands tall behind the wheelchair, from which two bags of a clear fluid hang. One of the bags feeds Tammy by delivering a steady supply of nutrients. A liquid lunch of sorts.

A tracheostomy tube runs from her neck into a ventilator. Her mouth is open, her teeth bared. Her eyes stare out and they are wet.

Tammy is crying. "You'll have to pardon Tammy," says Mark Breton, Tammy's husband of four years. "Tammy gets really emotional when she does these interviews."

Tammy suffers from bulbar ALS. Where the majority of limb-onset ALS sufferers begin to gradually lose mobility of their limbs, for those with bulbar ALS, it starts in their face, head and neck muscles.

According to the ALS Society of Canada, 86 per cent of cases begin with difficulty swallowing. In 93 per cent of cases, it begins with a loss of speech.

For Tammy, the first symptoms appeared in 2005. She was eating dinner one night and noticed that she was having trouble swallowing. Less than a year later, after a battery of tests, she was diagnosed with bulbar ALS.

Tammy continued to work as an intensive care unit nurse at the Perth and Smiths Falls District Hospital for over a year until her loss of speech started to interfere with her duties.

Tammy then moved to an occupational health unit. She worked there for another year until eventually that also became too difficult.

"As the disease progressed, it sounded like she had a mouthful of marbles," said Mark.

He looks over at Tammy. "And other things like when she tried to say 'oh,' it would come out as 'uh' instead, right Tammy?"

Tammy's head moves, the faintest of nods, barely noticeable.

Now, Tammy sits in her wheelchair, unable to move, talk, eat or do anything for herself. She remains lost in her thoughts.

Mark recalls a story about a time when Tammy had a hair in her mouth that was bothering her. Unable to ask for help or remove it herself, Tammy cried in frustration.

"If there's a problem with her

breathing, you hear the alarm," says Mark. "If she's in pain, you can see her grimace. There are little clues you pick up on. But a hair that's stuck in your mouth? How do you guess that? Eventually a friend figured it out and removed it for her. It was frustrating for everyone."

As if to echo his thoughts, Tammy's eyes water and she starts to cry again.

A nurse who loved her job and devoted so much of her life to caring for others, Tammy now depends on the care of other nurses. One of those nurses is Susan Hermer.

"People need to understand that the mind is fully active," says Hermer. "And also that ALS is not contagious."

Every second day, Mark and the nurses give Tammy what they call an "everything day." On these days, Tammy is asked to have a bowel movement. Mark uses the analogy of energy dollars. Everything Tammy does or has done to her uses energy dollars. Even the smallest things that we take for granted, like bowel movements or getting dressed are physically demanding on Tammy. And, there are only so many dollars in the bank – only so many energy dollars that can be used up before there's nothing left.

Tammy starts most days between 7 and 9 a.m. with a head-to-toe bed bath. The nurses dress her and fix her hair. A mechanical lift moves her to the wheelchair and she is wheeled into the living room in front of the TV where she watches A-Channel news, Ellen and The View.

In the afternoon, if the weather is nice, Tammy is taken outside to get some fresh air. To fill in the rest of the day, she will watch movies. Someone will sit and talk to her or read her a story. Perhaps she will have friends or family visit.

By 9 p.m., Tammy is usually in bed.

"There is still some quality of life there," says Mark. "Tammy wants to stay alive. She holds out hope that one day there will be a cure."

LIVE FOR TODAY

Life has changed for both Mark and Tammy over the past four years.

Prior to Tammy's diagnosis, they were both avid travellers and motorcycle riders. They enjoyed going to restaurants and loved one another's company. They met later in life on the Internet, were engaged in 2005 and married in April 2006. A second marriage for both of them, their kids from their first marriages were older and off on their own.

Tammy and Mark were start-



MARK AND TASMA BRETON AND NURSE SUSAN HERMER

ing a new chapter in their lives. Except that in February 2006, with Tammy's diagnosis of bulbar ALS, the chapter was being written a lot different than either of them could have imagined.

"People often say to me that they can't believe that I'm standing by her side," says Mark. "For sure, stresses are way up. Lots of couples divorce when faced with similar challenges. It's frustrating. Sometimes, I just want to be husband and partner – not a caregiver."

He looks at Tammy. "What's also hard is that Tammy sometimes feels that she is a burden to everyone."

Tammy's head moves slightly. Tears roll down her face.

On a physical level, their relationship has been reduced to simple kisses on the cheek. Sometimes, early in the morning, he will crawl into bed with her, hold her tight and just lie there.

"Relationship-wise, you're always adjusting to keep on track," says Mark. "It's not like it was but there is a still a quality of life there for us."

Still, the stresses have taken their toll and not too long ago, Mark was faced with his own mortality. He suffered

a mild heart attack, which he attributes directly to the stress of caring for a spouse who is dying of ALS.

"Live for today because tomorrow may never come," he says.

Watch for part four of this series when Smiths Falls This Week examines the available treatment options for those living with ALS.

SMITHS FALLS COMMUNITY HOSPITAL FOUNDATION

The Annual General Meeting of the Smiths Falls Community Hospital Foundation will take place on

Wednesday, September 22, 2010 beginning at 12:00 pm (Noon) in the Foundation Boardroom at 270 Brockville Street in Smiths Falls, Ontario.

Contact 613-283-9743 or sfchfoundation@bellnet.ca for details.

The Future of YOUR Care is OUR Mission!

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Guests must be over 19 years of age with valid, government issued photo id to enter the SLOTS & Dining Room; two pieces required if 19-25 years old.

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Rideau Volunteers

Invite you to join them for an exciting day

Free Guided Bus Tour to Jones Falls

- Hop on a bus in Smiths Falls and travel to Jones Falls
- Learn about near death experiences, whispering dams and the life and times of the people during the construction of the Rideau Canal.
- Learn about the natural features of the canal and surroundings
- Watch a Parks Canada Blacksmith work his magic and weave his tales of the past
- Find out how easy and rewarding it is to be a volunteer with the Rideau Volunteers

When: Sunday, Aug. 22, 10:00 a.m. to 3:00 p.m.
Where: Catch the bus at The Rideau Canal Museum, 34 Beckwith St. S., Smiths Falls.

Cost: Free to all who pledge to donate their time to either the Rideau Canal Museum (RCM) or the Rideau Environmental Action League (REAL). Lunch Included.

Pre-registration is a must by Aug. 19. Spaces are limited so book early. Contact Lynn Preston at lynn@realdealstore.ca or 613-283-9500 for registration and more information.

This event sponsored by:

Funding provided by: