



Dylan in his tired Daddy's lap

**By Anna J. Fortenberry**

The kids frolic in the pool outside. It's a normal scene during the summer break from school.

Kenzie has gotten taller in the last two years. She's a little brunette image of her mom, Jan. Cheery, inquisitive, and enjoying the moment with her granddad in the pool.

Dylan is a typical boy. He looks just like his dad, Gary. Same eyes. Same warm smile. Same quiet demeanor with a boyish charm.

Outside is child's play. Fun, laughter, splashing, enjoying a summer day.

Inside is the serious business of keeping Gary comfortable - and alive.

June 13 marked the second anniversary of Gary Suddath's diagnosis of ALS or Lou Gehrig's disease. Gary and his wife Jan's lives have changed dramatically in two years. Gary celebrated his 45th birthday in April and he doesn't know how many more he'll have.

ALS is a disease that takes away your life one muscle at a time. Life with ALS is difficult to even describe. But for two years, the Suddaths have come to know its cruelty. They celebrate the anniversary with reserved hope. Most ALS victims don't live to make it to their second-year anniversary. Milestones and anticipation of near-future events gives them strength.

“Gary is supposed to be Gibbs Racing’s or Denny Hamlin’s personal guest at Bristol on August 25,” said Jan. “This is his dream come true and a reason for him to keep fighting!”

But August seems like a decade away when you have ALS.

“It is the most exciting race of the season and it is almost impossible to get tickets to that race unless you know someone,” she said. She had tried to get tickets to the race before Gary was confined to the wheelchair but couldn’t.

“He progressed before I could so I gave up on that one. There is no way he can get in the stands now.” But a friend whose husband works for Joe Gibbs arranged the “wish” request for Gary with the help of NASCAR.

Anticipation and hope can sometimes keep people going.

The Suddaths contacted [news@norman](mailto:news@norman) shortly after Gary’s diagnosis back in June 2005. Their hope was that through publicity, people would learn more about this horrible disease. Through knowledge, they held hope a cure would be found...in time.

“I don’t regret this whole thing,” said Jan. “If one person was educated it was worth it but now a whole community knows. The problem (ALS) is not going away. It is getting worse. Gary is the most private person in the world. We had two choices – we could learn from this and teach others or curl up and give up. Giving up was never a choice.”

The Suddaths moved from their home in Stanley to the home where Jan’s dad lives in Westport. She could no longer battle Gary’s disease alone. Extended family and friends have stepped in.

Lives and the way we live them change. Normal isn’t so normal anymore.

The dominant piece of furniture in the family room is the hospital bed Gary uses. He can lie in bed or sit in his electric wheelchair and watch his kids just outside in the pool. A hoist sits in the corner ready for use to move Gary’s body from wheelchair to bed.

Jan, her dad JD and her sister Jennifer pull double duty. Sometimes nursemaid to the kids and sometimes nurse for Gary. The precision they have as they go about their task of maintaining his life is as natural as if they had been trained all their lives to do it. In two short years, they have learned a lot about the care-giving role they all play.

Friends come and go visiting Gary. From church family to Gary’s co-workers from Sun Microsystems, it is a whirlwind of coming and going.

Constant in his life is the disease. It is a disease that prohibits Gary from almost any movement at all now.

“Gary’s gone down a lot since you last saw him. Do whatever you have to do before you come,” said Jan, almost as a warning to shed the tears that might come after seeing Gary again. “This may be his last interview.”

And as Gary struggled to get words out, it was apparent that his ability to speak won’t be there much longer. He concentrates and wills the words to come from his lips but those words are often inaudible - frustrating for both Gary and the listener.

Doctors have told him he needs to quit taking food and water by mouth. He gets choked easily. His lung capacity is down to 30 percent. When he sleeps, the carbon monoxide builds in his lungs. He should already be on a ventilator.

“I have not decided about a ventilator,” Gary struggled to say recently. It is a decision that can help him live longer but he’s not sure. “I don’t want to put everyone through that.”

The energy required to speak is too much for Gary. His neck begins to hurt. JD takes time from the kids and comes in to adjust the neck brace on the wheelchair.

But relief doesn’t come. Gary can’t get anyone to position his body to make it

comfortable. Jan pulls the hoist over and begins the process of moving Gary from the chair to the bed. His legs hang like dead weight. His feet are twisted. Once she gets him lifted into the bed, she spreads out the fingers on his hands but they creep back into tight curls.

These are the harsh realities of Gary's existence.

Only a few weeks earlier, the family made the trip to Washington, DC for the ALS Conference. The trip was very difficult for Gary and took much of the little strength he still has left.

The Denver community had rallied for the ALS Registry Act of 2007 by calling Congressman Patrick McHenry's office prior to the trip to encourage his support of the Act that was being introduced before Congress. Jan was excited that he had decided to support it and credited that to so much pressure from their hometown community.

"The outpouring of support from your articles about supporting the Act by calling McHenry...the community needs to be thanked," said Gary.

The news of support the ALS community achieved in Washington was exciting but the exertion of the trip took its toll on Gary and the family.

"Gary's in such bad condition right now," Jan said after they returned. "He can't breathe. He can't talk. What he lost physically on that trip he can't get back."

But Gary's will to go on lies in his hope that someone down the line will be saved from this disease.

"What I start, I'm gonna finish," he told Jan in Washington. Disappointed that he wasn't able to verbalize the issues of ALS while in Washington, Jan told him, "The fact you couldn't speak gave more of an impact."

Jan has become more and more of Gary's voice. He can use a computer and spell out words one letter at a time through a magnetic dot that is on his forehead, but the process of communication is slow and tedious.

"Jan continues to be my ray of hope," Gary spelled out letter-by-letter. "She is my arms, legs and yes, sadly, my voice which includes my opinions but in her voice. Sometimes my opinions get lost somewhere in the translation."

Jan often lets friends and supporters know about their lives through her MySpace blog. It is her way to "tell" folks about their days without having to actually speak the words. Speaking them would be too difficult even for her to hear – the harsh reality.

Portions of one of Jan's recent blog entries:

"Seems like it's all going so fast. People are starting to come visit to spend time with him. They all amaze me with their strength when they are here...like everything is normal and they are hanging out with us like we did a long time ago."

She says the family enjoys alone time – time that comes sparingly. When the family time comes, they try to be as normal as they used to be.

"Tonight we watched home movies from when the kids were young and everything was normal. Kenzie and Dylan laughed at the antics of 1-year-old Dylan then 2-year-old Mackenzie. We saw birthdays and Christmas in our (old) house. The kids were doing great till they really started thinking about having to leave our house. Then when Gary walked across the screen, you could tell it was sorta too much for everyone. We commented on how thin he used to be...and how tall. When we heard him talk, it got really quiet. We all commented later on how he sounded different than we remembered. Kenzie thought he sounded like Elvis – that Southern accent of his. We saw him chase the kids through the yard...we had to turn it off not long after that."

Normal. There is no normal anymore.

Kenzie made Gary a card. How else do you express how you feel about this disease you don't understand when you're only eight years old? How do you deal with a disease adults can't even deal with?

"Dear Daddy, I am really sorry you can't walk. I can't understand you any more. I wrote this letter in green so you would feel happy."

Then she gave Gary a "Kenzie hug." And with all the strength he could muster, he hugged her back.