



## MY NAME IS LOLA

by Lola Rozsa,

as told to and written by Susie Sparks

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## Hail and Farewell

On the fourth of July, 1939, Lou Gehrig announced his retirement from baseball. I remember because Ted and I had only met a few weeks before, and it was a holiday so we were both at Ann and Ed's house in Olney, Texas. The sports reporters had been covering the story for weeks and everyone knew this powerful Yankee hitter was in a serious slump. He'd played more than two thousand consecutive games – hitting four home runs in one of them. However he was going through a rough patch; it seemed like he'd lost all his strength. He was still hitting the ball every time; it just wasn't going anywhere, but when he benched himself it was a terrible shock. We heard the hail and farewell speeches on the radio that fourth of July afternoon. The Yankees' manager described Lou Gehrig as "the finest example of a ballplayer, sportsman and citizen that baseball has ever known." And then the team retired his uniform number.

Sitting there in Terry Myles' office at the Foothills Hospital that sunny September afternoon in 2005, I remember thinking, that was sixty-six years ago. Ted and I have been married sixty-six years. Amyotrophic Lateral Sclerosis. I couldn't even pronounce the words, but I knew immediately what they meant. Lou Gehrig's Disease.

It wasn't my finest moment. I had gotten used to Ted getting old. We were *both* getting *old*, for heaven's sake, so stumbling and falling and dropping things was just what we did. Thankfully both of us seemed to have kept most of our marbles, and if we could keep

our sense of humour too, then it wasn't so bad. I was sure Terry had made a mistake. But there were all these other people in the room with us. Terry introduced them as our coordinated, multi-specialist team, and he started talking about known patterns and treatment protocols, but their names and titles escaped me and I found myself looking for the exit. This was not what I was prepared to hear.

But Ted seemed to be relieved now that it had a name. He finally knew what was going on and he could prepare himself. I suppose it was the scientist in him but, as soon as he knew there were people on hand who could supply him with the information he needed, he visibly relaxed. Terry told us that the ALS Society would be of enormous practical help. They would have equipment we could use that would make Ted more comfortable as time passed, and we went home armed with resource pamphlets and phone numbers and assurances that we could call any of them at any time.

I still hadn't accepted Terry's diagnosis, but by the time I walked into the house I knew I'd have to stop the revolving door of caregivers we'd had since we checked out of the assisted-living residence. Neither of us really had the patience to deal with any of them, and I guess I'd fooled myself into thinking we could get back to managing on our own, but right then I didn't have the strength to figure out what had to be done. Those first few weeks I seemed to be on an endless rollercoaster, circling between the highs of outright denial and raging at the injustice of it all, and then plunging into depths of fear and grief.

Ted, on the other hand, went into research mode. He read that ALS is a form of motor neuron disease caused by the degeneration of upper and lower neurons located in the spinal cord and brain. It's characterized by rapidly progressive weakness, muscle atrophy, and respiratory compromise. Motor neurons, among the largest of all nerve cells, reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body with connections to the brain. When they die, the ability of the brain to start and control muscle movement dies with them. With all voluntary muscle action

affected, patients in the later stages are totally paralyzed. But the disease doesn't affect the five senses of taste, touch, sight, hearing, and smell. Nor does it affect cognitive function. Over time, he would simply be imprisoned by his own body. There is no cure.

What *I* read came from Eleanor, Lou Gehrig's wife: "The cause of this cruel disease is unknown. The motor function of the central nervous system is destroyed but the mind remains fully aware to the end." What all of that meant, we would be forced to learn together. Ted never once complained. Ever.

It took me fully a month to get to a place where I could think straight, and thankfully it was Jane Rivest who both literally and figuratively took me by the hand to show me the way. Terry had said that Jane would be calling us to set up an appointment to meet the family and to help us discover how our treatment goals could be met with the assistance of the ALS Society. Jane's dearest friend, Betty Norman, had been diagnosed when she was only fifty-eight and, despite the fact that she had no experience as a caregiver, she looked after Betty for the duration of her eleven-month struggle. Since then, Jane has been a tireless advocate for those living with this terrible disease *and* their families. Quite simply, her primary goal is to make a positive difference – to make each day the best possible for all of us.

On the day we all assembled in our living room to meet Jane, I was still adamantly resisting Terry's diagnosis. But very slowly and thoroughly she answered all the kids' questions, and then laid out what services and equipment the ALS Society could provide, making it very clear that help was a phone call away. She immediately picked up on the fact that Ted had the marvellous ability to retreat into his head and that as long as his brain allowed him to keep imagining new ideas, he could stay fully engaged in his life. "Right now," she told Ted, "you might want us to arrange to have a chair lift installed so you can continue to work in your office downstairs. And if the time comes when you need a computer that is voice-activated, we can supply that as well."

The months that followed seemed to race by as Ted's physical limitations became more and more apparent. By that time, I was relieved that the round-the-clock care nurses from the Focus on Caring Agency were on site, and I grew to both appreciate and admire how capable they were as they took care of Ted. They became a critical part of our family. I realized that, had we not had their help, Ted would have had to move into the hospital. And as far as I was concerned, that was never going to happen.

But the disease was relentless. Ted was having muscle spasms and could no longer negotiate around the house with his walker. He had to move into a wheelchair. We arranged to have two hospital beds moved into our bedroom so he could be in a sitting position during the night to make his breathing a little easier, and then he required oxygen twenty-four hours a day. However, because I have COPD, I'm also tethered to an oxygen tank. Fortunately, though, we could still laugh every day as we tried to untangle ourselves from our respective air hoses while we wandered about in our respective wheelchairs. We were like a couple of double-dutch skippers snarled in our ropes.

Then, as the muscles around Ted's face and throat weakened and his tongue lost its strength, chewing and swallowing became more difficult. It took more time and energy to finish eating his meals and he started losing weight quite quickly. We were advised that it's important to correct this problem in its early stages, so we turned three hearty meals a day into six little appetizer-size mini-meals. Then we put the blender into overdrive and whipped up thick creamy vegetable soups and fruit smoothies of all kinds. But oddly, it was even harder for him to swallow thin liquids like water, so we had to add a thickening agent to it to make sure he could stay sufficiently hydrated.

As Ted moved through his illness, I realized he was teaching us what he valued most. He was still dreaming up new drilling techniques, and he took to reading articles in endless copies of the *National Geographic*, which he liked to tell us about, whether we

expressed any interest or not. His speech was slurred, but he had infinite patience with us and we figured out what he was trying to say most of the time. And then I happened to read something in the ALS manual that Jane had given us: “Hope, faith, love, and a strong will to live offer no promises of immortality, only proof of our uniqueness as human beings, and the chance to experience full growth, even under the grimmest of circumstances. The clock provides only a technical measure of how long we live. Far more real than the ticking of time is the way we open up the minutes and invest them with meaning.” Ted may not have written those words, but he had lived them every day of his life and he continued to live them to the end.

Through the Christmas season, we had lots of visitors. Karen and her little ones, and Mary Lil’s Cristina, I think, were his favourites. Mary Cristina would bring her flute and play for him while he tapped out her timing. I think it meant a lot to him because he could enjoy her and the music and he didn’t have to try to talk. But young Ted wasn’t coming by, and I couldn’t understand why he was staying away. I tried to contact him, but with no success, and, each time I tried, I alternated between worry and downright anger. But when I finally found out what he was having to deal with, I realized how we each have lessons to learn as we pass through our lives. As someone far more insightful than I has said, “If you learn from your suffering, and really come to understand the lesson you were taught, you might be able to help someone else who’s now in the phase you may have just completed.” Maybe that’s what it’s all about after all. At the time though, I was too filled with my own grief and so overcome by my own helplessness in the face of Ted’s illness that I didn’t realize I hadn’t had the opportunity to follow Nannie’s first rule of compassion: “When you are faced with something you can’t understand in someone you love, you have to take the time to really listen. Put yourself in his skin and see it through his eyes.” Although I wouldn’t understand what had happened and why until much later, young Ted finally let me know that he hoped that the decision he’d

had to make at that dreadful time in both our lives honoured the values his father and I had modelled for him.

Maybe that's what it's all about after all.

2006 arrived without much celebration that New Year's Eve because I had stumbled into a door and broken my right shoulder, and Mary Lil had fallen on the ski hill and did the same to her left shoulder a week or so later. Although I wasn't convinced I was *totally* decrepit, I realized that if my children were falling apart too, it was a bad sign. So, when she called to suggest we see the new year in together, I thought I'd better pull myself together just to prove I still could.

She brought along a bottle of chilled champagne so we could raise our glasses in a toast following dinner, and set it – along with a couple of champagne flutes – on the table in front of us. As the big moment arrived, both of us leaned forward to pour the champagne and realized that since she was sitting to my right, next to my broken shoulder, neither of us could reach the bottle. We were a pitiful pair. Even when we changed places, neither of us could get the cork out anyway. If you could have heard us giggling, you would have thought it was time to close the bar.

We were both so exhausted and emotionally drained by that time, I think Ted was relieved to hear us laughing for a change. He was entering the final stage of his illness and had weakened considerably so that talking was getting more and more difficult for him. Much of the time we spent just holding hands while I told him about conversations with people who had called to ask about him.

We also tried to keep him informed by telling him about all the nominees for the Rozsa Foundation Excellence Award, and I think he was rooting for Stephen Schroeder. As executive director, Stephen had been involved with One Yellow Rabbit Performance Theatre for fourteen years and, under his tenure, the budget grew to \$1.5 million, the donor base expanded, and audience numbers increased substantially. It was a remarkable accomplishment, given

the prolific activity of the company and the experimental nature of their work.

In February, Mary took me out for a birthday gathering and Ruth Ann stayed with Ted to watch the opening ceremonies of the Winter Olympic Games in Turin, Italy. She reported that he was dozing on and off, but at one point woke up suddenly asking, "Where is Mother?" Ruth Ann, thinking he was asking about me, explained that I was out for the evening with Mary. But Ted was confused and mumbled, "Well tell her to open the damn door!" He seemed to be talking with someone in his dream. Several years later, I would remember that experience when I had one of my own.

At this point we were all feeding him baby food whenever we could talk him into taking just a bite, but he never lost his dignity and he never uttered a word of complaint. By the end of February, Ted was no longer trying to talk, and Jane let us know his struggle wouldn't last much longer, so Ruth Ann, Karen, Mary Lil, and Cristina moved into the house to help care for him. The last night he was lucid, he seemed to be very agitated, and Jane came and arranged for a doctor to give him a shot of morphine, which calmed him down enough for us to have one last conversation. He talked about drilling, and then he looked at me for a long moment and said, "Well Hon, I love you. It's time for you to take my place." He closed his eyes and lost consciousness.

Two days later, I was sitting beside Ted on the bed holding his hand when he slipped away. Jane and the girls had all stayed with us throughout the long hours of our last vigil, and I know that if their love could have saved him he would be with us today. Bob Pynn arrived about ten minutes later saying that he had an overpowering feeling that he should be with us that morning, so he came right over.

Ted and Bob had both championed the CPO over the years and as archdeacon and dean of the Anglican Cathedral, Bob was a founding member of the Faithful City Team, a small group of dedicated people who view spirituality as critical to the social good. I thought



to myself how strange are the works of God – to bring my dear husband, a mostly un-churched agnostic, to a mutually respectful friendship with a deeply spiritual man of faith. I was so grateful for that friendship, particularly on that morning as I said goodbye to the man I had loved for sixty-six years.

Ted's funeral service was held at Grace Presbyterian Church. Bob Pynn led the service and members of the CPO played one last concert for him. In my heart of hearts, I know he was listening and that he was thankful for being able to help the orchestra grow to become one of the finest in Canada. He was a good and kind man. He left the world a better place.

Sixty-six years before, after Babe Ruth gave his remarks on the occasion of Lou Gehrig's retirement at Yankee Stadium, Gehrig stood as 62,000 fans thundered their hail and farewell. Ted and I heard him say, "Today I consider myself the luckiest man on the face of the earth. I have been in ballparks for seventeen years and have never received anything but kindness and encouragement from you fans. Look at these grand men. Which of you wouldn't consider it the highlight of his career just to associate with them for even one day? When you have a father and mother who worked all their lives so that you can have an education and build your body – it's a blessing. When you have a wife who has been a tower of strength and shown more courage than you dreamed existed – that's the finest I know."

Had he had the opportunity, Ted's thanks would have echoed those sentiments almost word for word. He also considered himself the luckiest man on the face of the earth.