

## **Janie and Roberta**

by

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It was April 11 and Roberta Schwarz knew her sister Janie would not live to see her 62<sup>nd</sup> birthday on September 24. For over a year, Janie had been misdiagnosed with myasthenia gravis and only two weeks ago—after her mother’s funeral— she was correctly diagnosed with advanced Amyotrophic Lateral Sclerosis. The doctors had advised her to start preparing a bucket list. So why not have an early birthday party for Janie, Roberta thought. Due to her ALS, Janie had a hard time swallowing and could no longer eat solid foods. Why not make it a Jamba Juice party—no food allowed. Janie could not eat, but she could enjoy a smoothie just as well as anybody. Roberta called the family, and everyone agreed to meet at the Jamba Juice in San Clemente. There would be balloons and presets – a proper birthday party. Janie would love that, Roberta thought.

Roberta had put Janie down for her nap earlier. She usually became tired in the late afternoon and Roberta always knew it was nap time by Janie’s wobbly gait. With her sister asleep, Roberta could now run errands. She had already started a list on her legal pad with an endless amount of things to do. Roberta’s brother Don and her husband Ed were in the kitchen discussing what they needed to do for Janie when they heard a loud thud, like something crashing to the ground. Roberta dashed to the hallway and saw that their five-level shelf had fallen over, sending dozens of knickknacks scattering. Next to the shelf, Janie lay flat on her back on the ground. She looked up at Roberta, her eyes wide. Roberta gently propped her up. Three drops of blood stained the carpet behind Janie’s head.

Roberta would later learn that Janie had gotten up to go the restroom. After taking a few steps, she had fallen back, grabbed the shelf on the way down, and hit the back of her head on the sharp edges of the wall heater. Janie had always been perfectly capable of going to the restroom herself, so Roberta could not understand what had happened. Roberta knew that caring for Janie would be a full-time job and she had accepted that responsibility. At least two people would care for Janie around the clock. But those same two people were in the house when the fall happened. How was Roberta going to be able to take care of Janie? How could she do this?

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### **April 4: One Week Earlier**

The phone rang as Roberta sat in front of her computer in her Portland, Oregon home. It was Janie’s social worker calling. Janie received Medi-Cal, so a social worker would occasionally visit Janie’s home to see if the health care she received was adequate. How nice of the social worker to call so close to the end of her shift, Roberta thought. It comforted her to know that Janie, who lived 1000 miles away in Hemet, California, was in good hands.

“Janie and Shawn’s trailer home burned to the ground,” the social worker said. Shawn was Janie’s son.

Roberta panicked. The first thought that entered her mind: “Are they okay?”

“I’m so sorry. I thought you knew,” the social worker said. “I should have known better than to have that be the first thing out of my mouth.” She informed Roberta that Janie and her son Shawn got out safely, but the fire had completely charred their trailer home in Hemet. Now Janie and Shawn were staying at a Super 8 Motel courtesy of the Red Cross. Janie’s dog Lacey ran out first, but her two cats could not be found, although neighbors saw one cat fleeing from the window, which was engulfed in flames. Janie’s close friend Fran, whom she had known for thirty years, had recently passed away and Janie had lit a candle to remember her. Janie walked out of the room to talk to Shawn and the candle had caught on something. The whole trailer was gone. Well, not entirely gone. The family was responsible for hiring someone to safely dispose the remains of the trailer. The social worker and Roberta talked for three minutes.

Roberta digested the information. She last saw her older sister at their mother’s memorial service two weeks ago. They had talked about Janie moving closer to the family after she was diagnosed with ALS so that she could be well cared for.

Janie and Roberta were six years apart and they had different groups of friends while growing up. When Janie was 19, her father had struck her and kicked her out of the house because she had become pregnant with Shawn. Roberta, who was 13 at the time, thought her sister would eventually come back home. Janie never did. The two sisters lived separate lives and saw each other once a year on their mother’s birthday. Their mother, who lived to be 93, loved to gamble, so Roberta and Ed flew to San Clemente every year and drove her to the Pechanga Resort and Casino. Janie came from Hemet and met them there.

Now things would have to change. Roberta knew that Janie needed to be closer to family because of her diagnosis, but the fire now forced Janie to move to San Clemente to live with their brother Don. Roberta would help Janie rebuild her life by getting her a new bank account and new identification because her paperwork had been destroyed in the fire. Roberta would also need to find a home for Lacey because the apartment complex in San Clemente where Janie would be living did not allow dogs.

First things first—Roberta had to go be with her sister. She called to her husband Ed in the next room and told him what had happened. They booked a flight from Portland to San Clemente.

## **April 10**

Roberta and Ed arrived in San Clemente . After stopping at her brother Don’s apartment, the three headed to the Hemet Super 8.

Roberta’s heart sank when she saw Janie. The doctor had said that Janie had months to live, maybe years, but Roberta knew it would be less time than that. Janie had drastically deteriorated since their mother’s memorial service. While 75 percent of ALS patients experienced “limb onset,” which affects the mobility of the limbs, about 25 percent of cases were “bulbar onset.” Janie fell into the latter category. Nasality and loss of volume in the voice were usually the first symptoms. Difficulty swallowing and the loss of tongue mobility followed. Janie had completely lost her ability to speak about a year ago, using only her pen and notebook to communicate.

Roberta knew that the shock of her mother’s death, uncle’s death, friend’s death, and now the obliteration of her home caused Janie’s dazed appearance. She couldn’t look anyone in the

eye. She looked halfway to another world. Yet Roberta also knew that another part of it was due to Janie's 20-year addiction to hard-core painkillers.

At their mother's memorial service, Janie had written a poem for her mother but she was unable to read it due to her illness, so Shawn spoke for her. Even before Shawn started to speak, close family and friends took one look at Janie and knew that something was very wrong. Her eyes were blank and expressionless, a look Roberta described as haunting. After the service, Roberta talked to Janie's neighbors in Hemet who said they had seen Janie falling-down drunk. She was binge drinking and taking as many pills as she wanted.

Roberta feared the combination of drugs and alcohol would eventually kill Janie. She knew her sister did not have much time left, but she wanted to prolong her life as much as possible. Janie had survived deaths and fires, and to lose her to an overdose would be too devastating, Roberta thought. So Roberta made up her mind. She wanted her old sister back and the only way to do that was to regulate Janie's medications, giving her only what was prescribed. She would also get Janie on a healthy diet, reduce her smoking and take her for walks along the beach, which was only one mile away. Whether she did this out of denial or love—or both—Roberta was determined to stretch out the last days she had with Janie for as long as possible.

After the drive from Hemet to San Clemente, everyone got settled in. Roberta and Ed walked Lacey and then put her in the garage. The landlord had allowed Lacey to stay one night, but tomorrow she would have to go to Paws Pet Resort and stay there until they could find her a home. (Janie had adopted Lacey about two years ago when her former dog Goldie died. Goldie had lived with Janie for 16 years.) After Roberta walked Lacey, she got Janie ready for bed. Janie could no longer speak. Roberta had to communicate with her through writing. She would verbally ask Janie questions, and Janie would write down her answers in a notebook.

After Roberta put Janie to bed, she talked to her brother Don about locking up Janie's meds. Roberta couldn't bear to see Janie's drug-addled expression any longer and she wanted Janie alert during her last days. So together, Roberta and Don placed 16 bottles of medication in a lockbox and put the key in a safe place. She would get only the amount prescribed. Janie would be mad as a hornet, Roberta thought, but she needed to do this.

Just as Roberta predicted, the next morning Janie woke up and asked for her medication, specifically "the white ones." She was referring to the hydrocodone pills, which were two levels weaker than morphine. Roberta explained to Janie that she would only get the amount the doctors prescribed. No one knew until later, but Janie called the police.

Ed was busy writing out Janie's morning, midday and evening prescriptions when two police officers approached him. Janie's prescription bottles littered the patio table. The officers questioned Ed, Roberta and Don and asked to see all of the pills.

"Wait a minute," one of the officers said. "Even if you were giving her exactly what the prescription says—which you are claiming that you're doing—there are 30 missing hydrocodone."

Roberta looked at Don. Don looked at Roberta. My God, only three days had transpired from the time the prescription was filled until the time we started caring for her, Roberta thought. Three days, 30 pills. Roberta had not counted pills. Janie had taken 30 in three days. Roberta felt like the wind had been knocked out of her. She remembered that Janie's doctor had told them that 30 pills had killed one of his patients. If Janie had taken them all at the same time, she would have died, too. Roberta shuddered. She and Janie did not have much time left, but she would not allow drugs to cut that time short.

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## **April 11**

Roberta held Janie in the back seat. When she saw that the blood kept flowing after Janie fell in the hallway, Roberta decided to take her to the hospital. Roberta helped Janie into the back seat of the car and Ed drove them to the San Clemente hospital. Try to relax, Janie. Try to stay awake. We are going to have the doctors at the emergency room make sure you are okay, Roberta told her.

They finally arrived at the hospital at 6 p.m. and Roberta was relieved to see her niece Erin's best friend Robin on duty. Robin got Janie admitted right away. The doctor ordered x-rays because Janie's neck hurt and he wanted to make sure the pain was not caused by the fall. Janie needed five staples to her head.

Roberta knew it had also scared Janie that she could no longer walk without falling. Roberta needed to come up with some sort of system. She decided to put a bell on the table next to Janie's bed so if Janie ever needed something, she would just ring.

After two hours, Janie was discharged. Roberta wheeled her into the waiting room where the family waited with presents and balloons that said "Happy Birthday." Janie was going to get her birthday party.

Aside from a sweatshirt and a denim purse, the most popular present Janie received was an assortment of bras. She had said that she needed bras after her entire wardrobe burned in the fire and that's exactly what she got. Black, white, magenta, lavender—Janie now had many to choose from. Since she had so many, Roberta thought a photo should be taken to show them all off. So the four women of the family, including Janie, put the bras on over their clothes and smiled for the camera. Janie was laughing and having a hoot. She would later write that this was the best wardrobe she had ever had. Janie sounded the most like Janie when she laughed, Roberta thought. She was getting her old sister back.

They returned to the apartment at 9 p.m. Roberta got Janie ready for bed and helped her use her walker. Roberta took one step to let Janie go. Janie pushed the walker away, took one step and fell back on her head that had five fresh staples in it. Are we going to have to go back to the hospital, Roberta thought? Luckily she didn't see any blood, so the best thing to do was to get Janie to bed. Roberta helped Janie to her room, tucked her in, touched her nose and kissed her on the forehead goodnight. She would do this every night.

Roberta did not know it then, but Janie would have only 17 more days to live.

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## **April 16**

Almost a week had passed since Roberta had arrived in San Clemente. Roberta was still getting used to Janie's lack of mobility and strength while Janie was getting used to her sister telling her to drink water from a blue plastic cup. Janie rolled her eyes and chuckled. Although she could not say it, her bright blue eyes conveyed a combination of annoyance and love.

Much to Janie's dissatisfaction, Roberta was trying to bring reduce chain smoking to a minimum. Janie had been smoking for almost 40 years, and Roberta understood it would be cruel to make her quit now. So they compromised. Roberta got Janie down to five cigarettes a day. That was good enough for her. There was no time for silly fights. Every moment mattered.

The two sisters who up until recently had only seen each other once a year now spent every minute together. Roberta took Janie to the bank and the DMV, everywhere she needed to go to reestablish the things she had lost in the fire. While waiting in the long lines, they laughed and reminisced. Roberta told Janie about her favorite memory of her. One year the carnival came to town and Roberta had spent a lot of time and money trying in vain to win a stuffed animal. She eventually gave up and returned home empty-handed. She cried as she told Janie about her attempts. Seeing this, Janie gathered up every penny she had and walked a mile to the carnival to try and win the stuffed animal for Roberta. Roberta couldn't remember what stuffed animal it was or even if Janie had succeeded, but this was how she would always remember Janie.

Roberta and Janie communicated the most at breakfast and lunch. Janie would choose whichever liquid she wanted and take her medication with, which Roberta would grind it up and put in her applesauce so she could swallow it more easily. While they did this, Roberta browsed through old photo albums and Janie picked out the ones she wanted to have. They would laugh over some of them together including a picture of Janie in high school, all dressed up, sitting on the lawn like a bathing beauty. There was also a picture of their 92-year-old mama, dressed in pink, her favorite color, sitting at the slot machine in Pechanga with a smile and a big thumbs-up.

Mealtime was particularly difficult one Friday afternoon. Janie's breathing had become more labored. Recently, she had been unable to eat solid foods and relied on liquid nutritional supplements. The second neurologist who delivered the news about the ALS to Janie told her she was one of the "lucky" ones because the disease would take her quickly. Roberta wasn't so sure if that was lucky.

Janie sat at the kitchen table waiting for her next meal. Roberta tucked a towel into the collar of Janie's shirt and placed one on her lap to keep the mess to a minimum. Janie's throat had become more constricted, the slow paralysis associated with ALS taking its toll. She often had a hard time keeping everything down. Twenty cans of Ensure, a nutritional meal replacement shake, occupied space in the fridge along with Trader Joe's organic yogurt, Janie's favorite. She had yet to find a flavor she didn't like.

"Ensure? You want a little Ensure?" Roberta asked. Janie gave Roberta a thumbs-up. Grabbing a can from the fridge, Roberta popped the top and handed it to Janie. Janie reached out, her hands adorned with four silver rings, her metallic maroon nail polish still intact from her recent manicure. Janie took it and began to sip. Roberta began to rearrange things in the kitchen to look like she was doing something. She knew Janie liked to do things herself, but that couldn't not keep her from occasionally glancing over at Janie from time to time, making sure she was doing all right. Janie began to cough and drops of Ensure dribbled onto the towel around her neck. Roberta rushed to Janie's side, wiping her mouth with a tissue. "Are you all right, honey? My timing must be off today. Are you gonna shoot for the ceiling?" Janie laughed. Roberta started laughing herself. That was their inside joke. That was how they got through the day.

Laughter was the best remedy. The night before Janie had been sipping cranberry juice and the juice went everywhere. "Good! You almost made the ceiling!" Roberta joked.

Roberta knew she would eventually have to return to Portland but she promised Janie that she was not going anywhere until Janie's new care provider was trained, not only when it came

to Janie's daily routines, but also how to make her laugh or calm her down. One tactic that Roberta devised was to put up a picture of a place Janie would like to be. Currently, a picture of vibrant fuchsia flowers taken on a past trip to Kauai rested against a water bottle on the kitchen table. Whenever Janie became anxious, Roberta told her to look deep into the picture, envision herself there and breathe slowly.

That seemed to work today as Janie continued to sip on her Ensure, her breathing more at ease. Roberta went back to cleaning the kitchen. She noticed the box of chocolate pudding her brother just bought for Janie, picked one up and said, "Janie, would you like a pood-ing cup?" in her best British accent. Not only did Janie love pudding, but she loved the way Roberta asked her if she would like some pudding. She also loved the fact that Ed was considered the "King of Pudding." Janie couldn't get enough. She was laughing and Roberta laughed as she used one hand to wipe Janie's mouth and another to hold her hand.

Roberta knew that she could not stay with Janie forever. She knew that their time was limited. But she had promised Janie that she would not leave until they found the best care-provider possible. Roberta made this promise when Janie wrote in her notepad: "What will I do when you and Ed both go?"

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### **Friday, April 23**

From the time Roberta arrived, Janie had never rung the bell that Roberta kept by her bed. Last night, Janie rang the bell for the first time. She felt like she could not take her next breath. Roberta stayed at Janie's side, propping her back up as high as she could get it. This would help her breathe more easily, Roberta thought. When this didn't help, she put the oxygen on and turned on her brand-new cable t.v. and Janie started to relax a little bit. Eventually she fell asleep and Roberta went back out to her sofa bed in the living room to get some sleep.

A little while later, Janie walked to the living room to wake Roberta up. Again, she could not breathe. She wanted more pills. Janie hit Roberta because she would not give her more. Roberta knew Janie was suffering from extreme pain, but she also knew she couldn't give Janie any more. It would kill her. Janie was already taking eight pills a day.

*I wanna go like Mama did. I wanna go easy. I wanna go peacefully. I wanna go painlessly. Please just let me go,* Janie wrote.

The next morning Roberta said, "Janie, I promised you not another night like last night. So now let's talk. Let's have that talk." Roberta had always let Janie make her own decisions. She had explained to Janie before she moved to San Clemente that she would no longer be in charge of her own medications. She also told Janie that her dog Lacey could not stay because the apartment complex did not allow dogs and that they would try to find a home for Lacey close by so that Janie could visit her. Janie had understood and agreed to all those things. Now Roberta had to comply with Janie's ultimate decision: Janie wanted to go into hospice. She knew she was going to die soon.

"I'm sorry I've been such a bitch," Janie wrote in her notebook.

Roberta drew a big heart with an arrow going through it. She wrote "I love you" inside of the heart.

"I love you, too," Janie wrote.

Roberta picked up the phone and called the doctor to inform him of Janie's decision. She read him the poem that Janie had written about her pain:

*The pain is getting too much God  
I'm so unhappy here. Please  
release from the heartache  
pain and tears,  
I'm only 60 but I've lived  
many lifetimes, before this  
one and this one beats  
them all,  
Pain inflames body soul  
and mind,  
I want to join all those  
that have gone before me  
In heaven with God.*

The doctor knew it was time. He had anticipated this; he was just waiting for Janie. The top priority became tackling Janie's pain so that she would be able to go gently. Roberta thanked the doctor and hung up. She made several more phone calls to notify the family of Janie's decision.

Janie and Roberta sat outside on the patio table. "All the family's coming over tonight," Roberta told Janie. "All the kids. Everybody's going to come to say goodbye, but you will recognize them, you will. For several days you'll still recognize everybody. Everybody will be together and we'll probably be outside and we'll just talk and say what we need to say. Huh, Janie? And write what we need to say, huh?"

Today Janie wrote to Roberta, "Will you stay until I die?"

Roberta had known all along that her days with Janie were numbered, but never did she think it would be less than one month. Roberta had envisioned trips over to the pier, walks along the beach, and a lot of fresh air for Janie.

But the ticking clock in the background had forced Roberta to become practical.

Roberta asked Janie to create a wish list, just like their Mama did before she passed. Janie wore four rings. Two of them would go to her son Shawn and his future girlfriend. The other two would go to her two nieces Erin and Alison.

Part of the wish list included what would be done at Janie's memorial service. Janie wanted the service to be somewhere where you could see the Pacific Ocean. She joked about playing "Blue Hawaii" by Elvis. Roberta and Janie had a good laugh about that one. Janie also wanted "Amazing Grace" and "Ave Maria" because it was played at their mama's service. After rethinking it, Janie told Roberta she really would like Elvis's "Blue Hawaii" after all because it reminded her that her ashes and Lacey's ashes would one day be dispersed over the Pacific Ocean. Janie and Roberta laughed and then they cried. Janie's death had become real.

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**April 26: Day 17**

Janie was in a dreamlike state. Roberta continued administering the hospice medication every hour as usual and Janie's pain had gone down. She kept slipping in and out of consciousness. One of the hospice nurses advised Roberta to place a baby monitor near Janie so that Roberta could listen to her breathing. The hospital bed arrived in the afternoon, but Roberta knew that Janie couldn't feel herself being lifted into it.

Roberta and Don had agreed to alternate shifts to administer Janie's medication. It was Monday morning and Don's shift had ended around 8 a.m. Roberta couldn't remember, but she went to check on Janie at 8:40 a.m. She was still breathing.

Roberta went to check on Janie again at 9 a.m.

"No, no, no," Roberta cried.

She called for Don.

Janie was gone.

Roberta did not have time to dwell. She had to continue to do what she thought was best for Janie. In life it was advising her not to smoke too much, reminding her to drink water, telling her jokes to lift her spirits. Now in death, Roberta needed to prepare Janie's body. She knew Janie was extremely private and would not want anyone to see her in this state. Janie always insisted on bathing herself. Roberta needed to continue honoring Janie's wishes even now, even when Janie no longer had a say. Roberta called the Omega society to come and pick up Janie's body for cremation. She called the older of her two nieces, Erin because she could not do this alone.

Roberta and Erin worked quickly to change Janie's diaper because Janie had not wanted a catheter. They began changing Janie into a new nightgown so she would look fresh and clean when the hospice nurses arrived.

Roberta and Erin turned Janie over. Suddenly, black bile came out of Janie's mouth. They both gagged. Roberta stopped herself from vomiting. She knew she had to clean Janie up. There were so many things she had to do before the hospice nurses arrived. Janie would not want them to see her like this, Roberta kept reminding herself. She would not want them to undress her. She would want them to see her clean.

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## **Saturday, May 1**

There was one more thing Roberta needed to do for her sister. Janie's memorial service took place on a sunny Saturday afternoon on May 1 at Linda Lane Park in San Clemente, overlooking the ocean. Three tables displayed flowers, pictures of Janie, and Janie's framed artwork. Her ashes stood in a floral floral urn that Don had picked out. From the ribbons, tablecloth and urn to the Pacific Ocean and the cloudless sky to the hint of blue that Don and Roberta wore in their clothing, Janie would have been happy to know her favorite color radiated everywhere. "Ave Maria" and "Amazing Grace" played from the speakers. And of course, as Janie had requested, Elvis's "Blue Hawaii." Roberta had kept her promise.

Distance, age and time had forced Janie and Roberta to grow apart. Yet those things no longer mattered when Roberta found out that Janie was going to die. Every day could have been Janie's last. So Roberta cared for Janie without hesitation and found strength in herself she never

knew she had. Roberta had no regrets because she knew that she had said everything she needed to. Janie was finally at peace, and in many ways, so was Roberta.

Like Janie, Don was also a very private person yet he cried openly as he talked about the sadness of Janie's death and the comfort in knowing she was finally at peace. Janie's nieces talked about how their aunt never forgot their birthdays and always gifted them with a little something every year. Roberta spoke about her time spent with Janie in her eulogy, which she called "17 Days with Janie," its title a vivid reminder and tangible measurement of just how short their time together had lasted.



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