

honorable mention, non-fiction

Never Mind the Lights, Where Are the Cabinets in this House--

Snowbound for the Weekend with John, my Dying Friend

by Aundrea

My friend John had been diagnosed with AIDS for almost two years when I got the frantic telephone call. John still had some use of his right side which had been damaged by small seizures.

"Please come," said John, "Nobody ever comes to see me any more, they only come to see Bill. And nobody will take me anywhere."

"Please come," said Bill, "all I want to do is sleep through the night and know there is somebody in the house I trust to do stuff for John."

"Are y'all having too much togetherness?" I asked, and they both laughed.

The plan was that Bill would pick me up at the Denver airport. I was perfectly capable of taking a cab or an airport shuttle to their house, but Bill needed a chance to acquaint me with how John's illness had affected him so far. We also hoped to have time to go over what tasks I would be performing for John as well as familiarizing me with the kitchen. I wanted, for example, to separate the cans of soup John liked from the ones he did not like so that as a blind person, I would not get them mixed up.

No such luck. On the way to Bill and John's house from the airport, two of the tires blew out on Bill's van, and we had to walk to a nearby church and get a ride from one of its members. We were so late getting home that Bill's next priority was how he could get to work with no car. "Bill honey," I exclaimed, "do what blind people do when the buses have quit running. Call a cab."

The few instructions that I got were delivered on Bill's way out the door. I had written down a number of phone numbers in Braille: Bill's work phone number, the phone number of the couple who lived across the street, the car phone of a friend who drove a cab, John's doctor, and the handicapped ride service which transported people in wheelchairs since John was now in one. "Here's the cordless phone," Bill said before leaving. don't hesitate to call me at work if you need anything. John can show you which of his medicines he needs to take and he knows when to take them. He just can't open the bottles by himself any more. Don't worry if he wants to come downstairs. It takes him forever, but he can still do it. We're probably going to move him down here pretty soon. Oh, and don't worry about him if he gets a chill. He'll make the bed shake, then sleep for hours. I told him which bedroom your luggage is in. See you later. Thanks, sweetie, I don't know what I'd do without you. I'll be back in the morning."

I assured him everything would be okay, but something told me that it would be several days before Bill would get to come home, and that this weekend would be filled with hard and exasperating work, along with wonder and warm memories. When I went back upstairs to check on John, he asked me if I would

bring him some orange drink so he would have something to drink during the night. He described the pitcher in the ice box, as well as how the orange drink tasted.

I asked Katie, the old golden retriever, if she had to go to the bathroom. I remembered that only some of the outside doors led into the fenced yard. I was not sure which ones these were and, of course, could not see the fence. I had my second dog guide, Rita, with me. Both dogs had to go and I turned them out of the door Katie had gone to, all the while hoping she had chosen the one leading to the fenced yard. I could have gone outside and explored but I didn't feel like putting my coat on again.

I found the correct pitcher in the icebox and was also relieved to find luncheon meat, cheese, and a pound of ground round for the next day. I set the pitcher on the butcher block in the middle of the kitchen, let the dogs in, and began looking for the glasses.

John, Bill, and I had a standing joke that they always remodeled the house just before I came. We're talking about a house with four living areas and a half-bath downstairs, two separate staircases, and four bedrooms and two bathrooms upstairs. That doesn't include the closets and basement. This time, however, I had been reassured that nothing major had been done to the house since my last visit. It had been several years since I had been there. Using the sound of the icebox motor, I walked to where I thought I remembered the sink being located. No sink, but I made a note to myself after sticking my hand in something greasy on the top of the stove, that if I got a chance I would at least do some cleaning.

After I found the sink, I reached above it to get glasses. I encountered only a wall. This seemed to me to be a waste of space, but I moved to where the dish washer was and reached above it to get glasses. More wall. I tried several more areas and encountered more wall. No cabinets. "Never mind the lights," I grumbled, "Where in the hell are the cabinets in this house?" It was then that the enormity of my plight hit me. There was a man upstairs who was almost half paralyzed. Though he could help with many tasks, he could no longer do anything completely on his own.

And I knew as sure as God grew little green apples, that Bill was NOT going to be back the next morning. Denver was in the middle of one of its worst snow storms. You are not," I told myself, Going to call Bill at work and ask him where the cabinets are in this damn house. You are going to handle things, that's what Texas women do.

I turned my back to the sink and leaned against it. Then in my mind, I sniffed just for one breath, I thought I smelled fresh paint. In my mind, John and Bill were standing in the middle of the kitchen with some other men. I could not hear what they were saying, but I realized they were pointing over my head.

I jumped away from the sink and began frantically opening all the lower cabinets - I knew where those were - until I found what I was looking for - a step stool hidden, of course, in the back of the pantry. I ran with my treasure back to the sink area, but I already knew what I would find. I had to stand on the top step of the step stool, but there they were, the cabinets. And they even had things you would expect to see in kitchen cabinets like plates, glasses, coffee cups, and serving bowls of different sizes. It was only

then that I realized that the dishwasher was warm, as if it had just cycled. There were clean dishes in it that I could actually reach and would actually be able to use. I know it is a "female thing" but I was so happy about having gotten some control of the kitchen that I hugged and kissed the dogs until they were hysterical with joy. I put most of the dishes up in the Cabinets, but I left some of them on the counter so I could reach them more easily.

I poured John the orange drink that he liked but which I thought tasted nasty and placed a few slices of cheese and some crackers on a saucer. I ate a quick sandwich and took John's snack up to him. He was having a chill and shivering to beat the band, so I knew he couldn't tell me where my luggage was. I left his room, making sure beforehand that he could reach the call bell.

As it turned out, locating my luggage was a piece of cake compared to finding the cabinets. She had already eaten, but I thought my dog guide might want a bedtime snack. "Rita, honey, I said, "do you want a milk bone?" Rita guided me out of John's bedroom and walked straight to the room where Bill had put my luggage and laid her head on my suitcase, wagging her tail and waiting for her snack. After giving my dog her treat, I climbed into my warmest pajamas, leaving the door opened in case John needed anything. Then I fell into an exhausted sleep.

I got up twice in the night to check on John. I had planned to turn him to help avoid bed sores, but he murmured that he didn't want to be moved at all, much less turned.

Although I am a light sleeper and wake up easily, it takes a keg of dynamite to get me out of bed at any time, especially in the morning. How I have made it to work for ten years, I will never know.

On this particular morning, I was actually the first to get up. For those of you reading this who know me, this is NOT a misprint; I really WAS the first one up. I was persuaded to do so by two warm dog tongues and two cold dog noses reminding me that it was time to be let out.

Before going downstairs, I began the arduous process of waking John up. I knew that once he was awake, he would want to get up. However, it was very hard to wake John up in the first place. He muttered sleepily that breakfast would be nice, and he didn't have any preferences. Being an AIDS patient, he didn't have much of an appetite. Since John didn't have much of a preference, I decided to fix what I wanted. I chose scrambled eggs and bacon.

I found a skillet, put the bacon into it and lit the burner. didn't know which knob turned on which burner, so I had to hold my hand over the burner and feel for the heat while I turned the various knobs. Then I placed a small lid on top of the bacon. I did not use the regular lid to the skillet. I wanted something smaller that would lay right on top of the bacon and keep it flat so the bacon would not have to be turned. Turning bacon, which likes to wrinkle up on itself, can be quite a challenge for a blind cook. When I thought the timing and the smell were right, I removed the lid from the skillet. I had found a pair of tongs, and I used them first to determine crispness - I like my bacon crunchy - and then to remove the bacon. I scrambled the eggs, served the plates, poured John a glass of milk and took everything upstairs. Then I ran back downstairs to make coffee.

I finally found two mugs, larger than I needed, but for the life of me, I could not figure out how to operate the coffee maker. There were no holes at the top into which to pour water, and the pot was so huge that even if there had been, I doubted if I could have picked it up to pour. This is a stupid coffee maker, I thought to myself. I finally gave up and looked in the pantry, where cans and packages of noodles were stacked precariously. There, sitting all by itself in the front row of cans was a treasure, canned, flavored instant coffee. Those cans have a very distinctive shape, but just to be sure, I removed the lid and used my finger to taste it. Thank you, God. I heated up water in the microwave, stirred the coffee in, and carried everything upstairs by using the edges of my plate on which to balance the mugs.

Just before I went upstairs, Bill called to tell me what I already knew, that he was snowed in at work and would not be home that day and probably not that night. On the phone, Bill was effusive. "I don't know what I would do if you weren't there."

"You'd call somebody else to come over," I said.

"Who?" he asked, "everybody else is snowed in, too."

"Don't worry, honey," I said. "I'll handle it."

"Oh, hey," Bill said just as I was going to hang up, "I forgot to tell you last night, we didn't remodel the kitchen but we did raise the cabinets to our eye level."

"That has to be a "guy thing," I said, and we laughed as we hung up the phone.

When I hung up, I felt a strange peace because I knew I would handle it. For one thing, I had every phone number in Denver that I could possibly need for this situation. I had, after all, found the cabinets. I felt like I was on a roll.

After breakfast, John and I laid around for a while talking about my work in child support. He read some of the newspaper out loud to me, talked to friends on the phone, and then helped me get him dressed. He could help with most tasks but was unable to perform any of them independently because of the weakness on his right side.

Then he decided to go downstairs for a while. I was secretly glad because I had lots of questions about all those cans in the pantry, like what were they?

I was terribly nervous watching John walk slowly down the winding staircase, limping and almost dragging his right leg but still using it as much as he could. I made it my job to keep the dogs out of his way. I also determined to keep myself out of the way. I hate to be hovered over myself, and I am too little to be of any assistance catching someone who is falling. I weighed about 95 pounds then and I am 4 feet, 10 inches tall.

So I took the dogs in the kitchen and busied myself with the dishes, still keeping an ear on the stairs. I made it a point not to sigh with relief when John sat down at the kitchen table. The trip downstairs had tired John. I offered hot chocolate topped off with a healthy shot of Bailey's Irish Cream, more so that

John could sit and rest but still be doing something so he could save face and not have to admit to me how tired he was.

After he had rested awhile, John began exploring the pantry. "Oh," he would exclaim, "I didn't keep this in there when I did the shopping." We set all the single-serving cans of soup that we liked on the butcher block and I got a pound of hamburger out to thaw for supper. I got sandwich makings out for lunch.

John and Bill had all kinds of food I had never tasted, including many kinds of mustard. John enjoyed letting me taste the end of the knife so I could make my choice. He also told me what was in their very well-stocked bar, and I removed the Bailey's Irish Cream, the Old Smugglers scotch, and some German wine.

When I suggested John start making his way upstairs while I fixed lunch, there was obvious relief in his voice. I was right; he was beginning to run out of energy again. I listened with my heart in my mouth while he dragged his right side laboriously back up the stairs. By the time I had made the sandwiches, he had only reached the first landing. I determined not to cry or hover. I cut his sandwich in half and wrapped it in saran wrap, in case he wanted to rest before eating, and got us some chips and drinks. I took my time wiping off the counters and loading the breakfast dishes in the dishwasher. I washed the skillet I had cooked the bacon in by hand since it was iron and dried it well. I let the dogs out then back in. Finally, I realized John had made it up to his room.

Don't you dare cry, I told myself while I gathered up the lunch so I could take it upstairs. More than embarrassing John, I was afraid I would never stop.

When I got upstairs, John was sitting on the edge of the bed waiting for me to help him ly down. After I got him into bed, I wiped his face and neck with a cold, wet rag. I ate my sandwich hurriedly so I would be available if John wanted anything, but he lay in bed just resting before he ate his. I was glad I had wrapped his up.

After he ate, John fell into an exhausted sleep. Even before he became ill, John was a very heavy sleeper. I went into my bedroom to listen to an audio book, knowing he would sleep for awhile. I drifted off to sleep and was suddenly jerked awake as if I was having a falling dream. I went immediately into John's room, though I hadn't been summoned by the call bell. When I had left him, there had been a very peaceful feeling in the room. Now there was tension in the air the way there is when you have the feeling your boss is about to say something bad to you.

What?" I yawned.

There was a pause. "I peed," he explained.

I knew better than to fuss over him. Years before this incident took place when we were still living in Houston, I had gotten a big stain on the back of my jeans while we were out somewhere. When we had gotten back to my apartment, John was very mater-of-fact. "If you will take those jeans off now I'll spray some stuff on them so the stain won't set in when you wash them," he had said.

I rubbed noses with him and purred, "Does that mean I get to take your jeans off you?" We both laughed.

And so began the process of changing his jeans. I had helped him dress that morning, but it's easier to help someone dress when they are up and helping than it is to undress someone who is too tired to do anything but lie in bed. Usually he could get to the bathroom okay, but when he was very tired, his bladder muscles couldn't wait. But although I had teased him about changing his jeans the first time, after changing him out of four pairs of jeans on the big, sloshy water-bed, I began to get seriously tired myself, and I knew he was. "Why don't you take a nap while I fix supper," I suggested. "If you put your catheter on, you won't have to worry about your jeans while I'm downstairs. This is your last clean pair. I'll go wash the others while I'm fixing supper."

Since he had full use of his left hand and partial use of his right, he could do most of the catheter task himself. At that time, John was occasionally wearing an external catheter which fits over the penis, not the type in which a tube has to be introduced internally. So he only needed my assistance with hanging and hooking up the bed bag. John hated using his catheter because it was uncomfortable, and because it symbolized his growing physical deterioration.

I carried John's heavy, wet jeans down to the basement where the washing machine was. I chose the water temperature I wanted by holding my hand where the water sprayed out and turning the temperature selector until I got warm water, not hot. I fixed hamburger meat casserole with noodles, tasting and smelling the spices in the spice rack till I found the ones I wanted. I chopped up onions, celery and green peppers and added cream of mushroom and cream of celery soup that John and I had picked out that morning. I found sour cream in the ice box and added that at the last minute. I heated up canned green beans, tossed a salad which I put in separate bowls and began taking supper upstairs. John was sleeping, but the smell woke him up. After he ate, he went back to sleep and didn't wake up till the next day. Our morning routine was only different in that John did not go downstairs. We had fruit and cereal for breakfast and generally just lounged around. I fixed soup for lunch and fed John as I had the night before. John was right-handed, and his right side was very weak.

That afternoon, we watched "The Princess Bride". Even though he was tired, John described all the action for me. I have not been able to watch that movie since. We had not seen Bill for two days and two nights.

Bill did come home that night, but just long enough to take a shower and change clothes. Someone with some sort of all terrain vehicle was picking him up to take him back to work. "Uh, oh," John exclaimed while Bill was dressing for work, "My catheter leaked."

"Shit," I grumbled. I was truly beginning to be tired by then, and exhaustion was getting the better of me.

"No, Aundrea," John said, "pee," I had to laugh in spite of myself.

I wanted to put John in a chair and wash the water bed sheets, but both men objected. For one thing, John was too tired to sit up that long. They also protested that the sheets and comforters were too heavy for me to manage when wet.

So, I began moving John to the other side of the huge king sized water bed. I could not simply roll him because he would have become entangled in the catheter tube. Bill had showed me how to fix the catheter leak and had already emptied the bag. I first moved the pillows against which John was reclining, Then I moved the upper half of his 6 foot 2 inch body toward the pillows. I moved his hips over and then his legs. It was like trying to move someone across a big bowl of jello. It took me four tries to get him all the way to the other side of the bed. "Aundrea," asked Bill, "would you let me know ahead of time when y'all are going to do this again so I can sell tickets?"

After I finally finished laughing I said, "If you think this was good just wait until tomorrow when I get John in and out of the big bathtub." Bill left the house screaming with laughter.

After Bill left again to go back to work, I brought the bottle of Bailey's upstairs with a bucket full of ice and our glasses, along with some cheese and crackers so John could have a snack later while taking his medications. I was beginning to think constantly about minimizing the number of trips up and down the winding stairs. Stairs are not a danger to me as a blind person. I grew up at the Texas School for the Blind running up and down the stairs in my dorm and sliding down the banisters. However, I was not only becoming physically tired, but I was also beginning to tire from the emotional stress of knowing that this might be the last weekend I would ever spend with John. My heart ached as I realized that although this was January of 1989, John would probably not live to see January of 1990.

When I got back upstairs with the Bailey's and all the other goodies, I realized the atmosphere in the room had changed again, and I knew it didn't have anything to do with pee this time. There was a heavy sadness in the room which had not been there before Bill left the house. I knew immediately what to ask.

"What do you want me to do afterwards?" I asked. In previous phone conversations, we had already established that "afterwards" meant after John's death.

"I was just thinking about that," John replied. So we had a very open and detailed discussion about the party that would occur after his death. We decided what music I would sing and other essentials such as who would bring which kinds of food. "I want it very loud and rowdy," he asserted. When the time came, We did our best.

The next day Bill was finally able to come home from work, but he was too tired to sell the tickets he had teased me about. We changed the sheets this time. He took all the sheets, comforters, blankets and bedspreads off the bed and got the wash started. The comforters were almost too heavy for me to lift while dry. Some big, healthy male or female person would have to get those things into the drier, but it wouldn't be me. Now it was time for John's bath.

While I had been packing to go to 20 degree below zero Denver, I had seen a picture in my head of my bathing suit lying in my bottom drawer. I packed it, having no idea why I would need it. I knew why when the bath began.

I was not big enough to pick John up and plop him in the bathtub as Bill did, so I had him stand on his good leg while I lifted the other one in. Using the water to absorb his weight, I got in the tub and allowed him to hang on around my neck while he transferred his weight to his weak side and stepped in with his good leg. I had put my bathing suit on while I was running the water. We sat in the tub together talking for a while, then I washed him all over including his hair. I was also careful about rinsing him for fear that if I left soap on him he might get some kind of horrible rash because of his weakened immune system. I dried him while he was in the bathtub on the premise that it would be easier for me to help get him out. It never occurred to me that I might drop him. For one thing, John was my friend and my age; for another, although his right side was pretty weak, he could still bear some weight on it. Fortunately, I got him out of the tub without mishap.

To my knowledge, that was the last time John got to take a bath in the big bathtub upstairs. Shortly after I left to go back to Houston and my job at child support, he moved to one of the downstairs bedrooms.

The next day Bill and I took John for a blood transfusion which always made him feel better. At his request we stopped on the way home at a store that sold books and crystals. John bought me a pair of crystal earrings which I still wear today, and I learned later that he had instructed bill to give me his chain with the crystal, which he had always worn until his death.

After we got home from the bookstore we had a conversation which was very empowering to me, "How much would you need to live on to stay up here as a secondary caregiver until John dies?" they asked.

I went back to Houston prepared to take a leave of absence from child support and move up to Denver to stay till John died. I was devastated when I learned that my employer would not guarantee that I would have a job when I moved back to Houston. I was also angry to admit that had I been sighted I would have just said, "Fine, I'm quitting. Maybe I'll just move to Denver for good." However, as a blind person, I didn't know if anybody else would hire me either in Houston or Denver. I let fear override my heart, and I still feel badly about it.

People who are alcoholics or who have abused drugs tell me that staying "clean and sober" is a battle that must be fought every day. For those of us with disabilities, maintaining high self esteem is a daily battle. Things are changing, but there is still a great gap between the capacities of those of us with disabilities and society's perception of our true worth. I have been truly blessed with the necessity and opportunity to fulfill the needs of other people. Need is the greatest tribute society can pay someone with a disability, and I am honored to have had my share of the opportunity to fulfill the needs of other people--my coworkers' needs as well as those of people who are dying.

John died in August of 1989. Bill has found a new partner and he and I still see each other often. I think of John when I plan parties or participate in any activity in which I delegate tasks, as John was a born



supervisor. I think of him often with love and laughter, and cherish the memories I have of the warmth and solidarity of his friendship.