



PHYLLIS LANGTON

WAITING

—Dedicated to Gentleman George

It is October of 2000, and George's appointment with the neurologist falls on Friday the 13th. On that ominous date, we sit in the neurologist's office as he tells us the news. "George," he says, "I think you have a motor neuron disease, ALS, commonly referred to as Lou Gehrig's disease. It causes rapid deterioration of voluntary muscle activity. You probably have six months to live. Go out and have a good time; do all the fun things you've wanted to do and haven't done, while you can still do them. The only treatment is a drug, Rilutek, which may extend your life another month, though it does have potential side effects, such as liver and kidney damage. Before you start it, I need to do multiple tests and extensive blood work. You should consider the drug. Come back and see me in a week."

I am devastated. I drop my purse on the floor when George answers him. "You tell me I have six months to live, but if I take a drug that involves more tests and possible liver damage, I may live another month or two, with a lousy quality of life. What the hell nonsense is that? My liver is working just fine, and it will stay that way until I die. I see no reason to return. Thank you."

George stand ups and prepares to leave. I watch his face and can see his lips drawn tight in a thin line that I recognize as controlled anger. His pupils are fixed. I know he has shut down and isn't going to listen, or negotiate anything. I hold his arm as we leave the office.

He has just been given a death sentence, and I am scared he might fall on the way to the car. He has been falling more often lately. When we approach the car he says, "Well, I guess I know what's going to be on my death certificate. That's more than you can say." He pats my arm as if to reassure me. With the wit, courage, and strength of that moment, he sets the tone for the journey we will travel.

It is now October 2002, two years later. The wicked disease is relentlessly devouring his body, eating its way through arm and leg muscles, and making its way toward the diaphragm muscle he must use to breathe. Just when his body adjusts to one change, without warning, he falls to another plateau.

And yet George is brave. He is also stoic, and gentlemanly, having been born in the 1920s in a polite community in New Jersey at a time when children hid their feelings and were to be seen and not heard. As for me, I am strong too, but I'm a scrappy fighter, with noisy, impish tendencies—a graduate of a Boston orphanage where I was dumped in the Great Depression of the early 1930s.

But while we are polar opposites on the surface, under the skin we're the same. We always manage to work through any disagreements, such as when he is cranky and stubborn when I use the handicapped parking spaces. He tells me to park some other place, or he'll stay in the car. He doesn't want to be viewed as a "cripple."

I try tough love, saying that he can sit in the car and enjoy his stubbornness if he doesn't want to help me with the necessary errands, or get out to enjoy the first sunny day in two weeks. Then I add, "There's nothing to be embarrassed about. You have this lousy disease and unfortunately you're dying, but you're just human." As I start to get out of the car he mutters, "OK, woman, get me out of here."

I reach over and hug him, run to the back of the car and pull out the lightweight leather transport wheelchair that I can throw in the back of the car when he has to walk any distance, or in the house when he is tired. After two severe falls, I insist we use the wheelchair in public. This is our compromise, as he objects to a heavy, battery-operated wheelchair that he sees as useless; he can't control his lifeless arms and fingers.

After dinner one evening in July, after we have finished watching the Wimbledon tennis finals in the family room, he is especially quiet. Tennis was always such an important part of our lives together and with our friends. We are feeling a little weepy as we joke about the fact that I still play for him in his men's groups, using his god-awful heavy racket, so that he is still "on the court" with his buddies. He watches from the balcony of the indoor tennis facility, and his friends tease him at dinner, telling him I am prettier and faster than he. On the way home he remarks how different the

game looks when he's sitting on the bench, as he coaches me on their playing strategies.

As I finish cleaning up the kitchen, I ask him to tell me about some of his greatest frustrations so far during this journey. He doesn't answer. I wonder if he's heard me since he doesn't wear his hearing aid anymore. Or perhaps he's gone to sleep.

Finally, he says, "I'm tired of waiting."

"Waiting? For what?" I ask.

"That could take all night. There's just too much to say."

"Well, I have all night. Let's talk about it."

I prepare him a hot toddy with his favorite Bushmills Irish whiskey, which is his only pain medicine, and a glass of pinot noir wine for me. I lift him from the wheelchair, tuck him into his favorite black leather chair, and cover his legs with a light, summer blanket, as his legs get cold and painful now when he sits for more than an hour. I place his drink on the cherry end table next to his chair so he can bend down and sip it from a long glass straw, without my help. I know this pleases him because he winks at me as he sips his drink.

We talk for more than an hour, with our eyes tearing up in pain and tender laughter. It is the first time he shares what it means to him to wait for each moment of living—and dying. George says:

"When I wake up, I wait to see if my eyes are getting worse and if I can move my head, arms, or legs. My eyes don't focus like they used to, and each day I can move less. I look back six months, three months and see what I have lost.

"I wait to see if I can still whistle. I worry that I won't be able to call you when I need you, if I lose my whistle. We joke that this is the only time I can get away with whistling for you without getting a shoe thrown at me.

"I wait for your smile.

"I wait for you to get me out of bed into the wheelchair; lift me out of the wheelchair onto the bidet; and then close the bathroom door and let me sit a few minutes, alone for a few minutes. You tell me it's time for bowel movements with Beethoven, as you turn on the Bose music system. You add that you would love to smell some sweet-smelling shit when you come back. You tease me and tell me there are no bowel movements in heaven and that's why all you men want to go there.

"I wait for you to get me back into my wheelchair, wash my hands