SICK PEOPLE DON'T EXIST AT THE PROM
(AND OTHER LETTERS TO A FATHER FROM HIS DAUGHTER)

An Honors Thesis (HONRS 499)
by
Barbara L. Warner

Thesis Director

Daryl B. Adrian
Professor of English

Ball State University
Muncie, Indiana

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What is it that has two parents --
One providing the seed,
The other, from its womb born,
Yet, has only a mother?

Answer: Me

Prologue

I always loved those tricky riddles in elementary and middle school. You know the kind -- where the answer is actually pretty obvious, but you make it a lot harder on yourself than you really should. Maybe I liked them so much because I figured out, somewhere along the line, that my life was a riddle, too. Because you see, I am a bit of an oddity and a riddle. I am here, so I have to have been fathered. And I am a daughter, fathered, but without a father. And -- here comes the tricky part -- my father is still living (if some people choose to call it that).

And just to make the whole thing even more confusing, consider this: my parents are not divorced, and my father did not desert me or my family.

My father is a victim. He is a victim of a disease which I have finally learned to spell and pronounce after 25 years of exposure to it: multiple sclerosis (it's always the second word that gets me). He has been very sick for a very long time -- over 20 years (do the math -- that's most of my life), and has gotten progressively worse throughout the years. For a long time he has been living in a nursing home and is completely dependent on others for his life. And he is completely dependent on me and my family to keep him going, reminding him constantly of where he's been, who he's known, what he enjoys, what he detests, and finally, and I have to tell you, most heartbreakingly, who WE are.

That's where I come in. I'm my father's youngest. Usually a pretty good position for a girl, but a pretty poor one in my case, because you see, as my father's memory got worse, along with the rest of his functioning abilities, he had less and less room in his mind to remember. Since I came along last, when his disease was much worse than it had been at the times of my two sisters' births, he had very little room for me. And what nobody but ME seems to understand is that the part that did contain me is nearly gone.

That's where this journey comes into play. I want my dad to know me. To know my quirks, my likes and dislikes, the way I feel inside. And the only road there is to be honest. To honestly tell him what it's been like being his daughter these past 25 years.
I hope to find my dad in this journey. I want to find him, peeking over the covers, as he tucks me in. I want to find him smiling proudly as I get my first hit in softball. I hope to see him, camera in hand, as I go out to my first dance. And, oh, Dad, I want you to be there when that organ music starts and I need a strong arm to lean on and a strong voice to give me away.

But I'll settle for a look of recognition in your eyes. Dad, when I walk into your nursing home room, and smile down at you, lying in your bed. I'll take that glimmer that says, "That's Barbie. She's my daughter."

Please forgive me, Dad. I don't really know you, but I love you.

And whatever you do, Dad, know that I think of you.

(Please, God, let him think of me, too.)
August 5, 1989

Dear Dad,

When I woke up this morning, it was raining. Not just a little drizzle or a light sprinkling. It was pouring, Dad. Thunder and lightning -- the whole bit. It really upset me because I thought that if it were raining, nobody would want to come to my wedding. Not that I cared if a bunch of people showed up -- I'd still get married anyway. It's just that you hate to see fruit kabobs for 250 people go to waste. Then I thought about you, Dad. I knew you weren't going to be there, even if it were a balmy 80 degrees with no clouds in the sky, you weren't going to be there.

And that made me sort of sad, Dad. Today's a big day in my life. It ranks third on the stress level scale. All my family and friends are going to be there. Some of them are people you haven't even met, but I know you would be there for me if you could.

Actually, Dad, I'd like to take back that last part. I would like to think that you would be there if you could -- because you really wanted to be there. Mom keeps telling me it's true. But is it true, Dad? I mean, do you really care that I'm getting married today? Do you even remember who I am? I'm the youngest of your three daughters, Dad. That "oops" that came along when Mom was trying to raise two kids, support a family, and help you through your newly diagnosed illness. Yeah, the SURPRISE curve ball that God threw you because he didn't think you had enough to do or worry about.

Anyway, if you do remember me, Dad, I would like to think that you would have wanted to be there for me today. To walk me down the aisle. Dave's going to do it. Not that I don't like Dave. He's always been more like a brother-in-law to me -- you know that. At least I think you do. He's Laurie's husband, remember? The blonde one who used to help you and your wheelchair get over the doorstep and into the living room for Christmas? Well, he's going to be my escort. It's just that he's a little shorter than me when I have my veil on. You were taller than he is, Dad. At least, once upon a time.

Well, I guess I need to get ready to go to the church. I just wanted to take this time out to let you know that I did think about you today, Dad. I know that you would be thinking about me, too, if you remembered that today was my wedding day. Or if you remembered who I was. But I did think about you today, Dad. And I want you to know that I really do wish you were going to be the one walking me down the aisle and giving me away to Brian. I wish you were going to be there to pat my hand and hold me possessively during our dance at the reception, and warn Brian to take good care of me. I mean, I know Mom will warn him, but it's different
coming from a man. I guess it scares them a little more, huh? I think it’s going to be a good day, Dad. A long day, but a good one. Please think about me. Please remember.
Dear Dad,

It was good to see you yesterday, Dad. I’m glad we got a chance to stop by the nursing home and show you how “dressed-up” we looked on our way out of town. It really made me feel good to see you get so emotional when you saw me, except I know that you get that emotional a lot of the time. Even when Mom comes by to feed you lunch and dinner every day. And you see her all of the time, but I told myself that those were different tears coming out of your eyes. Those weren’t just multiple sclerosis-induced tears that make you cry about everything, for no reason at all. Those were “I can’t believe my youngest daughter has gotten married” tears. Those were my tears — reserved for my special day.

Brian is driving and we got a late start getting on the road to Maine. I think he’s getting sort of tired, but we’re still so excited from yesterday that it’s hard to get down. We’re going to be gone for ten days, Dad. Then it’s back to school once again. I’m sitting out this first semester and substitute teaching while Brian finishes up. He’s graduating in December, Dad. He’s going to be an electrical engineer. Mom is so proud of him — you would think he was the son and I was the daughter-in-law. Why not? He’s the first member of our family to graduate from college and he married in!

I felt sort of guilty yesterday, Dad. I know that people were talking about you and wondering where you were. Especially people on Brian’s side, who don’t know that you can’t even control your bladder anymore, let alone escort your daughter down the aisle. And I felt guilty when I saw Mom sitting alone in that first pew. I mean, you were able to attend Linda’s and Laura’s weddings, so at least she wasn’t completely alone. But when Dave and I were walking up the aisle, I could tell she felt alone. She hates being the center of attention, you know that.

But I probably felt the most guilty because I really was able to enjoy myself at the reception. I mean I was scared that the DJ would forget and call for the traditional “Father’s Dance,” but he didn’t. I looked around yesterday and saw Mom talking with friends and enjoying herself and everyone was dressed up and looked happy and healthy and a big part of me was glad that you weren’t there.

It’s just that people don’t understand, Dad. They get really sickened when they see a catheter bag dripping urine (on a good day — urine and blood on one of your bad days). And they wouldn’t understand it when you started one of your really loud crying jags. Or started choking because the food wasn’t cut up enough or soft enough. It’s nothing personal, Dad. Really. They just don’t understand. They haven’t lived with it like we have for the past 20-odd years. I guess I’m more used to it now. Except I guess I’m still not
completely comfortable with it, huh? That's probably what your're thinking. Well, maybe your're right, Dad. Maybe I'm not comfortable with it yet. But I still think about you, Dad. I still do wish somehow you could have been there to see the flowers and hear the organ and smell the burning candles. It was really beautiful, Dad.

Thanks for crying when you saw me. Please remember me.
March 7, 1991

Dear Dad,

I got a call from the Social Security office today. Did you know that I still hadn't changed my social security number over to my married name until just this week? Isn't that awful? I've been married for a year and a half! But we need to get our taxes mailed in and I got a nice note from them last year telling me I needed to get it changed. But the office called me today because they have a conflict in my original birthdate when you and Mom filed the number for me in 1973.

Apparently, someone made a typographical error and listed my birthdate as 12/25/57! That would only make me 33 years old! So I have to take in my birth certificate to prove my real birthdate is 12/26/57. I just love red tape. You know, that phone call got me thinking, Dad. It got me thinking about when I was a little kid. I mean, I had a social security number before anyone else my age because I drew money from it due to your disability. So, indirectly, it made me think about you. And me. And us together.

Do you remember much about my childhood, Dad? I do. I remember going to the fair on Kid's Day (which was always a Wednesday). And usually Linda or Laura would take me because Mom was always working, running the nursing home, and you couldn't do anything. You just sat around a lot, that great big metal walker in front of you. And you watched "The Price is Right," and you argued with the television when one of the contestants bid too high or too low.

I remember one time, when I was about four or five, and you could barely even drag your legs behind that walker, and your arm strength was so poor that you could hardly hold up your torso to pull yourself along the floor. I remember standing on the end of our long couch and using your walker like a gymnastic bar, trying to hold myself up on the handles, like I had seen you do. And you laughed and told me to try harder. And I kept trying and you kept laughing. You looked nice and warm in your plaid flannel shirt. Your blue eyes weren't glazed over then, and I could see my fun reflected in them. Then I did it. I pulled myself up and balanced myself on your walker. And you got quiet then, Dad. You stopped laughing and you turned back to "The Price is Right," and you got quiet. I didn't know why. I wanted you to laugh at me again and smile at me and pay attention to me. But you just watched the television.

Now that I look back, I realize that I had done what you could no longer do. When I was a baby -- a baby with spindly limbs and a soft spot that needed to be protected, and wobbly legs and arms -- we were equals. You still could do more than I could and you were stronger. I looked up at you as you would walk past, "clumping" the shag carpet with your walker. But now I could hold myself up and you couldn't.
I was passing you by. Just like Laura had done, and Linda before her. I was your last hope, your last chance to be stronger andabler than someone else. But I passed you by like you were some hitchhiker on the interstate and I looked at you in my reareview mirror and said, "Eat my dust, Dad. I’ve got things to see, people to meet, places to walk and run. It’s just a matter of time, Dad."

No wonder Bob Barker was more appealing, huh, Dad?

I wanted your attention so badly back then, Dad. I really did. And I couldn’t understand why you would get so quiet and solemn and you would curse so loudly when you would jump into things. I didn’t understand why you had to lean on that piece of metal to get around when the rest of us didn’t. And nobody really explained it to me, either. I just lived like that.

Well, Dad, that’s enough for tonight. You are still in my mind and I am still in yours, I hope. I will write you again soon. Remember me.
March 8, 1991

Dear Dad,

Yesterday's letter got me thinking about the time when Laura got her braces. Do you remember that one? We had to drive to her orthodontist in Fort Wayne and we were all together. I must have only been six or seven years old and I was so excited to go to Fort Wayne. It always seemed like such a big city.

But one of the real reasons I was excited was because we were going to Azar's to eat after her appointment. They had spaghetti at Azar's and that was my favorite. Isn't that funny? It still is my favorite. Anyway, do you remember what happened when we got to the restaurant?

I remember you getting out of the car and hanging on Linda and Laura to get into the restaurant because you didn't want to use your walker. Mom was too busy keeping me in line and I remember how funny and wobbly you looked trying to walk between them.

The rest is kind of fuzzy, but I remember the other people in the restaurant looking at us and laughing and motioning at you, Dad. I didn't understand why. And I didn't understand why you were being so loud or why you were acting sort of mad. And I didn't understand the look of embarrassment on Mom's face. Or on Linda's or Laura's. All I knew, as Mom ushered us back out to the car immediately, you wobbling again between my sisters, was that I was not going to get my spaghetti. And I was upset. I didn't even know what the word "drunken" meant or why Mom said it to Linda or why Linda looked so shocked when she said it. All I knew was that Mom was looking at you, sort of mad, and saying something about your walker, and you just sort of laughed and looked out the window and said, "Yeah, yeah."

All I knew was that I was psyched out of my spaghetti and a Big Boy comic book. I mean, why should Linda and Laura have been upset? They didn't even like Azar's very much.

But after being at college and around colleges for the past five years, I've become pretty astute at noticing a drunk who is trying to pretend he isn't as he walks into a restaurant or other public place. And now, almost 20 years later, I realize that they thought you were drunk, Dad, and that we were there to sober you up. Isn't that a laugh? A middle-aged woman, two skinny teenaged girls and a little runty girl with long, dark pigtails and a Snoopy sweatshirt were going to sober up their good-for-nothing bum of a husband and father. I'm sorry that they thought that about you, Dad. And I'm sorry that you didn't either understand or care why they were laughing or pointing. But I want you to know that I care, Dad. Discrimination touches so much more than people realize — not just females or racial minorities.
And I never stare when I see a handicapped person enter a
restaurant. I do that for you, Dad.

I will write you again pretty soon. Please remember.
March 11, 1991

Dear Dad,

Hello again. I've been really busy in school, trying to get papers and projects finished up. How have you been? Mom said you've been drinking your liquids a little better. I hope you're not giving her a hard time. You know she doesn't need that.

I had to look back through some of my old papers from previous classes to get some information today. I came across a paper I wrote for one of my American literature courses about villains. Except in my paper, all the way through it, I spelled it "villians." I felt really dumb when my professor went through and corrected it every time I misspelled it. Especially since I've always sort of bragged to everyone about what a good speller I am. I guess I had to learn early, huh? Do you remember one of the first big words I learned how to spell, Dad? Remember the word "DISABLED?" I do. I had to learn that one in the first grade.

I remember my first grade teacher handing out those white index cards that said "PARENT INFORMATION" on them. We had to put down our phone number and our home address and I was so proud because I had memorized both. But for the blank marked "FATHER'S OCCUPATION," I didn't know what to put. So I had to ask my teacher. And when she came over and asked me what sort of job my daddy did, I had to tell her that my daddy didn't work. He sat at home, sometimes leaning on his metal walker, and watched a lot of television.

Of course, she gave me a real knowing smirk and said just to put "U-N-E-M-P-L-O-Y-E-D," which I did. But when I spelled that word for Mom that night and asked her what it meant, she wasn't too happy. That's when she taught me how to spell "DISABLED," and told me to correct it the next day on my card. My teacher sort of got pink in the face when I told her the next day, and she helped me print that word very neatly in the blank that she erased for me.

But I had no idea what that word meant either. No more than "UNEMPLOYED" or "LAZY BUM" or "BURDEN." I didn't know what any of those words really meant. I just knew that my father's occupation was being disabled. And the more I thought about it, putting that word on every one of my parent information cards for the next 11 years, I realized there was more truth to that than I had first known. You did spend all of your time being disabled. Just like Mom spent all of her time running the nursing home and Linda and Laura spent all of their time going to school and working and taking care of me.

But unlike other workers, you got no compensation. And then I realized how truly unsatisfying your life must have been. Must be even now. I just wish you hadn't given up on living, letting the multiple sclerosis take over. You are
in my thoughts. And in my prayers. Though I can't say what I pray for sometimes. Please remember.
March 13, 1991

Dear Dad,

At the grocery store tonight, I saw a man in an "Amigo" motorized wheelchair. I haven't seen one of those in forever. Do you remember your "Amigo," Dad? Man, that was one of the best times I remember.

That wheelchair went so fast, and I used to sit in your lap, or hang on to the back of your seat, standing by the battery and pretending I was riding on the "Batgirl" cycle. You used to love to pick me up and take me for a ride around the nursing home, back when you were still well enough to help Mom run it. I can remember Mom getting sort of mad at you when you would go too fast, and come close to hitting people in the hallways, but I thought you were great, Dad. I thought you were doing that to make me laugh.

I didn't realize then that you were losing control, Dad. That was the most "in control" I had ever seen you. You didn't need help, and you didn't need to hang on other people or on that stupid metal walker. You were in charge of the wheelchair, just like Mom drove the car or I rode my bike. But you were starting to see double, weren't you, Dad? Your eyesight was fading fast and you couldn't see a lot of those people you were about to hit, could you? You steered according to my squeals of joy when you were going fast. And pretty soon, you couldn't even hold on to the handlebars tightly enough to make it go. I was really sad when you couldn't drive the "Amigo" anymore. I had a lot of fun on that, Dad. I had a lot of fun with you. I guess it all sort of went downhill from there, huh?

When I saw that man in the grocery store tonight, Dad, I thought about us, riding around the halls and having a good time. And it made me feel like crying right then and there. Because I miss that part of you, Dad. That part of you that strove to make me laugh or smile. That part of you that longed to make me happy.

I don't know what the multiple sclerosis did with that part of you . . . but I'd sure like it back.

I will talk to you again, soon. Remember.
March 15, 1991

Dear Dad,

I turned on the television today and they were already talking about the Chicago Cubs training camp. I can't believe baseball is ready to start up again. Mom said you used to like the Cubs a lot. Oh well, there's no accounting for taste, huh?

Actually, I was really glad to see that baseball is getting ready to begin again. I love to watch it. Of course, Brian doesn't like it as much as I do, but it's kind of fun knowing more about a sport than him.

Do you remember when I first started playing softball, Dad? I wanted to belong to something so badly, and my best friend, Jennifer, had just joined a minor league softball team for the summer. I remember wanting to play so badly, but not knowing much about the game. I went to practice and I watched Andrea Perry's dad coach and throw and help his three daughters learn the fundamentals and I tried so hard to side up to them and learn something. But it seemed like I was always sort of behind, then Max (do you remember Linda's husband, Dad?) helped me. Remember -- he played baseball in high school and he was really pretty good.

Anyway, he helped me out a lot and I actually got okay. Not good or anything, but okay. And Mom came to all of my games and cheered me on. She cheered enough for both of you guys, Dad. She really did. She kept telling me that you had been on the softball team (they didn't play baseball then, did they?) in high school and that I must have gotten my coordination from you, since she was always so awkward. I really wish you could have been there to see me, Dad. Especially the night I hit the home run. Okay, I hit it against the worst team in the league, but it was my first, and I think, only home run in the six years I played summer softball. But I think you would have been very proud of me.

The sad part is I'll never know. But if anything I ever say does indeed get through to you and stick with you, I want you to know that there was a part of me that was proud to have shared something with you, Dad. Even if it was something as simple as softball, it meant a lot to me. Because, for once in my life, I had done something that reminded other people of my dad.

I had proven to myself that we shared more than our last names, that inside that pale skin and balding head lay a person who had been active and athletic, loving life and living it. That those legs that now lay, bent awkwardly and weakly to one side, useless and frail, once ran the bases and crossed home plate. That those hands that now shook uncontrollably had held a softball and thrown it.
I don't want to make you sad, remembering what used to be. But we had a link then -- a very tenuous one -- but a link. It was a good feeling. I carry it with me. Because I hope you would have wanted me to. Would you, Dad? I can only hope so.

Take care. I know -- what a dumb thing to say, huh?

Remember me.
Dear Dad,

Hi, Dad. It's been a few days since I've written, but I seem to get busier and busier as the year goes on. I'm almost done with all my classes -- finally! Can you believe it? I'm going to graduate college, Dad! I can't tell you how good it makes me feel to say that. And to say that to you, Dad.

Because I may not have admitted it to you before, but I never really expected you to live to see that day, Dad. Never. Not in a million years did I expect it. But here I am -- 23 years old, a fifth-year senior (I guess I really challenged you by not graduating on time, huh?), and my dad -- a 62-year-old man who has been bedridden for a majority of my life -- is still alive to see me finish up my classes. I never would have guessed it. Or even wanted it, I suppose.

Why should I have? I've been told you were or your "way out" so many times in my life. I especially remember the time when I was in eighth grade and I got the note at school. The trouble note. It told me that I shouldn't take the bus home, because my sister would be picking me up, and I knew that there was trouble. And I was right. When I got in Linda's van and she and Max told me to prepare myself because you were at the hospital and the doctor was saying you were going to die that night, all I could think was "How am I going to face my friends?" I was supposed to go roller skating that night. I mean, it was a Friday night, for God's sake. And I was way too embarrassed to tell any of my friends that my wheelchair-bound father was dying. Because death was gross, Dad. Fourteen-year-old girls shouldn't have to think about death. They should think about stuff like roller skating and boys and hanging out with their friends. Not stuff like diseases with long names or catheter bags. And most definitely not stuff like death or funerals.

But when I got to the hospital, and I saw Mom's puffy eyes and that really grave look on her face, I knew that it was time. And I hate to tell you this, but a part of me was glad. A part of me was calculating how much time I might still get to go skating if you were to die right then. I wouldn't have to tell my friends anything. As far as they were concerned, my dad didn't live with me. But hey -- that's no big deal these days. Maybe I could get rom to leave my name out of the obituary in our small town newspaper, and then none of my friends would have to know anything. Oh, yeah, Dad. I'm sorry -- believe me -- I'm sickened to think I had such selfish thoughts. But God, I was only fourteen, Dad. You put me in a really sticky situation, you know?

And then I remember Mom pulling me aside and finally explaining to me the seriousness of what was going on. How you were probably going to die that night and how I would
probably never see you again. Then I remember her telling me it was alright to go skating with my friends. She told me there was nothing I could do for you and I should go ahead and meet my friends at the skating rink. I mean, I was supposed to meet a boy there, Dad. I was fourteen. And he was really cute.

I did go skating that night, Dad. I went skating (whether you are aware of it or not) and I didn’t tell my friends anything except that my sister was going to pick me up because I had to be home early. And as I was skating, I remember watching the clock the wondering if you were gone yet. If I had missed your big exit, Dad.

Hope. Linda picked me up at 10 p.m. that night and smiled at me and put her arm around me. She told me you were doing a little better and they thought you might be okay. How ludicrous. Okay? You’ve never been okay. That’s kind of like the old joke — "Yeah, but will I be able to play the piano, Doc?"

I’m sorry I went roller skating and didn’t stay with you, Dad. I should have been there like Mom and Linda and Laura, listening to your shallow breathing, counting the silences in between when your lungs refused to take in more air. I should have been there to watch the residue settle at the bottom of your catheter bag and wonder how much pain it was causing you as it slumbered and traveled through your wrecked bladder. I should have been there to watch the IVs and the tubes pumping countless unknown fluids in and out of your skeletal body.

But I wasn’t. I was roller skating with a cute boy and my friends.

God, Dad. I was only fourteen. Please forgive me for that.

I will write you again. Please remember.
Dear Dad,

I think winter is almost over. I hope so. I know that I am really ready for a change. Are you? Stupid question.

I really love spring. I think it’s probably my favorite time of the year. Why shouldn’t it be? It’s warm, but not so much that it frizzes your hair or makes you sweat too much. And the trees and flowers always look and smell wonderfully. And then there’s always the prom.

That word sound familiar? Come on, Dad. Having three daughters, you’ve surely heard it tossed around a few times. I realized when I was walking through the mall that it’s time for the prom again. All the stores have their big, frilly dresses out in the windows and the men’s stores are advertising their tux rentals. Man, I can’t believe that’s been five years ago. Six years ago since my first prom. And Dad, you wouldn’t believe some of the dresses the girls are wearing now. I know, I sound just like Mom, but I swear I would be embarrassed to wear some of those outfits in a New York bar.

I stopped in a store the other day because I needed to buy an interview suit. Yes, I’m finally going to get a job, Dad. Of course, you are probably unaware that I’m even still in school, but I’ll be out pretty soon. Anyway, Dad, I was standing there, looking at interview suits, and I happened to look up and see and mother and daughter looking at prom dresses. And it really made me laugh to see the mom picking the nice, lacy pink dresses while the daughter kept reaching for the off-the-shoulder black numbers. I guess it hit too close to home.

Except I did pick one of those frilly, pink dresses. Do you remember it? My date and I stopped by to show you how we looked because Mom wanted me to. She didn’t order me to or anything like that (she was always pretty good about that), but I could tell by the wistful look on her face that she wished you could have seen me. That made me feel sort of good, and sort of “on-the-spot” too. Scott (my date) was not exactly the type of guy who enjoyed hanging out in old people’s homes. Except, as it turned out, we had to go to a different nursing home in town to show someone else, too. His great-grandmother. That was okay, I mean, you’re supposed to have a great-grandparent in a nursing home. But not a dad, for God’s sake.

I have to tell you, Dad. I really resented you for that. Not only were you not there with the Nikon to take pictures of me getting into the car or standing nervously next to my date, clunky high school ring and all — you were in a nursing home bed. And I knew you would cry really uncontrollably like you always do. You were ruining my first
prom and I hadn't even made it to the gym. And the sad part was -- you probably didn't even know it was going on.

Do you remember your reaction, Dad? I do. You cried, just like I knew you would. Only I couldn't tell if you were crying because you were happy for me, or because you could tell by the look on my face and the length of my visit (all of about five minutes) that I didn't want to be there. All I remember is wanting to get out of your room and pick up my friends. I wanted to go to the prom where sick people didn't exist. Especially sick fathers. Especially sick fathers of daughters attending their very first prom.

I have to admit that as soon as I got into the gym, Dad, I forgot about you. It wasn't easy, but I worked at it. I was not going to let you ruin my perfect night. And you didn't. Or at least I thought you didn't -- at the time.

But look at what I remember from that special night now. I don't recall the flavor of punch. I can't remember the name of the band. And even my "big date's" face is beginning to get sort of fuzzy.

What I do remember is your sobs. And I remember the way you were turned in bed when we walked in, brand-new white pumps and slick rental shoes scraping across the tile floor. You were turned, looking at the wall. Not asleep. Not meditating. Just looking. Looking at nothing. Maybe sizing up your life for the zillionth time. And you did look sort of happy to see me when you turned around. I really honestly believe that just for a second you recognized me and thought I was beautiful.

Those are my prom memories, Dad. Hits about the same time every spring. No wonder I skipped the nursing home visit my senior year, huh?

You know, when I read over this, I can see how you could probably come to dislike me. I wouldn't blame you. Just know that I'm truthful. I'm truthful because it's all I can give you to maybe ease the pain a little.

Remember.
Dear Dad,

I skipped a few weeks of writing. I'm having some motivation problems with my work lately, and I'm afraid it's starting to carry over into my personal life too.

But I have to tell you, Dad -- I'm enjoying our letters. These are some of the best conversations we've ever had. I know -- you're not getting much of a chance to contribute. But I can imagine what some of your responses might be if you could. And I guess that's enough for now.

I have to be in a wedding in a couple of months, Dad. I guess you can tell by my sentence structure that I'm not exactly thrilled about it, huh? It's for my old college roommate who is getting married this summer. It's not that I dislike her or anything. We've just sort of grown apart.

I don't know if you remember Susie at all, but she really remembers you. In fact, she asks about you every time we talk. This was one of the things that drew me to her in the first place, I think. She was one of the first people I had ever met who actually wanted to know about you.

I mean, sure -- I told some of my close friends in high school about your situation. Remember? I even brought in some of the highly curious and courageous to meet you. Of course, they stared and shuffled their feet a lot and talked to you like you were a three-year-old. And of course, we never stayed more than a few minutes. I can't remember who wanted to leave worse -- my friends or I. It's just that you didn't exactly put a "kick" into the evening, Dad. It was nothing personal. We just had more important things to do than sit around talking with an invalid.

But Susie -- she was different from the very start. She was a social work major which meant she was into analysis. And I mean analysis of everything. You know -- "Why do you feel like you have to go to that party?" or "Why do you really want to skip your class?" Since her mind worked like that, I knew my family secret (you) would not be that way for long.

She zeroed in on the fact that I rarely mentioned my father -- only my mother -- in my conversations. And being the amateur psychologist she fancied herself to be, she asked me questions about you. Were my parents divorced? Had my father died?

Now that I think about it, Dad. I think I must have been growing up during this time. I think that during my freshman year of college, I must have been maturing. Either that or I was so sick and tired of having to hide you that I told her upfront that my father had multiple sclerosis, and had since
before I was born. I told her you had walked with the aid of a metal walker through my early elementary school years, progressing (disgressing?) to an electronic cart (the Amigo), then a hand-pushed wheelchair, then a horizontal wheelchair (ordered special by my mother), then basically ended up in bed. I told her you were unable to feed yourself and had to be fed pureed food. I told her you were incontinent and had to be changed. I told her you were not always capable of carrying on a conversation, let alone remember who I was or what I was doing.

And she stayed, Dad. She didn’t run away screaming or shift her feet nervously or anything. She wanted to know more.

And more than that, she wanted to know how it made me feel.

I have to thank Susie for that much, Dad. I never realized that the way I felt about you and us was important until she asked me that question. It had always been just about you, Dad. Only about you. Now, it was about me, too. It was about how your illness made me feel, too.

And sometimes, I really dislike her for that. Because until that moment — my freshman year of college — I was numb. I had evolved from a lack of understanding to a deep embarrassment over the way you were different to a consuming sort of resentment over your inability to be there for me, forcing me to take my life to you. I had just lived a sort of detachment from that man in the nursing home who also just happened to have fathered me.

But my psychology-happy roommate insisted that I think about how it affected me, because that was the only healthy thing to do. So I did. And for awhile, the thought of how you did affect me drove me close to insanity. I don’t know if I’ve ever felt that much confusion, Dad. Or that much guilt.

And then, the day finally arrived that I had been dreading. She wanted to meet you. To meet the root of my psychological hang-ups. She wanted to see the actual flesh and blood version of what I believed to be my private shame. So I let her, Dad. But, to be honest, I let her meet you because I wanted her to see what it was really like. And how most it was to try to analyze my predicament.

I felt like I had betrayed you the day we visited, Dad. I was using you. I felt as if you and I had become a psychological experiment for her. And I must say I derived a certain amount of joy at her obvious uncomfortableness. I felt almost close to you that day, Dad. I was as if we had conspired together to drag her from the textbook world of Freud and Piaget into the reality of sickness and the dysfunctional family, into the sight of it. Into the stink of it. Into that drowning feeling I’m not sure I will ever
escape. Yet I felt guilt that day, too, Dad, over using you
to make a point to her. My only solace now is that I am sure
you have forgotten it. Just another memory thrown out into
the garbage as you sink deeper and deeper into God only knows
what.

She did analyze things way too much, Dad. And she drove
me nuts that way. But she helped me see that my feelings and
your feelings were linked, in a way. That your existence and
the way it affected my existence were tightly knotted. Even
if it felt like they were around my neck sometimes.

You take care, Dad. And drink your fluids. Mom
worries.

Remember me.
April 5, 1991

Dear Dad,

Hi, Dad. How are you since the last time I saw you? Mom said that you had been acting as if you were getting ready for another one of your "spells," but then you got to feeling better and eating more. That's good. I can always hear the pain in Mom's voice over the phone whenever you don't feel well. I guess that's the closest I ever really get to feeling your pain, huh?

I know that may sound really awful, Dad, but it's somewhat true. I see Mom and feel Mom as a real human being, but you, Dad -- your'e not exactly that to me. I mean, you are a human being, but when I stand over your bed and look down at you, you seem to be a little less than that to me. I can't feel it when you hurt or you're in pain, but I can sense it in Mom. And because Mom is such a real person to me, I get some idea of your pain. I know it must be bad if it makes Mom hurt the way that it does.

I was thinking about a conversation that Linda and Laura and I had with Mom a couple of years ago. That was one of the first times I was really able to sense your pain through her. It was my junior year of college and I was busy -- busy with my classes, busy planning my wedding that would take place that summer, busy with a social life and activities and so on and so on . . . But Mom wanted to talk to us about our thoughts on prolonging your life (life?) in the case of sudden breath stoppage, kidney failure, etc. In some ways, I couldn't believe she even wanted to talk to us about something so ridiculous. I mean, come on . . . what in the hell was there left to prolong?

But Mom was adamant about getting all of our opinions. I guess I should have appreciated the fact that she felt my opinion was important concerning your care. Like she said, you are my father, after all. But I didn't appreciate it at all, Dad. No. I was rather put out, actually, because I felt as if she was trying to drag my semi-perfect existence into her more-than-semi-hellish life. I didn't want to make that decision. As far as I was concerned, that decision had been made by the Big "G" long before I was even around.

So, I did what I had learned to do early on when it came to tough, group decisions in the family. Unless it had something to do with a vacation destination, and especially if it had something to do with you, Dad. I let Linda and Laura carry the ball and "yes" Mom at the appropriate times as she tried to convince herself out of her guilt and into her sense of reasoning that prolonging your life was stupid and cruel. I sat back and watched them tell her that any artificial prolonging of your life would be inhuman. I watched Linda insist that you never would have wanted to live this way (and for the record, she didn't either). I watched
Laura try to handle Mom with sensitivity, yet convince her to be firm once making this decision. And I just nodded when Mom asked me if I agreed.

Did I agree? I don't know, Dad. If you're asking me if I would have let you suffer pain from lack of oxygen, or if I would have allowed you to writh and wince from your failing kidneys, I say, "No, of course not."

If you're asking me if I ever prayed that when the phone rang late at night, it would be one of the nurses breaking the news to me that the nightmare was finally over, then I guess I would have to say... "I don't know."

What I do know is that you married a rock, Dad. She wasn't a movie star, and she wasn't an extraordinary cook, but she was a rock. I watched her trying to cope with that decision that day, and I knew that she would waver and she would question herself and her motives and she would probably even try to ask you how you felt about it, even though she knew that your capability for understanding certain subjects has unquestionably diminished. But she would always be thinking of you, Dad, when her decision came to mind. And she would try to remember that skinny, athletic guy with the pretty smile and giving nature. That's who she would be thinking about when she tried to decide how many more days, or weeks, or months, or, God forbid, years, you could take.

She raised us -- she ran a business for which she had little or no training -- and she still feeds you lunch and dinner almost every day.

They don't make them like that anymore, do they, Dad? I hope to be just like her.

Remember Mom, Dad. And remember me.
April 7, 1991

Dear Dad,

Well, here I am, Dad. I’ve been reading back over some of the letters I’ve written you, and I realize that a lot more was probably going on in both of us than I realized. And Easter Sunday made me realize this too.

When we were at the house on Easter this year, and Linda and Laura and Brian and I were getting ready to go see you, Mom said that you were still in isolation, and that we should be sure to put on the hospital gowns and gloves before we went in to see you. I knew you were sick again, but I guess I hadn’t been paying much attention to Mom that week on the phone, saying how sick you really were. To be honest, Dad, I’ve started turning a deaf ear to such things. You know how they say cockroaches will be the only living beings after a nuclear war? Well, I’ve resigned myself to the fact that you will be there to keep them company.

When we got to the nursing home, Linda and Laura took charge, as usual. I don’t know if it’s the fact that they are both nursing home administrators themselves, or the fact that they both still feel as if they have to protect me, but they approached the nurse right away, asking her about your condition, and leaving me standing rather uncertainly behind. I guess that’s where I’ve always been standing in this family, sort of uncertainly behind others.

But I’ll never forget the nurse’s words. She said we didn’t need to put the gowns or gloves on unless we “wanted to . . . you know . . . HUG” you or anything. Hard to believe we would want to do a gross thing like that, huh, Dad? But did she think you weren’t a human being? For the first time, I think I saw it, Dad. I saw my own attitude toward you mirrored back to me, and I hated it. It overwhelmed me the entire time I stood in your room, watching Linda and Laura, half-competing to see who would break down first and put on the protective clothing and touch you, Dad. It bit at my insides as they both rushed to don the lightweight coverings and then rushed back to your bedside, saying things like “How do you feel now, Dad? Is it better with your head positioned like this?”

I almost felt privileged -- as if I was getting a small glimpse of what life had been like before I came along. The father with his two beautiful little girls -- competing for his attention, maybe a ride on his shoulders or a tickling match . . .

And I was still standing behind them. Making observations, as always, and wondering if you were counting and noticing that you were one daughter short at your bedrail.
But you know what, Dad? As I watched your restless and erratic-moving head shake back and forth, burrowing into your pillow and away from all of us, I realized something very important. Linda and Laura were coping too. I thought maybe I was the only one still uncomfortable with you, Dad. But they were, too. That's why they had rushed to touch you, Dad. That's why they leaned over you and spoke in such soothing tones and honestly, honestly tried to make you feel more comfortable, despite the futility of that prospect.

And I realized that my way of coping -- my detachment and resentment, my confusion and unsettled way of life -- was my coping. I couldn't rush to hug you and soothe you because I never had. I had known you as an unapproachable, sometimes untouchable entity, from day one. You and I had never been a regular old father and daughter team. Not the way you once had with Linda and Laura.

That's when it hit me, Dad. I did love you. I did feel you. Isn't that what all this detachment and pain inside of me is about? It's evolved into this, and I must admit I don't know that I always loved you. But if I didn't love you, then I couldn't mourn you, and I do, Dad. You are still alive, but I mourn you and I mourn our situation. I mourn the fact that we never did have that relationship and I mourn the fact that I never knew what it was like to have a "father" and I feel honest-to-God black grief for the way I might have turned out. For the trips and the talks and the laughter that could have been, but I will never know.

But I'm not alone. As I watched Linda and Laura that day, Dad, I saw them mourning too. Their mourning was no heavier than mine, but it was very different. They mourned for what had been, Dad. They mourned for that man they had once known, that man who would twirl them around and tickle them and play with them. They had tasted of the wine and fallen in love with it. Become intoxicated by it. And then they had it jerked away. But not quickly and painlessly. Oh no, they had had it pulled away slowly, slipping through their hands like a long, painful rope, burning their skin until they finally had to let go.

I longed to taste of that wine, Dad. But the bottle was empty by the time I arrived. And that rope? I reached for something to hang on to, but when I came along, the rope had been pulled up and put away somewhere where I would never again find it.

I begged for a glimpse, Dad. Linda and Laura had glimpsed and wanted to see more. All of us had had the door slammed in our faces.

When I left on Easter, Dad, I saw you look at the wall. You looked blank. And I hurt from that look. But for one of the first times ever, I didn't feel as empty as before. That hole your absence had left in my soul had been filled by grief. But at least it was no longer empty. Remember me.
What has two legs and two arms
But cannot move them?
What lies in bed but has the power
To move others, without moving itself?

Answer: My dad

Epilogue

I saw my dad two days ago. My mom is concerned because his false teeth do not seem to fit his mouth very well and she is wondering if his features are beginning to shift. Why not? That's something he hasn't tried yet.

When I saw my dad, I tried to talk to him, but mostly I watched his television and watched people walk past his door, some smiling, others grimaced. I wondered what I looked like when I finished visiting with my father.

Dad looked restless as always, and his eyes, a little glazed and unfocused today. It's all a part of the game that we're all stuck playing, I'm afraid. Watching my dad fall apart bit by bit and wondering what will fall next . . .

What a way to live, huh? (for all of us).

But I've realized that I've got my way of coping. And so do my sisters and my mom. Whether it's feeding him lunch and dinner every day, or rushing to soothe and comfort, or just standing back and observing -- we've all found ways to deal with this.

And Dad? How does Dad deal with this?

Realistically, he burrows his face into his pillow and looks at the wall blankly, and, I would suspect, prays that God will come and release him from this humiliation.

Ideally, I hope Dad thinks about the times he took me for rides on his Amigo. I hope that when he looks at the smooth wall, he sees my face on Christmas morning when I got my guitar and my red pedal-car. I hope that he is thinking of that one, curled Fokaroid I've seen where he is holding Linda and Laura in his arms and smiling happily. And I hope he's thinking of Mom's pretty dark hair and bright brown eyes when they were newly married -- the picture sits on his cabinet, lest he forget.

I've come to the conclusion that maybe it's a mixture of both of these things -- the realistic and the idealistic -- that crosses the vast expanse of his aching and damaged mind as he tries to cope with multiple sclerosis.
And two days ago, when I left, he smiled at me and I realized that he may not remember me. But he knows me. Maybe the same way your great-grandmother knows your touch, even though she is blind. And maybe the same way a baby knows its mother moments after being brought into the world.

But I believe he knows me now. And that makes me an important person in his life. Because he doesn’t know much anymore.

I love you Dad. And I’ll remember you forever.