

## The Hand that Feeds

*All the art of living lies in a fine mingling of letting go and holding on.*

*~Havelock Ellis*

It is Friday afternoon and traffic on Golf Road is starting to build. I am immune to it as I travel west, against the flow. I pass the shopping mall, horse barn, museum, and construction zones. My thoughts are on my dad as I near the nursing home. I greet Carol at the desk, check Dad's mail, and make my way to The Neighborhood, where the residents who have Alzheimer's and dementia live. I press the code and enter the secure unit.

This afternoon, the other residents are out in the living room watching *Animal Planet*. I wave to Alfred, and he smiles. I tell Ellie that her necklace is beautiful and she hugs me. I take Judy's hand, and for a moment she stops shaking.

I knock on Dad's door, and enter. It's 5:30 p.m., and he has been up from his afternoon nap for about an hour. Now, he's consumed with pain. Jeff, his private duty caregiver, tells me that Dad was complaining about his ankles so they are propped up on the footstool. I thank Jeff and hand him his weekly check—ever since Dad's strokes, Jeff has been instrumental in nursing Dad back to life. I check the diaper supply and stock the fridge with Ensure. Dad is leaning back in his wheelchair, eyes closed, mouth open. I hear a moan, and I walk over, sit on the bed and take his hand.

Music is one of my best ways to communicate with him so I start signing to him about Daisy and the bicycle built for two. My pitch and tone are way off, but I don't care. It's one of our favorite songs, and after a minute his eyes open. I ask him if he's ever ridden a bicycle built for two. He says no, and I remind him how he used to put our dog Rusty in the grocery basket of his old bike and give him rides around Evanston. Finally, I get a smile. Then the moaning starts again.

I ask where it hurts: this time, it's his shoulders. Jeff says he's already had his pain medicine and we're waiting for it to kick in. I ask Jeff if the hospice volunteer came today. He says yes; Dad says no. I believe Jeff. I put on some music. Ellington. We've changed the words a bit.

In our version, it's "If you want to get from Sugar Hill to Harlem, you better take the A train." We sit. His hands are soft. Softer than mine. His arms are splotched with purple and red marks. I take note of a few new bruises and cuts.

It's dinnertime, and lately Dad has been taking his meals in his room. Jeff brings in some soup. Tomato barley. I stir it, taste it, and scald my tongue. After a few minutes it's ready and I ask Dad to open his mouth. He does, takes a bite of soup and makes a horrible face but it stays mostly in his mouth. He chews for almost a minute and I wonder how that's possible. I don't see him swallow, but the chewing stops. I try with another spoonful, and another. Four more bites and he's had enough. The bib is covered with spills. I wipe his mouth and nose. I haven't seen him eat this much in months. Jeff brings in his plate.

Chicken and mashed potatoes. I know Jeff usually ends up feeding him Ensure, yogurt, and dessert—that seems to be all Dad will take these days. But I'm here, so we

try for solid food and whole nutrition. And he eats. It surprises even me, but his eyes are closed and he's reluctantly accepting every bite I bring to his mouth. Chew, chew, drool, chew, spit, moan, chew, swallow.

With each bite I feed him, I am reminded of what his doctors and the hospice team keep saying—as long as he has nutrition and is able to take food, he could survive for quite some time. And I think of the pain he is in. And I think of the loneliness in his eyes when I'm not there. And I wonder if what I'm doing is helping or hurting. He is chewing, swallowing, digesting. He is surviving. But is that what he wants? Is it worth it?

Jeff sees that his plate is almost empty and remarks again how special our connection is. "He doesn't eat like that for me," he says. And I can't smile, because my stomach is churning. I'm thinking thoughts no daughter wants to admit to having.

I have to leave. Suddenly I don't feel safe here. I clean off his mouth, give him a kiss, tell him I love him. He smiles, unable to say it back but I know he's thinking it. I type the code and bolt out the door. Back in the car I punch the stations—NPR, XRT, there has to be something to clear my mind, because I can't handle silence right now.

I find Wilco and settle in for the twenty-minute drive home. I stop at Mom's long enough to guzzle a glass of wine and pick up the laundry I did earlier in the day. Then I'm on my way, alone with my thoughts. Fighting with myself over the need to hold on and the need to let go.

~Carrie Jackson