

Dear Joe & Linda,

Greetings! It's February 8, the day after Marge's 95<sup>th</sup> birthday. Here's a conversation about age that she and I had last week:

Greg: You have a birthday coming up soon.

Marge: Really?

Greg: And you're going to be really old.

Marge: How old?

Greg: 95.

Marge: Oh, no, no, no, no, no. You're mistaken about that!

Marge wasn't denying that she was going to be 95; rather she thought it was a completely silly idea. How could she possibly be that old when she feels so fabulous.

And she *is* still fabulous, with all of her peculiar mannerisms and distinctive ways of doing things. Her ability to converse sensibly has fallen away, but the person sitting next to me is totally familiar. She can be exhausted and listless when I pick her up, but the minute we enter a public space where she feels comfortable (such as a doctor's office) she shifts into performance mode. She's on stage, Marge, the perennial center of attention. And she pulls it off without missing a beat, charming everyone in sight.

The hard truth of the matter is that Marge is entering what is probably her 12<sup>th</sup> year of a progressive dementia that is most likely Alzheimers, a degenerative disease that usually runs its course in 11 years. According to all reports she has beat the odds, and I am assured by her neurologist that her personality will remain intact to the very end—because from a neurological point of view the patterns of her personhood are deeply established and supported by many neural conduits. The rest, however, is up for grabs and what goes and what remains is pretty much a matter of chance. Eating, for example, seems to have largely slipped away—the recognition of food as food, the connection between hunger and eating, the routine behaviors of mealtime.

At first it was alarming, but it's been easy to remedy. At the Meadows, where she lives, an aide feeds her—and at our house we fix only her very most favorite foods. Feed her one spoonful and she wants more. Model how to use a fork or spoon and she's good to go. And she has a great appetite. We KNOW she loves macaroni and cheese, so that's what Bob fixes. Variety might misfire. Now that I'm over the shock of this new stage, I find it really amusing. Of course Marge's personality and her interactional repertoire would last beyond her capacity to recognize food. That's why she's so memorable.

I wrote last year about her telling me that she hasn't always followed the "rules" and sometimes this has made people mad. It was a strategy, she said, that gave her a lot of freedom. Here's my take on this: In the absence of loving and supportive parents

Marge constructed her own personal world, all of it according to Marge. It was her way or the highway. That makes Marge tough to steer now when she doesn't understand what's going on. When I pick her up, for example, sometimes it's impossible to convince her to wear a coat. She simply will not do it. So we walk hand in hand to the car, with me carrying the coat, and the minute we hit the winter air she changes her mind.

Today I took her to have her teeth cleaned. Last time we tried this it was a bust. But you never know what might happen a second time around. We figured out how to position me so that I was right beside her and we cheered her on when she opened her mouth and praised her for lying still. Eventually she got hold of some dim memory of this process and did everything she was supposed to do right on cue. Her health is perfect, vital signs, organ function, everything. An infected tooth, however, could be devastating.

If you're thinking this sounds pathetic, it isn't, not in the least. Marge is loving and curious and personable, the darling of the aides at the Meadows. When I showed up today she was dressed to the nines, make-up, jewelry, a great hairdo, wearing the new embroidered jacket that Bob and I had just given her for her birthday. She looked like a million bucks, as she often does because she's so incredibly striking. While I was telling her how beautiful she was, I heard a lot of tee-heeing from the two young women aides in the next room who had helped her get ready. They routinely give her that extra time because she's so charming, so appreciative, and so stunning. All dolled up she looks like the queen of the world—all the more so because she's so incredibly old.

Even the institution where she lives bends over backwards for her. She has gold-plated care that costs a fortune, and she's there on Medicaid, Earl's meager savings having long since run out. They have recently offered to move her to the Special Care Unit where there is a much higher staff to resident ratio. So her future is assured. She can live out her life in a place where she is loved and appreciated and will have exactly the care and support she needs to live as a full a life as possible. When the building administrator called to suggest this I told him that I thought it was a great idea but there was no way we could pay for it. He replied, "Greg, this is not a financial conversation, this is a care conversation." They are doing this FOR Marge even though it's outside their business plan.

So here's my refrain: Despite all of these changes Marge is still here—alive, well, and fabulous among us. The disease has taken her language, her memories, and much of her awareness of the conventions and routines of everyday life. But she and I can and do have intentional animated nonsense conversations (badabadabadaba), we rub our foreheads together, we make funny faces, and we laugh and laugh and laugh at the sheer silliness of it. In those moments there is no dementia. When I came to pick her up on her birthday one of the aides asked her, "Is this you son?" She stuttered and stumbled as she often does when she's looking for words and finally came out with, "He is himself." Still sharp, still thinking, still making the best of a tremendous challenge.

*I send my best.  
You*

