

*Join us in wishing  
Marjorie  
a Happy 94<sup>th</sup> Birthday*

*February 7, 2010  
From 4:30 – 6:30 pm  
Potluck*

*RSVP 802-483-9557*



Dear Joe & Linda,

1-25-10

Hello again. Here I am with Marge's birthday letter. (I'm addressing this to both our friends here in Vermont and friends and family in the Midwest.) Marge will be 94 on Sunday, February 7<sup>th</sup>, and this year it again feels right to have a party. You're invited. It will be on the early side because Marge runs out of steam in the evenings. 4:30 to 6:30, potluck. We'll provide drinks, Bob will conjure up a big batch of something to anchor the meal, I'll bake bread, and Pat Hannegan is bringing a carrot cake. No need to coordinate. These events always work out well when left entirely to chance.

It's my memory that I didn't have time to write a birthday letter last year, so I'll catch you up on two years of Marge-news at once. 2008 was full of goodness, but it also had its challenges. Chief among them, Marge had bouts of dizziness and began falling. The first few times she escaped unscathed. But eventually her luck ran out and she fractured a bone in her left arm and dislocated her elbow.

The first day was excruciating as she re-discovered the intense pain in her arm every few minutes because she had no memory of her injury. She was like a tormented child in a cloud of stinging hornets that she could neither see nor evade. Just when the situation seemed completely unbearable she somehow mustered the neural capacity to hold her arm immobile. But by then the pain had taken its toll and she was no longer able to walk without support.

Almost immediately, though, she started building back, pushing herself to regain lost ground. During this period of intense focus, she had moments of inexplicable clarity when lost memories would suddenly come into view. One evening as she and Bob and I were sharing a picnic supper, out of the blue she remembered her longtime friend, Fern Shull, and observed, "Fern was the most patient person I've ever known." From my memory, that's Fern exactly. Which goes to show that when Marge says, "It's all still in here, I just can't get at it," she's right.

Eventually Marge regained her ability to function independently and the use of her arm—and the dizziness passed and she stopped falling. But with the injury, as with every illness, Marge had lost more cognitive ground. In practical terms this means that it's harder for her to make sense of the world around her. She's stopped commenting on the lights at night in Rutland or noticing all of the cars at the dealerships we're passing or wondering where we are going and what is going to happen next. But when I ask her how she's doing, she tells me that it's marvelous to be watching everything. It's exciting, it's a wonder. It's glorious to just be here.

There you have it. More and more is lost and yet in fundamental ways Marge remains unchanged. Take for example our trip to the optometrist. Marge had lost her glasses so we were starting from scratch. When the nice lady who was helping us came to the realization that Marge wasn't playing with all of her marbles (to use a phrase of Bob's), it was clear that she expected me to hurry the process along and choose the frames for her. I, on the other hand, was certain that no one could make the right fashion decision for Marge other than Marge. Sure enough, about ten frames into the project Marge announced, "This is it!" And she was right. The frames she chose are perfect for her. Just when I start to wonder if she's completely losing touch, she pops up again in full glory and surprises me. Out of the muddle comes clarity.

Although she has no idea who her grandchildren are on a conscious level, at some deeper level she is perfectly oriented. Nowadays when she comes to supper she's contented for only a very short period of time and then announces, "I think it's time for me to go." We know that we need to hop to, because when she's ready to leave there's no holding her back. At Christmas, however, she was fascinated by our daughters and watched each of the girls with keen interest. And for a change she was in no hurry. We were amazed, in fact, not only by her attention span but also her physical endurance. Like a kid who had been partying a bit too eagerly, on the day after Christmas Marjorie—who is always up at 5:30—slept until noon.

In the midst of all of the Christmas activity she turned to me and said, "You know, I haven't always followed all of the rules." With an opener like that the only thing that I could think to say was, "How did that work out for you?" "Well," she said, "it made some people mad, but it gave me a lot more freedom." Boy, did that ever sum her up for me! I can remember some of those people that she used to infuriate, and I can also remember the pleasure she seemed to take in creating an uproar.

Chief among her critics was of course her mother, about whom we still hear a great deal: "She keeps moving things around. I had it all laid out and she came in and mixed it all up. I couldn't do anything." It used to be that her stories, like this one, were about something that we could eventually figure out. Now they appear to reflect a world of constant activity that exists only in her imagination: "He came to see me today and we had a good time. He took some of this and some of that and he thought it was alright etc etc." We have no idea what this is about, but Bob and I listen and agree and we have a good visit. In a sense it's just like talking about the weather. And she's always amusing us with her vivid language. One day as she was settling into the car she told us that she was glad to get away because of all the smacking and whacking and cracking. At times like that we laugh and laugh and laugh together.

Marge is much-appreciated at the Meadows, the residential care facility where she's lived since Earl's death. The aides are her buddies and take extra time with her, doing such special favors as painstakingly brushing and braiding her long gray hair. At least once a month we find a new piece of clothing in her closet, with no indication where it's come from. Presumably someone thought it looked like Marge, and they were right. On holidays she's dressed to the nines—wearing her rings, necklaces, and earrings—looking regal and just exactly herself. The Meadows has had an ad in the local paper for several years that features a photo of Marge with the banner headline FABULOUS. It amuses me to think of that, still a star and the center of attention even at 94.

The challenge for Bob and me is to meet Marge where she is, and that place changes from day to day. Some days she's exceptionally lucid and others she's literally out to lunch. I'm only sad when confusion overwhelms her and she's desperate for relief. Fortunately those times are few and far between. Mostly she does what she's always done, making the best of the cards that she's dealt with verve, style, and aplomb.

P.S. As we were taking her home this evening she said, "I wanted to talk and make everything normal, but nothing made sense. So I squeezed out of that one." And again, "When you're around I get fancy."

Best, Guy

As many of you know, last year Marge and Bob and I were the subject of a short audio documentary that was produced by our friend Erica Heilman. Much to our surprise versions of this piece broadcast on three nationally syndicated public radio shows and we received messages of support from people all around the country. Now the piece has been nominated for a Peabody, which is the radio equivalent of an Oscar.

In case you'd like to hear this piece, which is called *After the Forgetting*, I'm including internet links to each of several versions on the Web sites for "Day to Day," "Soundprint" and "Hearing Voices," as well as a link to Transom (a showcase for work by independent producers) where the complete half-hour piece is available along with photos of Marge and an essay by Erica Heilman. Also included below is the text from the Peabody nomination packet.

**Transom:** <http://transom.org/?p=518>

**Soundprint:**

[http://www.soundprint.org/radio/display\\_show/ID/781/name/After+the+Forgetting](http://www.soundprint.org/radio/display_show/ID/781/name/After+the+Forgetting)

**NPR:** <http://www.npr.org/templates/story/story.php?storyId=98450439>

**Hearing Voices:** <http://hearingvoices.com/news/2008/12/after-the-forgetting/>

*After the Forgetting*, produced by Eric Heilman for Vermont Folklife Center Media

Imagine this: Your mother doesn't remember your name and she doesn't know that you're her son, but she loves being around you. She likes it when you take her out for a drive, even though she has no idea where you're taking her or whether you'll bring her home again, assuming that she has a home. If this strikes you as farfetched, think again. This is the context of *After the Forgetting*.

Many, many Americans are facing the challenges of caring for an aging parent, and chief among these challenges is the mystery of advancing dementia. An absolute diagnosis of Alzheimers is possible only postmortem and the ravages of the disease cannot be stopped or reversed, only slowed. But beyond diagnosis and treatment lies an even greater challenge as a family struggles to respond to an ascending arc of loss, which is simultaneously both their parent's and their own.

*After the Forgetting* focuses in on the experience of one family and their evolving responses to a capricious and ever changing disease. In many ways Marge, the mother and central figure of this piece, is an outlandish character. Having lived most of her adult life in rural Indiana, she has invented a persona that is vivid and one-of-a-kind. Marge's gay son, Greg, feels an easy intimacy with his mother, and for Greg's husband, Bob, Marge is a kindred spirit and fellow traveler.

*After the Forgetting* draws on audio recordings made with Marge, Greg and Bob over the course of a year, combining formal interviews with live mealtime conversation. At one time or another producer Erica Heilman, Greg, and Bob each took the initiative to record a particular meal, and the interviews were conducted both by Erica and Greg. Since Erica is a longtime family friend, the creation of the piece became seamlessly a part of the times that Greg and Marge and Bob spent together, yet another version of an ongoing informal dinner party.

When *After the Forgetting* was completed Marge was ninety-two. Her dementia had been evident and her cognitive loss progressive for over nine years. In those fleeting moments when Marge is able to pull herself to the surface, she hopes for the possibility that the confusion will subside: "Tomorrow I'll be myself again." But the dementia deepens and with the passage of time new losses occur.

Here is the way the issue is usually framed: As someone loses the ability to remember—in Marge's case, both present AND past experience—are they still the same person? If they don't remember that you've just done something for them, was it nevertheless worth doing? If this person is your parent, does any element of that relationship endure?

The answer that *After the Forgetting* offers to each of these questions is an unqualified "yes," not through self-conscious sermonizing but rather by quiet example. Putting love at the very center of things, Marge and Greg and Bob's relationship forms and re-forms around the connections that are possible on any given evening of any given day. The focus of *After the Forgetting* thus is not on what has been lost but rather on the astonishing abundance of what remains.