

Sometimes it's about tough choices

by Jon Strum

The Spring 2008 issue of **Momentum** published the following letter to the editor:

“I am insulted and near tears about Jack’s story in ‘Through Thick & Thin’ (Winter.07–08). I have no problem with his taking a trip to see family in Europe, but it sounds like there was no mutual discussion. ‘I made the tough decision to put Vel in a nursing home’ is so demeaning. Jack had all the power. Vel had none. We deserve better than that.”

This letter struck a nerve, so I read the original article the letter-writer referenced. In short, Jack, a 68-year-old retiree, is the primary caregiver for his wife, Vel, who is unable to leave her bed. Jack bathes Vel, administers her meds, arranges all of her medical appointments and handles all of

An MS family caregiver and blogger writes about the necessity of taking care of yourself.

the household chores as well. Vel is also dealing with cognitive impairment, which has left Jack feeling isolated.

If you were to subtract about 20 years, Jack and I have an awful lot in common.

And so I feel somewhat entitled to my opinion here. Most of us know that if you line up 10 people with MS, you’ll find 10 different sets of symptoms. And because the disease progresses, there’s a wide variance in just how profoundly people are affected. Should it progress to the point that it has for Vel or my wife, Jeanne, it seriously affects every aspect of their lives. Fortunately this is not what every one with MS inevitably faces.

What’s most clear to me about the letter-writer who is feeling “insulted and

Guide for family caregivers

Caring for Loved Ones with Advanced MS: A Guide for Families, edited by Dorothy E. Northrop, MSW, ACSW, and Debra Frankel, MS, OTR, offers guidance for families when a family member has advanced MS so severe that the person can not be left alone for any extended period and has complex issues. A PDF of this 112-page book can be downloaded at nationalmssociety.org/advancedms or call **1-800-344-4867** and ask for a free copy.





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Paintings by Sylvia Moss: “Sunglow” and “Evening Blue” (both 48" x 40", oil and mixed media on canvas)

near tears” is that she may not have traveled as far down the road of disease progression as Jack’s wife has. I pray it never happens.

Whether Jack knows it or not, it’s vital for him to take that trip to Europe. Caregiver burn-out isn’t something that we talk about often, but it is a huge issue for people in situations similar to Jack’s and mine. If Jack doesn’t take care of himself—if he stops doing things for Jack—he runs the risk of ending up clinically depressed and of no help to his wife. And then we’d have a household with two victims of MS and **no** able caregiver. That’s infinitely worse.

The letter-writer points out that, “Jack had all the power. Vel had none.” I’m sure that Jack would trade that arrangement in a heartbeat if he could, but when your loved one has serious cognitive impairment, it’s dangerous

to give them an equal vote in matters—even if you’re desperate for those times when the two of you could make mutual decisions about the future.

What Vel deserves most is to have Jack at her side, making her as comfortable as possible for as long as possible. In order for Jack

to do that, he can’t lose himself in the process.

Jon Strum lives with and cares for his wife, Jeanne, who was diagnosed with secondary-progressive MS in 1997. He maintains a blog about his experiences at mscaregiver.typepad.com; this story is a slightly modified version of a post on February 12, 2008.

Who Can Help?

Visit nationalmssociety.org/Servicesquestions for a list of practical questions to explore when families anticipate making decisions about increased levels of care—or call us for a copy. Should it be care at home, in an assisted living residence or skilled nursing facility?

The list of questions is not intended to be inclusive or complete. It’s meant to help people start these difficult conversations and sort out the appropriateness and quality of available services and programs for their individual circumstances.

An MS Navigator™ at the nearest chapter is an important resource for good local information and emotional support. Be sure to call **1-800-344-4867** as the discussion continues.

What are the options and what are the offerings when a person with MS needs help with daily living?