

## **The Caregiving Tightrope**

*Senior Digest, January 2013*

My friend Linda (not her real name) is who Ellen Goodman calls “the designated daughter”---the family member primarily responsible for planning and providing care for her aging parents. (It’s most often a daughter, if there is one.) She had relocated her elderly Mom and Dad to Rhode Island four years ago, and had put her career on hold while she and her sister helped care for them.

Linda called last week, very upset. Her Dad, whom she had reluctantly placed in a nearby nursing home after his Alzheimer’s had become too much to handle at home, was becomingly increasingly combative. She feared that soon the nursing home would ask that he go elsewhere. She was at wit’s end after searching for someone, some place that could tell her “what comes next” for him. She said nothing she tried was helpful: calls to toll-free help lines, a discussion with her father’s geriatrician, a consult with an elder care specialist.

As we talked longer, Linda got down to what upset her most. She felt very guilty because she had been unable to save her Dad from the ravages of Alzheimer’s and now she couldn’t find a place that could give him good quality of life as he deteriorated. She recalled that when her brother died some years ago, she was the one who had to give her parents the bad news. Now she feared she would be bringing bad news about her Dad to her Mom.

I referred her to a clinical social worker who specializes in relationships between adult children and their parents. Unless she can get some support and figure out how to care for herself as well as her Dad, she might not be able to help him. Linda’s situation mirrored what numerous studies tell us: family members responsible for caring for an elderly parent or spouse often experience serious prolonged stress resulting in physical and mental health problems.

My takeaway from all this is that there should have been someplace that could have helped Linda figure things out, and equally importantly, given her some support. Someone she could trust that wasn't trying to sell her something. Two years ago the Senior Agenda Coalition helped enact a provision in law that our state elder services department was required to provide "options counseling" about long-term care to anyone who needed it. As a result the state conducted training in long-term care options for hospitals' discharge planners and staff from senior-serving agencies. That was a first step, but it's not nearly enough. Caregivers like Linda need ongoing support and advice, so that they don't feel like they're walking a tightrope without a net.

There are sources of that support on the Internet in some blogs where caregivers share experiences and try to help each other. One of my friends, a caregiver for her elderly mother and father, has researched those sources and compiled a descriptive listing of them. We published it in our recent Conference program and would be glad to share it with any readers who e-mail to [senioragendari@yahoo.com](mailto:senioragendari@yahoo.com) or call 351-6710.