

## ***THE CRISIS OF CAREGIVING***

***PATRICIA P. SMITH***

Good afternoon.

Before I begin, I want to thank our hostess Barbara Risser for her hospitality today and perhaps more importantly for making a difference by her tenure as President of FLCC. Thank you, Barb!

I'm also sorry to disappoint everyone by setting aside my original topic, *More Souvenirs* and replacing it with something more serious.

My subject today is focused on a worldwide medical crisis that is affecting women and men of all ages and socioeconomic position. This crisis spills over into our lives here in Canandaigua and affects people we know and care about. Parents, spouses, siblings, children, friends, acquaintances, and individuals we pass on the street or see in Wegmans. The crisis I speak of is the impact of Family Caregiving on the lives of the caregivers. (*I should mention here that all of my guests are caregivers.*)

I was inspired to choose this topic by several things. First, my almost 15 years of experience as a caregiver for my husband John, who has Parkinson's disease. Secondly, by getting to know caregivers who deal with other diseases: Alzheimer's and other memory loss, PTSD, lingering cancers etc., some for spouses, some for parents or siblings. Lastly, by my current challenge, participating with a team of 8 caregivers from around the country to help craft a special Caregiver Summit to be held in Portland Oregon in September. The Caregiver Summit is spearheaded by the National Parkinson's Foundation and will be presented in concert with the 4<sup>th</sup> World Parkinson's Congress. This consortium of medical professionals from around the world will share their research and discuss potential breakthroughs, all with the carrot of a cure.

My objective today is to send each of you away with a new perspective on this crisis. None of what I am about to share is a complaint or a whine. It's merely a statement of fact.

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First, let me share a few statistics. These were garnered from *Caregiving in the US*, a research report published by the AARP Public Policy Institute/National Alliance for Caregiving. (June 2015)

- Based on data collected in 2014, an estimated 34.2 million adults in the US provide unpaid care to an adult aged 50 or older. This represents 14.3 % of all (239 million) adults age 18 and over in the time period studied.
- In 2009, the value of these free services was estimated at \$375 billion a year. almost twice as much as the \$158 billion actually spent on paid homecare and nursing home services combined.
- 24 percent of caregivers have been caring for the recipient for 5 or more years. Half of these or 12% have been doing this for more than 10 years, making family caregiving the foundation of long-term care.

- The majority of caregivers are women (60%) and half had no choice in taking on these responsibilities.
- 1 in 10 cares for a spouse. 78% of these have no outside help.
- Almost half (48%) of care is in the patient's home.
- The personal care provided includes facilitating two or more activities of daily living (ADLs). These include getting in/out of bed or a chair, dressing, getting to/from the toilet, bathing/showering, feeding and dealing with incontinence. Older caregivers have difficulty with administering these ADLs, most of which are repeated several times in a 24-hour period.
- Care also includes instrumental activities of daily living (IADLs): Transportation, grocery/other shopping, housework, preparing meals, managing financials, giving medications/injections, and arranging for outside services.
- Up to 70% of family caregivers manage medications for their loved ones. Many are asked to perform medical/nursing tasks for which they are not trained.
- As the disease progresses the level of care will expand to include monitoring the health of the recipient, communicating with health care professionals and advocating with providers, services and agencies.
- 60% of family caregivers were unaware that they were caregivers until they interacted with the medical community.

Then there are the statistics on caregiver health and well being:

- In 2009, more than half (55%) of family caregivers said they postpone or skip medical appointments for themselves. 63% reported poor eating habits and 58% indicate worse exercise habits than before caregiving responsibilities.
- 20% of female caregivers over 50 years old report symptoms of depression compared to 8% of their non-caregiving peers. (I believe that in many cases this is extreme fatigue/exhaustion.)
- 40% of caregivers reported high levels of physical and emotional stress. Extreme stress has been shown to cause premature aging and can reduce the caregiver's life by as much as 10 years.

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So what does the research mean? (The American Psychological Association published the following in June 2006):

- Informal caregivers are a significant sub-population whose health is now known to be at risk. In addition, because they are more likely to be women than men, they face greater vulnerability in terms of both health and financial loss. Solid evidence of the health impact of caregiving gives psychologists and doctors insight into the close links between chronic stress and physical health. It also underscores the urgent need to support caregivers, not only to alleviate their suffering but also to reduce the cost to society as a whole.

How is the research used?

- Public policy and the health-care system now formally acknowledge the role played by informal caregivers, who are the invisible, untrained, unpaid "frontline"

workers of elder care. Well-meaning organizations such as the Alzheimer's Association provide support groups and training; state and local agencies are developing respite-care programs to provide essential breaks; caregivers are encouraged to practice relaxation techniques, attend to their health and cope actively with stress.

- Ten years later, implementation is still in its infant stage. Techniques/programs continue to focus on helping the caregiver cope with the disease in question rather than addressing the very real Caregiver needs, which are not disease specific.

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Now that I have buried you in statistics, I would like to switch gears to put a face on Caregiving. In my research, I came across this op-ed piece in the Washington Post. The article – entitled *I have Parkinson's — and my wife is its invisible Victim* -- was published earlier this month on March 4. The author is Don Rigenbach, a freelance writer. Let me read from it.

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## The Washington Post

### Opinions

#### *I have Parkinson's — and my wife is its invisible victim*

By Don Rigenbach March 4

Probably the only good thing I can say about having Parkinson's disease is that it has introduced me to the unexpected helpfulness of others. Any time I venture out with my sturdy cane, people go out of their way to open doors, offer a helping hand or instruct their kids to stand aside as I shuffle past. Some teenagers will even extract themselves from their smartphones to offer assistance.

Yet people seldom offer to help the woman who struggles to hoist me from the car seat, push my chair up to the restaurant table or quietly cope with my unseen, round-the-clock needs and demands.

My wife, Jan, is struggling to do the things she did in the era we call B.P. — Before Parkinson's — along with most of the things I did. Every day, the most urgent tasks steal time from mere daily requirements. While I'm waiting for her help getting me dressed for my Thursday breakfast group, she's racing to dress herself, care for the dog and plan her workday before she drives me to the cafe. Whatever Jan is doing can be interrupted when I suddenly need help getting out of a chair or pulling up my pants.

Sometimes I say thank you. Often I don't, because I'm already thinking about something else I need her to do for me.

The little sensitivity I'm able to show for her situation comes in response to her occasional signs of exhaustion or pleadings for understanding, as well as from an eye-opening article I happened upon about the widely unrecognized plight of the "well spouse"

This article prompted the author to buy his wife a membership in the Well Spouse Association, based in Freehold NJ. He goes on to say his wife is grateful for her membership. Continuing with:

But don't kid yourself — or me — by thinking, "How sweet! Despite the torture of Parkinson's, he's worrying more about his wife than himself."

Most days, that's not the case. In my experience, as one's universe becomes smaller, one is more inclined than ever to view oneself as the center of it. Whenever I do pause to contemplate what would happen if Jan's role and mine were reversed, what I'm really experiencing is more a fear of inadequacy: Would I have the strength to be for her what she is for me?

Indeed, the healthier partner is the invisible victim of progressive diseases such as Parkinson's, Alzheimer's, multiple sclerosis, late-stage cancer, amyotrophic lateral sclerosis (Lou Gehrig's disease) and many others. She — or he — has the most endless of thankless jobs, till death — or abandonment — do us part.

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The second story I'd like to relate appeared in a Democrat and Chronicle op-ed this past Saturday, March 26. The author is Kevin Hylton and in it he talks about his wife Yvonne:

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*Rochester Democrat and Chronicle*

### ***Impact of Parkinson's***

Kevin Hylton

"Most people think of Parkinson's Disease as something that affects much older people. But my wife, Yvonne, was only 44 when she was diagnosed. Now, at 52, she just *acts* much older. She shuffles, talks quieter, takes longer to do everything, can't sleep through the night (so I can't either).

That's the way it is with this disease — it impacts everyone it touches, and everyone seems to know someone with it."

He goes on to say that "PD is a progressive neurological disorder that slowly, relentlessly robs people of physical and cognitive abilities. It afflicts well over a million people in the U.S. and more than 4,000 in the Greater Rochester area — along with an untold number of relatives and caregivers. Currently there is no cure and its cause is unknown."

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## *Our PD Story*

The last story I'd like to share is what's happening in my house, how John and I are coping with this long term challenge of PD. And, I want to emphasize that what I am reporting is not unusual.

Before Parkinson's, John and I each assumed a set of responsibilities. Mine were focused on maintaining the inside of the house, our financials and dealing with plumbing, heating and A/C. John's on the other hand included everything outside: lawn care, landscaping, snow removal, etc. plus all things food related: shopping, menus, meal prep, etc. He loves to cook! We each managed our own medical, dental, medications and any other appointments: hair care. etc. Each was free to get involved in community projects, make friends, all the things we were used to doing. And, there were many things we enjoyed together: Travel, visiting friends, hosting meals/parties/fundraisers.

Then around the year 2000, pre-Parkinson-diagnosis issues arose. John had year-long back problems (he could stand/lie down but couldn't sit without excruciating pain) and he had hammertoes that required surgery. In 2002 when he was unable to rise from a chair, he thought it was more of the same. Turns out a lack of dopamine was the culprit and Parkinson's was diagnosed by Dr. Robert Knapp. John was prescribed a magic pill (Sinemet) and the problem was solved. We left shortly thereafter for Great Britain, a trip we thought we'd have to cancel.

The magic pill and variations thereof stayed the demons for a few years. Then the symptoms took on the attributes of a sinusoidal curve no matter if meds were taken as directed or not. Some days/times of day he would again require assistance getting out of his chair or bed. John continued his outside work but often I would get a call from his cellphone asking me to "come get him", that is drive a vehicle to where he was on the property and bring him back to the house.

By the Fall of 2007, John's ability to walk was compromised. He had the Parkinson shuffle and unsteady gait. He was headed for a wheelchair. I was helping him in/out of chairs and accompanying him to all of his appointments.

At this point, Dr. Knapp sent John to Strong Neurology, specifically to Dr. Frederick Marshall, a Movement Specialist. This encounter resulted in Deep Brain Stimulation (DBS) surgery in February 2008. DBS created another magic moment. John was once again able to do more of the things he enjoyed — like creating the art show, Women Artists of the Finger Lakes and founding the Parkinson Support Group of the Finger Lakes — and I could relax a little.

There were ups and downs from 2008-2014 but John and I continued to soldier on. Our partnership of shared responsibilities started to change.

Soon, John was willing but no longer able to perform outside maintenance, lawn mowing or landscaping. So, he hired and managed the outside help. The next change was to medication management. Despite an MS in Clinical Pharmacology, this became

daunting. I took over the process and developed dosing reminders for him (a key on the pillbox and a cellphone alarm).

My 2014 Lymphoma diagnosis/treatment followed by John's broken hip last year created a bigger change. When he came home from rehab it was clear he needed more care than I could give him and I needed a break. There was also the spectre of "what if something happens to me". We needed to get our legal documents in order.

So began an odyssey to move out of the shadows of informal caregiving into a more managed approach. This is a process we are still pursuing. We have retained a geriatric care manager and an agency aide comes four mornings a week to help John get out of bed, bathe, dress, etc. We foresee the need to add an aide in the evening to perform the reverse ADLs.

The geriatric care manager was instrumental in helping us place John at the VA for respite care while I recovered from my recent Cataract surgery with restrictions on bending/lifting. We wanted him to be safe and no other Ontario County facility was able to accept a patient for respite who required transfer. I am happy to report that John received fine care with a smile and a lot of respect. And, the most amazing thing was that his meds were administered on time every time. No other medical facility in Rochester has been able to do that for him.

That takes care of the medical side. What about all of the other responsibilities? Now in 2016, even meal planning/preparation falls on my shoulders. John still participates in decision-making after I've done the research but I can't delegate a complicated job to him. And, many projects can't be hired out.

What are the biggest issues in dealing with this problem?

1. Time: There is never enough. As John's needs become greater, time for me becomes scarce and I need to be sure he's safe before I go anywhere. Recently, I had an opportunity to take the better part of a day for myself if I cancelled a meeting with some women friends. At our next get-together, they asked what I had done. My answer: I went to the outlet mall to be fitted for new bras, something I had on my list for over a year.
2. The Sinusoidal Curve: There is no way to predict when John will need help getting out of a chair or bed, or need help getting ready for bed in the evening. The latter process can take up to an hour to accomplish.
3. Lack of Freedom: I can't just leave him even to go to Wegmans or Walmart. John has the same issue since he gave up his driver's license last Spring.

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In closing I would like to leave you with some thoughts. Reach out to the caregivers you know. Don't just inquire about the patient. Ask the caregiver how she/he is doing and listen to the response. It will be much appreciated. A smile and a hug go a long way.

Don't presume that a smiling, well dressed/put together patient got there on his/her own. It's quite likely he/she had some or even a lot of assistance coordinating their attire and maybe even extra help putting on each piece in proper order.

Thank you.