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WEEKEND BREAK

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'TREASURE WHAT YOU HAVE TODAY,' BUT PLAN

By **JOAN HERMAN**
 For *The Daily Astorian*

I am alone in my kitchen, crying in the dark. My husband, John Gaasland, had gone to Urgent Care two hours ago for chronic exhaustion and was then abruptly sent across the street to the emergency room. Now he's on the phone telling me he is being admitted to the hospital.

I cannot think straight. I am worried sick for my husband and sad that I cannot be with him. But, guiltily, I am perhaps even more concerned for myself. Stuck in a wheelchair, I cannot be alone overnight and feel utterly helpless. John has been my sole caretaker.

I have multiple sclerosis, a sometimes-progressive disease (as in my case) of the central nervous system. When I was diagnosed in 1998, I had only a wobbly foot that would come on after three miles of running.

Eighteen years later, I am in a wheelchair full-time. My dear husband is essentially tethered to me for all but several hours when he gets out to run errands alone. It is his respite time.

If there is anything I hate most about my condition it is my loss of independence and my ever-increasing vulnerability. I hate that I can't do, in many cases, even the simplest of tasks. Signing a check, holding utensils with my right (dominant) hand — forget it.

I hate that I have to rely on my husband, of all people, to help me with the most mundane and oftentimes intimate tasks of daily living — not exactly romance-inducing, but we certainly have true intimacy.

No Plan B

On that night about six weeks ago, I hated that I couldn't be with him.

Yet I had made no Plan B for such emergencies. I procrastinated setting up a safety net "until tomorrow," partly because I had no idea where to begin. And making plans would have meant admitting that just such an emergency could occur.

Before John and I married in 2014, a close friend asked John, point blank, if he was certain he wanted to take on the burden that comes with marrying someone with a debilitating condition.

John probably should not have divulged his friend's words to me. Is that how she sees me — as a burden? But she was right; caring for someone with a serious disability is a huge burden — literally.

I fear the responsibility is tiring John out. Being worn down from having to care for me, and on top of that, do everything else around the house, likely made John more susceptible to an opportunistic infection.

With no plan in place for just such an emergency, the night John was admitted to Columbia Memorial Hospital, I put out a frantic plea to friends on Facebook, of all places, and also started making phone calls.

I was lucky that a dear friend, J., who prefers not to be identified, was available to come stay with me. Another dear friend recommended I call a young woman who happened to be strong and needed money. She could assist with transferring my no-longer girlish figure.

For three days, these two women took John's place, transferring me into and out of the bed, dressing me, preparing meals and assisting me in the bathroom.

As for John, his kidneys began to heal with treatment, and he was released from the hospital three days later.

The problem still exists, though, of my needing care with daily living tasks, and John burning out from having to be caretaker, housekeeper and cook.

Options?

While John was still in the hospital, a nurse friend suggested we seriously consider having regular in-home care to relieve him.

"We can't afford that," I blurted out.

I had to retire at 55 due to disability and now receive Social Security disability payments. John, who is 65, also is on Social Security and receives a modest pension from his former employer, the state of Washington. We are far from rich, but we do have more resources than many people.

Neither private insurance nor Medicare, which I start on Dec. 1, covers in-home caregiver services, unless the patient has just been released from a skilled-nursing facility, and even then, only for a limited time.

This amounts to a gaping hole in health-care coverage for the hundreds of thousands, if not millions, of Americans like me, who are otherwise healthy but cannot care for themselves.

One bright spot is that lower-income seniors and people with disabilities who qualify for Medicaid can receive in-home care, with prorated charges, depending on the recipient's income.

I do not know what will happen if John dies before me or can no longer care for me. I know it's pointless to worry about this possibility, but I do.



Joan Herman and her husband, John Gaasland, were married in August 2014.

Submitted Photo

EVEN SO

'LATE FRAGMENT'

The title for Joan Herman's column comes from the poem "Late Fragment" by Raymond Carver

And did you get what
 you wanted from this life, even so?
 I did.
 And what did you want?
 To call myself beloved, to feel myself
 beloved on the earth.

Meanwhile, John and I have decided to take a small monthly disbursement from my retirement account to pay a caregiver to come in two mornings a week to allow my night-owl husband a little more sleep.

I also am registering with other local in-home care providers, if and when the need for more helpers arises. I have compiled a list of contact info for friends and neighbors who can help in a pinch. I never want to be left in the lurch again, as I was six weeks ago.

"You can only take it one day at a time," my nurse friend has told me when I've shared my concerns with her. "Treasure what you have today."

Indeed, I do. And still I worry.

Joan Herman is a second-time Astorian who was co-owner of Bikes & Beyond and a former reporter for *The Daily Astorian*. She will contribute an occasional column about living with disabilities.



Joan Herman and John Gaasland visited Mount Rainier in July 2012.

Submitted Photo