What Happens When the Caregiver Gets Sick
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THE CAREGIVER’S SILENT PRAYER

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Dear GOD, please make me strong, even when I don’t feel that way; make me fearless in crisis even when I shake in anticipation of the next challenge; make me knowledgeable even when the problem is off the chart; and make me do right even when I don’t know what I’m doing….

WHAT HAPPENS WHEN THE CAREGIVER GETS SICK?

Widespread flu during these winter months calls attention to a feared issue faced by many caregivers: what to do when you yourself get sick and the person you are caring for is almost totally dependent on you.

My husband survived a massive stroke in 2001 that affected his right side. While fully cogent his physical capabilities have been greatly reduced. Confined mainly to a wheelchair, he requires my help to dress, shower, toilet, walk, and exercise. Normal routine has set in but the unforeseen sometimes happens. Over these eleven plus years, despite the vitamins and exercise, I’ve been hit by shingles, flu, viral pneumonia and, most recently, a kidney stone. All hell breaks loose because many of these episodes occur on weekends, holidays, evenings and during blizzards (we live in Cleveland) when my respite care worker is unavailable and I’m completely on my own.
Fear immediately sets in: how can I take care of my husband when I am unable to move? Family is far away and friends and neighbors, even with the best of intentions, aren’t trained to pivot him from wheelchair to chairlift to toilet. They blanche at the sight of a urinal and, at best, are anxious to leave within an hour. My attitude toward agencies with last minute calls for help has soured because even with directions and requirements they too frequently send people unprepared to deal with our problems.

I’ve tried to avoid these circumstances by exercising regularly and keeping myself in working condition. When I’m sick, I rely on my respite worker whom I use three times a week, four hours per shift. While she’s here I can fall comatose into a spare bed and sometimes even extend her hours. But since she is also a caregiver for her mother, her time is finite and I am again on my own.

For four recent days I could barely move and only crawled out of bed to bring a food tray to my husband, going up and down using the chair lift. As I could, I dressed him and he remained downstairs working on his crossword puzzle at the kitchen table. At night, however, bending to remove his leg braces, shoes, and pants, deep breathing didn’t help much and when finished I’d retreat as far away as possible and cry. The pain was so severe that it made labor (three children with natural childbirth) seem easy. My husband was a good sport and he stayed in bed as much as possible while I slept the sleep of the dead, at least for a few hours at a time. Pain does that to you.

But while he was patient, the fear in his eyes was obvious. He worried not only for me but for himself. When the caregiver goes down, everything around crumbles as well. I’ve sometimes thought how wonderful it would be to rent a mother, someone who would hover over and hug me (not on my left flank), prepare chicken soup, and make all the fear go away. Usually it’s my job to soothe and make things better but I would be more happy to share the responsibility.
During this most recent bout, I thought I had a backache until four days later when I realized the pain was coming from my left flank above my kidney. By that time my internist supported by medical tests said that I had passed a stone on my own.

Fortunately for me, the pain finally subsided after more than eight days and life began to look more like it was worth living. Still the question remains about what happens the next time. Life is creative and no doubt there will another challenge, hopefully not soon.

Here are some of the lessons I’ve learned along the way (with the caveat that I’m still learning as I go) that I hope to apply:

**LESSONS LEARNED AND STILL LEARNING**

- Keep a 2-week supply of meds in proper cases to correspond with times of day for dispensing.
- Prepare a list of responsibilities by time of day so that someone taking your place will know what is required.
- Don’t be afraid to call EMS if you are really in trouble and isolated (my husband chose my time with the shingles to fall out of bed).
- Keep some extra meals and soups in your freezer to cover several days; also keep handy the names of restaurants that deliver.
- Prepare a list of people to call for help, beginning with those who might stay the longest but involving others who could offer even an hour or two; include phone/cell numbers and addresses; above all discuss this plan with people on your list and make them familiar with your needs.
♦ You might even find it helpful to check out an agency for the "just in case" when you have no recourse; seek recommendations and referrals.

♦ Make long-term plans for your stroke survivor should you become seriously ill or worse. Choose a healthcare facility and perhaps even file application papers in case you are unable to do so later. Even though these facilities operate on a space-available basis, at least they will have your paperwork and some familiarity with your needs.

♦ Make sure you have your medical records and those of your loved one in special binders, updated, and easily available to stand on their own.

♦ Also have an updated medical power of attorney and regular power of attorney for each of you.

♦ As a spousal caregiver you should have your financial papers in order, in a safe but obvious place, including: wills, life insurance; medical insurance, Social Security/Medicare records, bank statements, and safe deposit information. Each of these should be clearly marked in separate folders for yourself and your spouse.

Most of us consider ourselves indestructible, even with infrequent bouts that shake us...or at least we’d like to think so. But things happen and, based on the responsibilities we carry, these steps are necessary to will ease our minds should a crisis occur.