

Caregiving When the Caregiver is Ill

by Sharon Dardis

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Many caregivers worry about what will happen to their loved ones if they become physically or financially unable to provide care. What will happen and what will they do if they cannot fulfill their own expectations regarding what they think it means to be a “good” caregiver? A solution may not be as easy as one might expect.

One thing I've learned about caregivers is that there is no right or wrong way of doing things. Every caregiving situation is unique and fraught with difficulties and challenges, but also with rewards, inspiring stories and lessons. I believe most caregivers worry about not being able to attend to the monumental tasks of caregiving.

When I was a practicing hospice nurse, my initial home admission visits were a chance to meet potential new patients and their families. During that time, an important goal was to identify and designate the primary caregiver. We could never assume a “typical caregiver,” any more than we would assume a “typical patient.”

There were all levels of abilities of caregivers, yet sometimes I'd leave that first visit wondering who would be taking care of whom. Back at hospice, during team meetings, each admission was carefully assessed and discussed. Needs were identified, and care plans were constructed. We were well aware that the key to the success of good patient and family care would be the primary caregiver.

Caregivers come in all forms: young, middle-aged, old, confident, fearful, well-qualified, not-so-qualified, terrified and even physically challenged. I recall one caregiver who was

confined to a wheelchair. This person, while dealing with significant health issues of their own, turned out to be fully capable as a caregiver. All things are possible with the right support, encouragement and understanding.

In thinking about what happens when caregivers become ill, my thoughts turn to a friend who found herself in this situation. She surprised me by talking about her spouse's caregiving for her during the time she became ill. She suggested how her being sick helped him realize all she'd given to him during his illness.

Recognizing that her husband was still in recovery himself and wasn't anticipating what she needed, she reminded herself that as the ill caregiver, she had to ask for what she needed. It's OK to ask for help, and if the person you've been caring for is able to give even a little bit, help that person out by defining your specific needs and accept the reciprocity of care.

My friend continued, “Learn to accept help from others, but also learn to say ‘no.’ Express what you yourself need, and recognize your own limits.” That's good advice for any caregiver, whether healthy or ill, whether on the giving or the receiving end of things.

It's difficult to be ill when you've been the long-term advocate and caregiver in the family. My mother was the primary caregiver for two chronically ill husbands, first my father and later in life, my step-father. When mom was in her late seventies and became ill herself, she remained fierce about her defined caregiving role. “I'm the caregiver,” she'd say sternly to all of us, “I'll do the caregiving here!”

Obviously, my mother was specific about her needs. For her, it was important to feel needed. Gradually, with her failing health, she required more and more assistance from my step-dad who was able to help. As he cared more and more for her, he gently provided what she required emotionally, allowing her the dignity she needed to still feel she was somehow still in control.

Looking back now, I imagine them to be a good example of reciprocal care, a caregiving team. Granted, not every situation has that fluidity.

It is important for all caregivers to practice self-care and maintain good health by:

- ◆ being kind to yourself and listening to your body,
- ◆ watching for signs of anger or sadness,
- ◆ eating a healthy diet,
- ◆ exercising, and
- ◆ making good sleep habits a priority.

There's more than one way of doing things. Try to think creatively. Ask others for their ideas and how they've managed. If you are losing interest in things you used to enjoy, eating or drinking too much or sleeping too little or too much, it might be necessary and important to seek professional help.

The “Caregiver Space” suggests the following things you can do to create a plan for yourself in the event you become ill while caregiving.

- ◆ Have a back-up plan.
- ◆ Identify who might be able to step in to help if you are unable to fulfill your caregiving responsibilities.

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- ◆ Make a list of potential caregivers you might ask to help you.
- ◆ Document important information regarding your loved one, such as medications, routines and doctors.
- ◆ Create a list of possible family, neighbors and friends you can call in an emergency.
- ◆ Research and keep a list of competent home health care agencies or long-term care facilities, just in case.

Caregiving is the hardest work you'll ever do. You're bound to find yourself feeling unwell now and then. Even caregivers are allowed to be sick. But you can create a back-up plan for those times to allow yourself the space to rest and recover.

Remember the surest way to maintain your strength and health is to make it a priority now to take care of yourself. Other caregivers may also have ideas on how to cope during the stressful tasks of ongoing caregiving. Reach out to them and try to share with one another.

Taking care of a loved one is ordained, tough and sacred work. It's certainly done more easily when the load is shared. Identify ways you can stay healthy now during this time of caregiving. And remember, if illness does strike, be prepared ahead of time by identifying others whom you might lean on if you become ill.

About Hospice of the Red River Valley

Hospice of the Red River Valley is an independent, not-for-profit hospice serving all, or portions of, 29 counties in North Dakota and Minnesota. Hospice care is intensive comfort care that alleviates pain and suffering, enhancing the quality of life for patients with life-limiting illnesses and their loved ones by addressing their medical, emotional, spiritual and grief needs. For more information, call toll free 800-237-4629, email questions@hrrv.org or visit www.hrrv.org.