

The Toll of Caregiving  
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Long term caregiving for a spouse seems so straightforward but it's actually complicated and exhausting. It involves multiple, presumably unsophisticated tasks: keep the loved one safe, protect him from embarrassing himself, keep the mood in the house calm, keep your own self under control, give adequate attention to your own physical and psychological state, and keep the routine and rhythm of how life used to be. Those multiple duties are difficult or even impossible to achieve and some of those tasks may be incompatible with others of them. The non-care giving public doesn't appreciate the emotional and physical drain of caregiving.

I've had lengthy conversations with numerous caregivers and I hear the same things over and over: "I just want my spouse to continue to do what he enjoys", or "I just want her to be happy", or "I just want to keep him as good as can be". The problem is those lines focus entirely on the patient and neglect the needs of caregivers. No wonder, because many caregivers neglect themselves. In the short term that's selfless and admirable; in the long term, that doesn't work. Neglecting one's own needs exacerbates stress and frustration, and too often leads to the early death of the caregiver, the ultimate problem for the person who was the original patient.

We know that family caregivers are likely to have depression and anxiety, and we know that those symptoms exacerbate any number of other problems such as cardiac disease and diabetes. We know that immune systems are weakened by stress. We also know that feelings of anger, guilt, loneliness, and exhaustion feed stress and depression, and those are universal caregivers' feelings. Who wouldn't feel that way after answering the same question for the hundredth time, or when there's no privacy and he even follows you into the bathroom?

So, what to do? First thing that family caregivers must do is acknowledge the toll that the illness is taking on themselves, and find ways to alleviate that stress, even if that means the patient must spend time in a program or other environment he doesn't want to be in. Support groups for the caregiver are helpful because they remind you that there are others going through the same thing and who understand even when you get angry; support groups also open the possibility of learning about approaches you haven't previously considered. One on one therapy can also help to teach approaches to manage stress. Also, do not give up activities you love because your life must have some focus other than caregiving. Furthermore, see your health care provider for a check up. Are you getting enough exercise? How are you sleeping? And, refuse to do things that take psychic or physical energy that you're short on: let your children have the holiday meals at their homes for a change. Next, accept offered help and be specific. When a relative says she wishes she could help, tell her that she can take your husband to her house every Tuesday for two hours.

Caring for yourself isn't selfish. Quite the contrary; it's the only way to survive over the long haul.