

Caregivers must keep "a slice of selfishness," UW social worker

May 9 2012, By Molly McElroy

Several years ago, Wendy Lustbader cut back her counseling, teaching and writing career to spend one year as a caregiver. Her mother-in-law, in the final stages of colon cancer, moved from Florida to be looked after by Lustbader and her husband at their home in the Montlake neighborhood of Seattle.

As most caregivers would predict, it was a rough year. "I got so desperate, I read my own book," Lustbader, an affiliate associate professor at the School of Social Work at the University of Washington, said of "Taking Care of Aging Family Members," her 1994 work on caregiving co-authored with Nancy Hooyman, professor in the UW School of Social Work.

A part of the book on loneliness had particular relevance. Lustbader's mother-in-law had her rich community of friends back home, and Lustbader and her husband had been trying to make up for that loss by spending all of their [leisure time](#) with her.

"I read in the book that no matter how hard you try, no matter how much of your life you give up, you can't take away another person's [loneliness](#)," Lustbader said. "The guilt that kept getting in the way of our going out on our own Saturday nights lifted. We were released."

Lustbader is a nationally known speaker on how to cope with aging, disability and end-of-life issues. She draws upon her caregiving experience and her expertise as a counselor to give lectures and

workshops for caregivers around the United States and Canada.

She'll speak at the Washington state "[Challenges in Caregiving: Giving Care, Taking Care](#)" conference, to be held June 4 in Tukwila, Wash. (Pre-registration is required and space is limited. See sidebar for more details.)

"No one understands like a fellow caregiver, and this event will be a chance for people to experience an incredible community of family caregivers," Lustbader said of the conference. "It's a marvelous relief to be with others who really understand how you feel."

Lustbader will give practical advice on how caregivers should take care of themselves, something caregivers often neglect. One caregiver proudly told her, "I kept a slice of selfishness for myself." Lustbader agrees. "I'm going to advocate for people to keep that slice. That reduces bitterness and resentment," she said. "And, who wants to be taken care of by someone who is resentful?"

She suggests that at least one day a week caregivers should set aside time when they're "back in life somehow." It could be a weekly card game, a part-time job or something else. "We get patience from the perspective which comes from getting away," she said.

Caregivers should also hold on to their hopes and dreams, which is the topic of Lustbader's keynote talk at the June 4 conference. To this end, she advises caregivers to understand how guilt and resentment can bubble up when people have to put their own lives on hold.

"It helps people be honest with themselves, that it is natural to feel thwarted and captive when they can't pursue their own aims. Everything is for the sake of the person whose illness has taken center stage," Lustbader said.

Grief can arise during situations of giving and receiving care, stemming from many sources, she added. Spouses of people with Alzheimer's often yearn for the personality their partner once had. Sometimes people coping with chronic pain turn inward and become entirely self-oriented, leaving family caregivers bereft with the feeling that the person they love and have depended upon has vanished.

Lustbader urges caregivers to attend support groups where they can grieve openly and receive comfort.

In her 1993 book "Counting on Kindness: The Dilemmas of Dependency," Lustbader describes caregiving from the recipient's point of view and gives insights on what ill people wish their caregivers knew. One caregiver gave the book and a yellow highlighter to her mother, asking her to highlight anything that expressed how she was feeling.

"It spurred them to talk deeply, for the first time in their lives," Lustbader said. "Many people use this book as a tool of understanding. Some even read it long after the person they took care of is gone, and it helps them comprehend what went on during those difficult times."

Lustbader will use humor and storytelling to convey her knowledge at the caregiver conference. "People don't remember didactic material," Lustbader explained. "They remember stories, and then the wisdom contained in the story comes to mind when they need it the most."

Caregivers who seek Lustbader's counsel frequently have these questions:

I feel so guilty thinking ahead to when the caregiving will be over; does this mean I'm insensitive or unloving?

Lustbader says that caregivers should keep thinking about their own

lives. "Think about how there will be life after caregiving, and don't feel guilty about it." She encourages [caregivers](#) to think about what they will do after the responsibility is over, even though that time will bring sadness. "Looking forward to when you're free is totally natural and people should indulge quietly in this; it brings perspective. Lift your head from your labors and see life as a whole."

Why does my mom yell at me when I'm being so good to her?

"Don't take it personally when a dependent person takes out their anger and frustration on you. This is a universal problem: we bite the hand that feeds us," Lustbader said. "We do it because the caregiver is the safest person. We have nowhere else to let out the frustration of being dependent."

I'm resentful toward family members who aren't helping – what do I do?

Emotions often run high between siblings in caregiving situations, especially when old rivalries and resentments present themselves. Lustbader says, "You never regret the care you give, but people do regret the care they didn't give." She points out that research shows that the grief process is relatively simple for those who have provided care to a loved one, but it's more complicated for those who weren't involved. Also, there is solace in knowing that our children are learning from our caregiving. "I think that's why the Fifth Commandment says you will get length of days when you honor your father and your mother," Lustbader said. "Caregiving gives you hope that when your time comes, [people](#) might go out of their way to help you."

More information: For more information on Lustbader's work: www.lustbader.com

Provided by University of Washington

Citation: Caregivers must keep "a slice of selfishness," UW social worker (2012, May 9)
retrieved 14 May 2024 from <https://phys.org/news/2012-05-caregivers-slice-selfishness-uw-social.html>

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