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1210 words

How to Overpower the Demands of Caregiving

Claim Time for Yourself
Get the Right Equipment
Cope with Anger

Lessons Learned in

Letters from Madelyn, Chronicles of a Caregiver

By: Elaine K. Sanchez

Madelyn Kubin was recovering from open-heart surgery. She had osteoporosis, macular degeneration, restless leg syndrome, and severe hearing loss. She lived on a farm six miles from a town of 10,000 people in the middle of Kansas, and she had very little money. And then, on October 31, 1993, just a few months after Madelyn's 70th birthday, her husband suffered a debilitating stroke and she became his caregiver.

For the next six years Madelyn maintained her contact with the outside world, and perhaps her sanity, by writing letters – big, fat, fantastic letters in which she disengaged her emotional monitor and wrote openly to her daughter about what she was going through and how she felt about it.

There are many lessons for all caregivers in Madelyn's experiences. Here are a few, illustrated with excerpts from the book *Letters from Madelyn, Chronicles of a Caregiver*:

Claim Some Time for Yourself

Set aside some time for yourself each day to do something you enjoy. Read, meditate, or go for a walk. Let your loved one know this is YOUR time, and you do not want to be disturbed.

It took Madelyn a few months to figure this out, but on February 6, 1994, she wrote:

"The one place where I don't give in to Quentin is when I want to sit up and read at night. He never wanted me to do that when he was well. Now he says he can't sleep if the light is on, and the noise of the turning pages bothers him. He never has any trouble sleeping in the daytime. The dishwasher can be going, the TV can be on and the sweeper running and he can sleep without any problem. I told him last night to not worry if he couldn't sleep while I was reading, because he wouldn't have any trouble when it's daytime and I'm working. I need some time for myself, and if he can't sleep, he will just have to stay awake."

During the next five years Madelyn continued her quiet nighttime ritual and she maintained her sense of humor. On February 17, 1999, she wrote:

I have been meditating, doing Reiki and listening to Mozart morning and evening. I have been feeling great and have a lot of energy. I like the tape you folks gave us the best of all. I have listened to it over and over, but would probably not recognize it if I were to hear it someplace else. My sister and I are alike in that way, unfortunately. She said she can always recognize the Star Spangled Banner because people stand up. That sounds funny, but it really isn't that far-fetched for people who are as deaf to music as we are.

Get the Right Equipment

Installing the right equipment will enable your loved one to maintain some independence, and it will protect you from unneeded physical strain. Sometimes the solutions are simple and relatively inexpensive.

Madelyn learned this soon after Quentin's stroke. On February 6, 1994, she wrote:

It's harder all the time for him to get out of bed. Thank goodness Greg came home and installed the ceiling hoist. I honestly don't know what we would do if we didn't have it. Last week I happened to be in the bedroom several times when Quentin was struggling, and I helped him up with the hoist. Then one night, I had severe chest pains. It used to never scare me, but it's hard to not get real concerned now, as I am needed very much. The pains didn't last too long, but I did learn that I just can't be pulling him up all the time.

Over the course of the next several months she made some small changes that made a big difference. On August 21, 1995 she wrote:

I came up with an idea in the middle of the night that Quentin approves of. Our bathroom door opens back toward the toilet stool, and it is so hard for him to get around it. I suggested we take the door off and have it open the other way.

By changing the way the door swings, Quentin could use his walker to get into the bathroom. As it is now, he has to use the cane to get into the bathroom, and that is not very satisfactory when he is so wobbly.

I also suggested putting a railing on the wall next to the stool, and he thought that was a good idea. We will get the materials when we go to town tomorrow. I'm also going to see about a "monkey bar" like they have on hospital beds to help a person get up. I want to see if I can get one that will work on his bed."

You Will Get Angry Sometimes – Learn to Forgive Yourself

Providing care for a loved one can be exasperating. It is not unusual to become angry and frustrated. Recognize that you are human, and sometimes you say things you wish you could take back. Don't dwell on your harsh words. Forgive yourself and move on.

On June 12, 1994, Quentin insisted on helping his son following a wheat field fire. Madelyn was scared and angry because he stayed in the field too long. She wrote:

"At 8:00 o'clock I called him on the radio and asked if he was going to work all night (in a not-too-nice tone of voice). He assured me that he was almost through. He finally came dragging in at 9:30. I'm not at all proud of myself, but I met him at the back door hollering, "If you have another stroke it had better by-God kill you!"

I went flouncing off to the living room. He came in and said he was sorry – he just hadn't realized how late it was. I was still mad and

informed him that you didn't have to be particularly smart to know when you watched the sun go down, dark settle in and the moon start to shine that it was time to quit.

I'm still convinced the reason he had the stroke was because he'd been working too hard. When he said he was retiring last year, he promised he wouldn't work on Sundays or after supper any more, but he still came in every night between 9:00 and 11:00 pm.

I feel I was entitled to be scared and mad, but he did look so good and happy that I'm sorry I jumped on him the way I did. He hasn't had much energy since. Who knows whether it's because he worked too long and got too tired, or because he was reminded so forcibly that he can't work and live the way he has for the last 48 years."

Madelyn survived her caregiving experience by taking care of herself physically, mentally, and spiritually. Although there is nothing that can make the job of caregiving easy, there are resources and support groups that can help a person cope with it. For more information and to order the book *Letters from Madelyn, Chronicles of a Caregiver* visit www.LaineyPublishing.com.

Resource box:

Elaine K. Sanchez is a successful author and speaker whose passion is helping people find hope and humor in aging, illness, and long-term caregiving. The Midwest Book Review praised her book saying, "Details about surviving the day-to-day labors of physical caregiving as well as a big picture about what truly matters in life make *Letters from Madelyn* an invaluable read, cover to cover, especially for anyone coping with a loved one's slow deterioration."

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