



A Burden Shared Is a Burden Halved

By: Hilary Mincenberg, activities coordinator at RoseCrest Assisted Living at St. John Community

When it was suggested to me that I might benefit from an Alzheimer's support group for caregivers, I remember smiling politely and thanking the well-meaning party. I also remember my exact thought as I turned away: "Oh you think so, do you? You don't even know me! I certainly don't need to emotionally dump on strangers who, like me are barely keeping it together. Why would I do that to them? Why would I do that to myself?"

I was missing the point.

It wasn't about something being done "to" me or to anyone else. It was about something being done "for" me and for others who were on the same journey with a loved one with dementia.

To say that I was resistant to the idea would have been an understatement. I could not accept that I deserved, let alone needed, any help.

My mother was the one who was sick. She had been diagnosed with Alzheimer's disease five years prior to being moved to Pittsburgh, where I was her primary caregiver. I believed, therefore, that my entire focus should be on her care. I did not understand that I could become sick as well – sick with the stress of caregiving.

The progression of my isolation had been insidious. I had not noticed that I had begun to cancel social engagements because "Mom might need me." I could not see the connection between my inability to concentrate enough to enjoy a movie and my obsessive wondering about Mom's condition and care. I had failed to notice that friends had stopped calling. No one knew what to say to me anymore.

There was only one topic, as far as I was concerned. I had, in fact, created my own little world, with my mother and myself as the only inhabitants. Everyone else had minor roles to play. No wonder I thought I was all alone, that my situation was unique and, therefore, that no one could fully understand how I was feeling. Having cut myself off from anyone or anything that might have helped me gain some perspective, I was overwhelmed with feelings of self-doubt and hopelessness.

I didn't realize there was help available to me. It was out of desperation that I finally "gave in" and agreed to try a support group.



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At the meeting, I found myself blurting out that I had had a terrible interaction with Mom that day. Not only had my mother not recognized me but, for the first time, she had swung at me defensively. It wasn't the action that had rattled me. I understood it – intellectually. It was how it affected me emotionally that had left me completely unnerved. I was so angry, I told the group, I was ready to “spit bullets.”

And I was ashamed of myself. I had to admit that, even though I knew it was irrational, I was angry at the disease, and yes, for a split second, angry at my mother. I was horrified by that admission. I was feeling like an abandoned child, I told them. If I was going to have that kind of response, was I even emotionally fit to be around Mom?

Finally, I took a breath. I waited for the appalled silence and judgmental looks that I assumed would follow. Neither happened. Instead the group assured me that every person there had similar feelings at one time or another. This was a revelation to me. It was also a tremendous relief.

From that point on, I was able to open my mind and heart to what the support group had to offer. I learned that, although I might feel overwhelmed sometimes, that was not the same thing as actually being overwhelmed. I learned that Mom was not the only person affected by her diagnosis. I was going through something profoundly difficult, too.

Acknowledging this was neither selfish nor self-centered.

I learned that, since there was no instruction book for going through this experience, no emotion I felt would be considered weird or inappropriate by anyone else on the same journey. I learned that we, the family members, were all coping as best we could and that no two ways of doing this would look exactly the same.

I learned that all of us had the similar questions as well as similar emotions. Was it wise to take our loved ones out to a restaurant? Should they be told about the death of a dear childhood friend, or should we just not mention it?? How were we to live with ourselves if we didn't tell them? Wasn't that lying?

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As we discussed each issue, possible solutions emerged. I learned that it was alright to laugh together when a “strategy” went very differently than anticipated. Laughing at ourselves made it possible for us to feel safe, accepted and not judged. I learned how it felt to trust a group of strangers, solely on the basis of our common choice to be with our loved ones on their journey with dementia.

There is a saying that, “a burden shared is a burden halved.”

For me, that support group experience proved this to be true. However, it gave me so much more. There is a healing power in not only receiving help, but in giving it. Perhaps the support group’s strength was simply its ability to generate hope. The hope that, together, we family members could do this – walk with our loved ones to the very end. The hope that, when this significant, precious time with our loved ones was over, we would be better for it, that our lives would reflect everything we had learned from the experience.

The support group helped me be the kind of daughter that I had always wanted to be. For that, I would always be grateful.

My hope is that anyone with a loved one with dementia would take the opportunity to join a support group and receive the same understanding, compassion and help that was made available to me.