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Alzheimer's and Dementia Resource Center of NYC

Newsletter #13 – July 2022

BEING A CAREGIVER

Caregiving under the best of conditions is difficult. I have taken the liberty in this newsletter of sharing my experiences as a caregiver. I would welcome hearing from you about yours. The e-mail address is ira@asherman.com.

SHE WILL ALWAYS BE THE LOVE OF MY LIFE

Ira Asherman

Slowly but surely, I am losing the woman I love and married some forty plus years ago. Every day my wife sinks deeper into her own private world, a world I can rarely enter or understand.

We are living with Alzheimer’s, and it hurts in ways I could never have imagined. I am now her caregiver. Nothing prepares you for being the caregiver to one you love. It is painful and humbling. However, if you allow it, caregiving can also be very rewarding. It has forced me to dig deep to find skills I never knew I possessed. Despite all the heartache and tears shed, I believe it has made me a better person and a better husband. I have become more caring and understanding. I have found ways to move forward. As painful as this journey is, I know that somehow, I will get through the day.

For both of us, life has become an emotional roller coaster.

One moment she screams at me, curses me, scratches me and indicates I am not worth having around. Fifteen minutes later she gives me a big hug, kisses me, tells me how much she loves me, and allows me to hold her as we slowly dance to one of our favorite songs. Those latter moments have become far fewer and she is barely able to articulate what she feels. Her behavior, however, tells me how scared and frightened she must be. I cannot comfort her. I cannot make the pain go away, and there are no medications that will do it for us. As for a cure, that is still an unfulfilled dream, a dream unlikely to come to pass in our lifetime.

The early years were not nearly as difficult. Yes, she asked the same question multiple times, forgot where we were going, whose home we just left, and what show we had just seen. However, we managed to attend the theatre, the ballet, concerts, dined out with friends, and continued working and traveling.

Over the years, however, these activities have lessened, household chores are a thing of the past, and I have watched Alzheimer’s slowly imprison the woman I love. Physically, she is still there, and at times she looks as beautiful as ever. Most of the tasks we take for granted -- be it eating, dressing, showering or toileting require some degree of planning and at least one person to help her. When she asks for her mother and calls me Daddy, I cringe.

We have terrific aides with us six days a week. We still go out for walks, shopping, lunch, and occasionally to the ballet or a concert. She still attends a variety of programs designed for those with dementia and their caregivers. She has a beautiful voice and has loved being in the Unforgettables chorus. She enjoys siting in the neighborhood park watching the children.

Unfortunately, even these pleasurable activities at times can prove to be a challenge as we are never sure how she will react or behave. She has been known to resist leaving an activity or a taxi but rather to sit and wait. Waiting for what we are not quite sure. Be it day or night, sleep has become her favorite activity, the one time during the day she seems comfortable and at peace.

Alzheimer’s is a terrible disease and the pandemic has made it worse. It takes people in small bites. You watch someone you love slowly disappear before your eyes. For every family, the road is different but one thing is constant - the inexorable destination. Regardless of the road traveled, you will be filled with pain, regret and guilt. It never ends. You will sit home at night and realize that you have no one with whom to discuss today’s political events, last night’s show, your taxes or a recent visit from friends. You will quickly realize that you are alone and that will not change.

That person I love so dearly is slowly vanishing before my eyes and there is not much I can do about it. Don’t get me wrong. She can still make me laugh, give me one of her special hugs, and when she sings or hums one of her favorite songs, I know my wife of forty plus years is still in there. Yes, you can slow down the progression of the disease, but it will catch and pass you and leave you wondering what just happened and why. But try to find the joyful times, as even Alzheimer’s caregiving can surprise you with rewarding moments.

News From and About our Community

A word of thanks to the following:

- our friends at Lincoln Center Moments for a great season of both virtual and live programs.

- To Tania and Dale of the Unforgettables chorus for bringing us a live concert. The first in several years.
- to the folks at the Rubin for running a Saturday program for caregivers. A great idea.
- To the folks at the Intrepid for sponsoring dances with RB cares and providing UBER cars to get us to the Intrepid and back home.
- Connect to Culture for their in-person program with the Orpheus Chamber Orchestra.
- Congratulations to the folks at the NYU Family Support Program who recently got their funding extended through June of 2027. A great vote of confidence.
- To the following for publishing event calendars

  CaringKind

  Connect to Culture,

  Alzheimer's Foundation

Note from Ira:

Check the event calendar on our website on a regular basis. We are constantly adding new events.

Get your name on our mailing list. Email your request to: contact@adrcnyc.org

We have a new telephone number.

212-243-0386.