

Newsletter #16 - March 2023

Where is the Event Calendar?

A Word of Explanation

For the best several weeks we have not published either our newsletter or our weekly event calendar. Recent health issues have limited my ability to complete either activity. It is unlikely we will resume the weekly calendar. We hope our recently published Resource Manual will give you a list of all the organizations in NYC and that you can get on their mailing lists. Doing so will allow you to keep up to date on the programs you are most interested in attending.

In this newsletter I have taken the liberty of including my most recent paper titled, "When the Caregiver Needs Care". I hope you will find it interesting and would welcome any comments that you might have. It follows:

When the Caregiver Needs Care

by

Ira Asherman

I've got a problem that feels uniquely mine. However, it is a cloud that hangs over all caregivers: what happens if I get sick and can no longer care for my loved one?

For the past ten plus years, I have been my wife's primary caregiver as she and I learned to live with her Alzheimer's. With the help of two aides who worked days, we were doing more than managing. In fact, we were doing quite well.

Then my world flipped 180 degrees as what had been a chronic ailment for me, suddenly decided to become aggressive, requiring seven days in the hospital. Panic! Who would care for my wife in the evenings (my province) and who would give her the Insulin she needed to control her diabetes? The agency we worked with quickly supplied three women to cover the evenings. As for the diabetes, several of our neighbors who had experience giving shots to parents helped out, as did a friend who was a nurse and another who was a physician. Ad hoc it was but it worked. We got lucky. Aides are not allowed to give shots.

After leaving the hospital, it was clear... I was in no position to resume my responsibility of taking care of my wife. Not only did *she* need help, but so did I. The caregiver now needed care!

An aide during the day was no longer going to suffice, I now had to face the reality of round the clock assistance. I needed someone in the house overnight as I could no longer be there if my wife needed me. Not a very comforting thought; it scared me. Caregivers provide care... now what? This was painful in a way I had never anticipated. I could not provide. I had learned to navigate Alzheimer's ups and downs, but this was new, this was not supposed to happen. The three women stayed with us as I came to fully appreciate my limitations.

Despite her Alzheimer's, my wife knew something was amiss. She could not articulate the problem, but it was clear to her that I was missing, and when I returned, we now had three new evening aides in the house sharing each week. If I had any doubt about my situation, the aides were a clear sign that my life had changed. The caregiver now needed care. What new challenges were ahead and could I meet them, challenges for which I am not even remotely prepared as I am not even clear as to what they are likely to be?

While I was in the hospital, the situation was clear-cut: more assistance was required to take care of my wife. I had to acknowledge that I was unable to provide the nighttime care I had previously provided.

My situation highlighted an important responsibility of a caregiver that may not often be discussed: planning in advance for what to do if the caregiver needs care.

Resource Articles

- Being Patient -- Brain Bug? Clinical Trial Tests Antivirals to Treat Alzheimer's
- Web MD Why Don't We Have a Cure for Alzheimer's?
 Note: There are several other articles on Alzheimer's in this website.
- Mayo Clinic -- Alzheimer's treatments: What's on the horizon?
- Cake -- How to Cope With Family With Alzheimer's: 14 Tips.
- Verywell Health -- Caring for a Spouse With Dementia or Alzheimer's
- Woman's Alzheimer's Movement (Cleveland Clinic) Dr. Barbara
 Ella Milton Jr., A Q&A About Caregiving And Her Book Heeding the Caregiver Call
- Alzheimer Society (Canada) -- Understanding how your relationship may change

Check these Ted Talks

- A mother and son's photographic journey through dementia
- How to meaningfully reconnect with those who have dementia