

## **LESSONS I HAVE LEARNED:**

### **My Years as a Caregiver**

**by**

**Ira G. Asherman**

For the past twelve years, I have been the primary caregiver for my wife who is living with Alzheimer's. The years have not been easy. They have been filled with both heartache and joy. Years in which I have learned a great deal about myself, and the issues involved in caring for a loved one who is steadily fading away. In looking at the following lessons, do not assume I have done them all. That is far from accurate. However, I learned both from what I did and what I was unable to do. Not only will you be caring for a loved one, a difficult task by itself, but you will be assuming responsibility for most if not all household tasks; tasks that in the past were likely a shared responsibility. Either responsibility alone could be overwhelming; put the two together and you have recipe for trouble.

These are among the lessons I have taken from this journey:

## **RESOURCES**

### **Meet with your Advisors**

As soon as possible, you want to meet with your accountant, your lawyer, insurance agent and, if you have one, your financial advisor. Your goal is to ensure that your will is in order, that your spouse will be cared for should you pass first and that you understand your financial resources as this can be a very expensive journey. If you have long term care insurance, make sure you understand the coverage along with any waiting periods.

## **EMOTIONS**

### **Allow yourself to be angry**

You will get angry both at your loved one and at yourself for getting angry. Allow yourself the anger. You can't stop it, but you can recognize what triggers it and can prepare yourself for the moment. For me, it was repeatedly asking the same question or making the same statement. In time the anger will begin to dissipate, and you will be kinder to yourself and less frustrated and annoyed with your loved one. Your partner is not doing it to drive you crazy. Alzheimer's is taking hold and will not let go.

### **Accept the feelings of guilt**

They are part and parcel of allowing yourself to be angry. Remember you have done nothing wrong.

### **You will not Understand**

As the disease progresses and your loved one's ability to communicate with you drops, life will become a lot more complex. Things will happen and they will not be able to explain, and you will become both frustrated and frightened. There is not much you can do but trust your instincts as to what steps are necessary. Early on, we found ourselves spending more time in emergency rooms. Over time we learned and were able to deal with situations on our own.

## **THE DISEASE**

### **It does not get better**

Alzheimer's is one of those diseases for which there is not yet a cure. So, your loved one is not likely to get better. The most you can hope for is that they do not deteriorate too quickly, and you can have them with you for an extended period of time.

### **There is no formula**

Alzheimer's does not progress in any one specific way. This journey is not a straight line from Stage one through Stage four. This journey is filled with twists and turns that will continue to challenge you. Everyone you speak with will have a different story to tell. Some progress quickly – others do not; some are aggressive – others kind and gentle; and some are able to eat their meals – others require liquefied food or being fed.

### **Medication**

Now for the first time there are drugs available for those in the early stages of this disease. Make sure you have a physician who is familiar with the new drugs now available, and the clinical trial process as new drugs are constantly being tested.

## **AIDES**

### **Hire an aide**

If you have the financial resources available, hire an aide. Doing so will make your life a great deal easier. The aide will give you free time as well as doing those tasks that you wish were not part of your day. Most importantly, allow the aide and your partner to build their own relationship. The quality of their relationship in no way diminishes you.

In fact, the exact opposite is true. Your goal is twofold: to have them get so comfortable with each other that they can go on their own; and you are comfortable allowing them to do so. If all works well, the aide provides you with the freedom you need to recover and to be ready for the next day. Except for certain doctor's appointments, my wife's aide takes her everywhere.

### **Learn from your aides**

Your aides bring a lot of experience to the job. You are not their first assignment. Watch them and learn from them. Do not be afraid to ask them questions as to why they are doing certain things. All the aides we have known have been more than willing to share their knowledge.

## **ACTIVITIES**

### **Get out of the house**

Get out as frequently as you can. It is very easy to stay home. Watching television can be a safe way to zone out. If you have hired an aide, plan activities for the three of you. It need not be something fancy – sitting in a local park can be ideal. Try to go to those places that you enjoyed in the past. They have the potential of bringing back happy memories. We go to modern dance performances as Sandy still seems to enjoy it. We sit in a row that does not require walking up any stairs, and our aide comes with us. We are lucky we are within walking distance of two dance theatres.

### **Go out for lunch**

It has not always been easy, but we make sure to go out for meals several times a week. Lunch is usually the easiest as there are fewer people in the restaurants and many places have lunch specials. It's good to frequent the same restaurants so that the staff become familiar with you and your situation. I usually take the time to explain our situation. I have found the restaurant staff to be very helpful and understanding. Recently, I have printed cards that I give to staff to explain my situation.

### **Look for programs in your community**

We have found so many great programs at museums, local concert halls and private organizations. Sandy loves to sing, and she is part of a chorus that provides so much pleasure for her and for us when we go to her performances. At your museums check for "access" programs. These typically include programs for folks with disabilities.

## **Virtual programs**

Virtual programs have proliferated since the Pandemic. They are ideal, especially for those of us with a limited ability to get around. Their great advantage is you need not travel. Just sit in front of your computer. Try to balance the virtual programs with in-person activities. The latter provide a warmth and intimacy that virtual programs cannot match. Our experience is that they have made a real difference. Many organizations offer programs and activities designed for people with Alzheimer's and dementia. We have recently prepared a manual of all the NYC based programs. Many of these programs are virtual and can be accessed by anyone/anywhere.

## **FAMILY AND FRIENDS**

### **Talk to your friends**

Tell your friends what is going on with your loved one. The more they know, the more they will be able to help you. For a several years, we continued going to the theatre with friends. We were three couples, and the women were wonderful. If my wife needed the bathroom, one of them would always go with her. It was a wonderful statement of love and caring. Tell friends what your partner particularly likes to do. One friend always sings with her.

### **Speak with family members**

As with friends, family members can only be helpful if they know what is going on. Do not sugarcoat what is happening. Let them know how they can be of help. We spent two weeks in Europe with family members. Prior to our departure, we spent several hours talking about what was happening and what they should expect. This is a trip we could not have taken if family members had not traveled with us. Speaking with family members has also allowed family functions to be less filled with tension and more enjoyable.

## **YOUR HEALTH AND EDUCATION**

### **Find time for yourself**

This is a must because you will need it. Do something that gives you pleasure. Go to a museum, take a walk, go to lunch with friends, anything that gets you out of the house and away from your day-to-day responsibilities. And make sure you keep in shape. {Can you do this without an aide?}

### **Find a support group**

Every city has support groups. Do not join just any group; find one that works for you. They are available both in person as well as virtually and at all hours of the day and evening. Do not let this opportunity pass you by. You will need support. This is not a journey you can make on your own.

### **Educational programs**

You cannot make this journey without information about the disease and its progression, legal and financial issues and improving your technical skills in helping your loved one. Love and caring will not be enough. The Alzheimer's Association, The Alzheimer's Foundation and Caring Kind all conduct programs, and many are virtual. Also check your local universities as many have Alzheimer's and Dementia research centers.

## **SECURITY**

### **Make your home Alzheimer's safe**

As Alzheimer's becomes more and more a part of your life, the need to make your house safe becomes more pronounced. We have added bars in the shower, a shower seat, special seat on the toilet, removed carpets where appropriate, and added an alarm system should my wife decide to take a late-night walk. Yes, it happened. As another act of love, friends purchased a recliner for my wife. Other options are to add ramps and bed rails.

### **When you need Care**

Put a plan into place should you get sick and be unable to care for your loved one. This is something I failed to do, and it cost me dearly.

---

The one abiding truth is that everyone's story is different and that you will be on an emotional roller coaster, from early in the day to when you turn out the lights... and often after that. Look for joy. Caregiving is filled with heartache and sadness. However, it **does** have moments of joy. Savor those moments and share them with others. It also provides real opportunities to learn and grow.

## THE WRITER

Ira lives in NYC with his wife Sandy. They are the founders of the Alzheimer's Dementia Resource Center of NYC [www.adrcnyc.org](http://www.adrcnyc.org). Ira can be reached via e-mail at [ira@asherman.com](mailto:ira@asherman.com).