



## 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 but they have been filled with both heartache and joy. They have also been years in which I have learned a great deal about myself and the issues involved in caring for a loved one living with Alzheimer's. The lessons, at times, have been painful but nonetheless valuable. In looking at the following, do not assume I have done them all. That is far from accurate. However, I learned both from what I did and what I failed at.

Among what I have taken from this process are:

- **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 the same question or statement over and over again. In time it will begin to dissipate and you will be kinder to yourself and less frustrated and annoyed with your partner. Though it may feel that way, they are not doing it to drive you crazy. Alzheimer's is taking hold and will not let go.
- **It does not get better.** Alzheimer's is one of those diseases for which there is no 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. 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 they be liquefied or they be fed. This can be frustrating as it makes planning very difficult.
- **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.

- **Give your aides their freedom.** Allow your aides the freedom and responsibility to do their job. In the beginning I spent more time with my wife and her aide, but as time went on and my trust level increased, I have spent less and less time with them.
- **Learn from your aides.** Your aides bring a lot of experience to the job. You are not their first job. Watch them and learn from them. Do not be afraid to ask them questions as to why they are doing certain things. All of the ones we have known have been more than willing to share their knowledge.
- **Embrace the cultural differences.** On a totally different level I have learned from our aides. They have represented a variety of countries – Georgia, Mexico, Nigeria, Sierra Leone, Mali, Haiti and Guyana. Each country with a very different culture, foods and how spicy the food needed to be. A new world and in several instances a great freshly prepared meal. Food I would never have experienced. It was a lot of fun.
- **Get out of the house.** It is very easy to stay home. Watching television can be very easy. Get out as frequently as you can. 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 place that you enjoyed in the past. They have the potential of bringing back happy memories
- **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 restaurant and many places have lunch specials. Frequent the same restaurants and speak to the staff. Let them know what is happening. I have found restaurant staff to be very helpful and understanding.
- **Talk to 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 number of years, we continued going to the theatre with friends. We were three couples and the women were wonderful. If my wife needed the toilet, so did they; and if they were going, they always made sure to take Sandy along. It was a wonderful statement of love and caring.
- **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 and let them know how they can be of help. We spent two weeks in Europe with family members. Prior to leaving 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. Our aides have attended bar mitzvahs, graduation parties,

Passover dinners, birthdays, bridal showers and family barbeques. They have all become a part of our family.

- **Find time for yourself.** You will need it. If you have hired an aide, this will be much easier. 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.
- **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.
- **Limit virtual programs.** Virtual programs have their place. Especially for those of us with a limited ability to get around. 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.
- **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. As another act of love, friends purchased a recliner for my wife. Other options are to add ramps and bed rails.

Caring for a loved one with Alzheimer's is not an easy task. 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 the time you turn out the lights. Look for the joy! Caregiving is filled with heartache and sadness. However, it has moments of joy. Savor those moments and share them with others. It also has real opportunity to learn and grow. Do not let those moments pass you by.

### **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) or by phone at 917.270.5087.