

Eighteen of us met for a meeting on this beautiful November 18th. It was sunny in the 50's and little to no wind. We were blessed to have Sylvia and Ann L with us, as well as Nancy. Nancy works in the outreach office and opened it up for us last week. She had to do the same this time because the workman still have their things in our room and the tables are all leaning against the walls. We are still hoping to be able to use it in 2 weeks. But if not Nancy will come to our rescue again. She is so sweet and attentive to us. She moves chairs around and straighten up the table and the couches and made sure everything was just right. She is a god sent, and we love her.

Sylvia looked soooo good. We had all been so concerned. She had Ben with her and he was as good as gold. He was so distressed by the separation from his wife and by living at Sunrise Asst. Living. He asked Sylvia if she had been hurt. He understands that something was wrong, and that is probably why he became aggressive at the facility. They are a true love story. Sylvia had a spot removed on her breast and one on her lung. She went through radiation therapy five years ago with breast cancer. The doctor said she did not need Chemo therapy. She is now taking a pill, for which Sylvia is very happy. She came home from the hospital after two days, Ben came home the next day. The operation over and being reunited has seemed to calm them both. Help is definitely needed in the home. They have been going through an agency called Dignity because it is recognized by their long term insurance. In a little over a week they have gone through 5 aides. They do not help, and Sylvia has not been able to connect with them. For the 5 days they paid out over \$1,000. They are now going to use Happy Days Home Care - submitted by Elaine. For \$525. a week you get a live in who will work with a cousin or friend to split the week. Right after the meeting Sylvia went to meet the woman at the Merrick Station. She would then bring her to her daughter Allison's, where they could both interview the woman. Elaine said that they have certificates showing they have had training, she should ask to see that.

Allison, Sylvia's daughter came to the meeting today. She surprised us with 2 big boxes of doughnuts. She wanted to show her appreciation for our help and concern for her mother and her family. She brought her son Ethan who went straight to his Grandpa Ben. We all talked and soon we watched Ethan holding Ben's hand and taking him out for a little walk. They are a very loving family and they are in this together. Sylvia also thanked us for the balloons we sent her, Elaine arranged to have them sent and the money was taken from our treasury, so it was from all of us. We also used our money to get a \$25. Memorial in Caregiver New's for Ann L's mother Ann. As you know she died last Sunday from pneumonia and infections. Her body was breaking down for days, her blood pressure and vital signs kept dropping. The doctors let the family know that they were just putting off the inevitable. Ann would not survive. It was at this time that she turned to her daughter and told her she didn't want this anymore, no more. So, Ann said to stop everything, no more tests - let her be in peace. After a short time the hospital called Ann in the morning and told her it was time, she had to come to the hospital. Ann said she had to shower and she'd be there within the hour. A few minutes later they called back and said she had to come now. She did. She was with her mother as she passed. That is something that brings us great comfort. To be with them at that moment. I think it is because no one wants to die alone.

Ann has had conflicts with her sister Eileen from day one. Her sister has always had her eye on their mother's money, Ann has always had her eye on their mother. Eileen had a hissy fit at the hospital blaming the doctors for not treating the infection sooner or better. She verbally attacked Ann at the funeral home. But Ann just concentrated on her final gift to their mother, and somehow they got through it all. At the funeral there were many friends and relatives. Ann was able to avoid her sister and comfort herself with the other guests. After selling her mother's house and splitting the money, it will truly be finished. Ann's life has been on hold for over 3 years, now she has it back. The pain of losing her mother will be with her for a long time, but Ann gave herself a real gift. Over the years she tape recorded her mother and herself talking in the kitchen. She will be able to hear her mother's voice forever.

Nancy also talked about the death of her father a short time ago. She has been dealing with her mother's inability to move on. She will not go to a bereavement group, she doesn't want to socialize, she has no hobbies. She just sits in that house, a house that is so full of Harold. Nancy feels uncomfortable there herself. She went from caring for her parents to caring for her mother. She has no time to mourn. She has to be strong. When I

asked her how she was coping, I could see the pain in her eyes. She is having a problem with the finality of death. She'll never see her father again. There were bad times and he suffered many indignities, but at least she could spend time with him. No matter how hard she tried she could not put a band aid on her father's disease and make him well. Now no matter how hard she tries, she can't make him reappear in her life. She feels powerless, when in reality she is a strong intelligent woman who attacks problems and comes to the aide of those that need her. Her faith will eventually help her, because she knows that she will be with her father one day and he will be whole and well.

Annette also has emotional turmoil. Gene has always been antisocial and refuses to go out of the home, or even out of his room. Her son visited with his girlfriend who is in a wheelchair and Gene was rude to her. The young woman did need special accommodation, but she was able to care for herself - yet there is the possibility of his being jealous. Annette feels like a widow, she is unable to do things with her husband, and she attends all functions alone. She wants to spend Thanksgiving with others, but Gene will not go. Her daughter Joy knows that this will mean that her father will not be part of the day and is naturally upset. She wants her family together. Annette has given up trying to include her husband. The mother and daughter had a big confrontation. I have met all of Annette's 3 children, they are all wonderful, caring adults. They have watched their father battle AD and their mother have 5-6 surgeries in the last year and a half. They have pulled together to care for both their parents. They have given their love and their support 100%. But it has been a long time and it has taken a toll on everyone. They are all frustrated, and from now on it will be very easy for anyone of them to snap. This time it is over Thanksgiving. The thing to remember is that they love each other very much, and when they say things in anger, and they will say things in anger, they have to know that this disease has made all of them victims. They want to be happy, they want to be normal - but since everyone has their own idea of happy and normal - they won't be able to please everyone. There are two goals that have to be met here. Gene must be safe and cared for, and each other person involved has to independently do what they need to do to cope. Passing judgement helps no one. Annette thinks of her daughter as being someone special - I do also. She prints out these minutes of the meetings for her mother, and is there if needed. As upsetting as this situation is for Annette, I know it is equally awful for Joy. This will pass. If one of them died tonight - the survivor would live with guilt for the rest of their life. We all know this reality and that is why we apologize, make amends, and do whatever we can to improve relationships.

Nattie has a similar situation about where to spend Thanksgiving. She has decided to spend it with friends who go the extra mile to accommodate her and Jim's needs. She will not be pressured to have a family gathering where she has to tend to everyone and everything. Her friends will not allow her to lift a finger. When you are a caregiver, your happiness and contentment has to mean something. Natti has someone with Jim today. Last meeting he fell off a chair because it had wheels and he bent to pick up his hat and the chair rolled back. He had a big red bump for days. Sunday she took him to the hospital because he was vomiting. They took a catscan and there was no damage. He has improved ever since. But her need for help in the house grows each day. The pressure of doing this alone for so many years, is catching up with her.

Eleanor went to Florida and the aide did a good job of caring for her mother Ann. But now the aide is feeling overwhelmed. She is 72. She walks for 2 hours every morning, then has to watch her stories in the afternoon, and later in the day she is asking Eleanor to take over some of the chores for her. Either a new aide is needed, or Asst. Living. She visited unannounced at a place called Maple something in RVC. She liked it. There is a transitional unit between the regular population and the AD people. Her mother is right at that stage. They are locked down and the place is like a small apartment. The problem is that money is an issue. She can only afford to keep her mother there for so long, and if she goes to the AD unit it will be more expensive and beyond their means. At that point she is concerned about getting her into a Nursing home when the money runs out. It is true there would not be a dramatic need for a bed for her, but there are ways. The most used is to have her mother admitted to a hospital for whatever reasons you can get a doctor to sign off on. Phantom pains, a fall that needs x rays and observation, etc. Once admitted, you refuse to have her discharged. At that point the social worker will assist you in getting her placed in a nursing home. You will be asked for 3 choices - the first with an available bed is the one she will be sent to. In the mean time Eleanor is meeting with a financial planner to see

about the possibilities for Asst. Living. Her mother Ann is nasty and won't leave the house. As long as she is in this stage, there will be problems finding help and keeping her in the home.

Pat and her mother Mary are both trying hard to do the right thing. They just can't decide what that is. Tom is in a facility, Pat wants to keep her father there and Mary wants her husband home. She feels he deserves to be in his own home, she would want that if the roles were reversed. But, we are talking about the ability to safely care for her husband at home, and Pat feels it is beyond her mother's abilities. Aides can be unreliable and her mother will find a way to over tax herself. Mary said that Tom is much better in the facility. Bringing him home could change that. We often feel that placement is like throwing them away, turning them over to strangers. We still have the same control and can visit whenever we want. Mary liked the thought of visiting him and just enjoying his company. Not worrying about cleaning or feeding him. She also sees that her daughter is starting to burn out. Pat spends time dealing with her parents everyday. She can not picture herself having her father back home and having to worry about both of them in that house again. There is no anger or power struggle going on here. Both women respect and understand the other's feelings and so I see an agreed upon outcome for all of them.

Muriel has been trying to take care of her husband Al, and of course she is frail and tiny and it takes a lot out of her. She has changed his diapers and done for him for many years. She is looking for a little help. Right now she has Senior Respite with him on the Saturdays she comes to meetings. She is so very stressed out. She has so many thoughts going through her head that she is unable to hold onto any of them. About a month ago she told us she had a man working in her home and when he left she found her jewelry missing - things from her mother. She called him and asked for it back saying she would not press charges, and he pleaded he was innocent. That he would never do that. Well, wouldn't you know it - she found her jewelry, she had hidden it in a shoebox. I had told her that many patients take things and hide them or throw them in the garbage or toilet and we never find them again. That's when she hid them so well that she forgot about them and where they were. When she found them she was so embarrassed. She called the worker back and apologized. I'm sure he understood and was grateful that he was no longer under suspicion - but Muriel feels so ashamed. She really needs some time off or some pampering or a chance to have fun. She has to relax and get rid of all that pent up tension - it can do you in. But little Muriel is one of the most active seniors I have ever seen. She is out and about all the time. She went to a EAC Senior Respite function and Jean came up to her and reminded her that she was in our group. Again Muriel couldn't focus and place her.

Jean has had nothing but problems lately. Her husband Art was in 2 daycare programs and keeping active and coming home after being tired out. It was easier for her and better for him. Then he began to fall asleep at daycare and both programs dropped him saying he was not participating and therefore not benefitting from the program - lies. He was benefitting and so was Jean. She had time to herself. After a few days home with no structure, Jean so a huge decline in Art. He had no desire to do anything. No reason to get out of bed. She was able to get respite 2 days a week and then with the encouragement and endorsements from Elaine she went to Broadlawn and got Art in their program. He has been there for a short time, but he is already his old self. He gets up each morning anticipating his day. Daycare is one of the best things we can incorporate into our lives.

Elaine was so full of information once again about Broadlawn - she knows the name of everyone who works there and exactly what goes on. She was excited to help Sylvia with tips about Happy Days Home Care. Her mother is doing well since she had her medicines evaluated during the summer. She is back at Broadlawn and doing well with her live in aides. Elaine is able to bounce around the country and live her life without feeling pinned down. But, she has a potential new problem. Her mother Albina's sister also had AD. She calls Elaine all the time complaining and talking nonsense. Her aunt has 3 sons and none of them are taking Elaine's advice. She has given them so much information - even printed things out, they take it say thank you and don't act on it. Elaine feels that she will be dragged into this. To be frank, she will not be just dragged in - she'll push open the door and take over. Within a few weeks she could have an aide with her aunt - who now lives alone - and have her going to broadlawn. She could have it all put in place and then bow out. Her aunt would be cared for and she would not be getting phone calls from her or her sons. I believe that she will go for it, because she can, and

because she could do it better than anyone else in a fraction of the time.

Martha returned again this week. She really feels comfortable with us. She needs the feedback. She doubts herself mercilessly. So much so that she sometimes does nothing at all. She feels she needs help in the house, but she is not ready to have someone in the house. Elaine said none of us ever wanted that. But, we bit the bullet and made our lives better. Martha is one of those people who can find a dozen reasons not to do something that needs to be done. She has no confidence in her own abilities to change and adapt. If you want to be rich and famous you have to study and practice. If you want to go on a vacation you have to make reservations and plans and pack the right things. If you want a big Thanksgiving affair - you have to invite people, shop and cook. If you want an aide in the house you have to shop around, interview, work out their responsibilities, and find a place to be alone in the house when they are there or a place to go like the movies or shopping. Nobody will take care of your patient or your house or your cooking or laundry - the way you do. But, give them their space and let them do it their way, but with the same outcome you want. Believe me, when you get the taste of not having to do housework or caregiving 24/7 - you will jump at the chance to get more hours of freedom, very quickly.

Another thing that Martha does is that she worries about doing the right thing the right way. I have said this so many times - there are no right or wrong answers and what ever you choose will make you feel sad because you are getting deeper into the world of AD. Everything is trial and error, and the good thing is that every error can be changed. You are not locked into any decision. We can tell you what we did, but it may not work for you. Still you have to try and keep trying till it works out, and then be prepared to change and try other things as your patient goes into different stages. It never ends and all you can hope to do it to keep up with all the craziness. In group you understand one true fact, this is not just happening to you. You are by no means alone. And you can always find someone to reassure and encourage you. Just keep moving forward.

We had a new woman visit us today her name is Liese - pronounced Lisa, but she prefers to be called Lee. Right after she arrived Muriel came in and Lee kept looking at her. It turns out that not only had they met, but Muriel had told her about this group and that's why she was here. But, once again poor Muriel had no recollection of the very important meeting in Lee's life. It wasn't until Lee said it was raining and we were parked next to each other, then the light bulb went off and Muriel remembered everything. She got up from the table and the two women sat and chatted through the whole meeting. I believe it will be a good relationship for both of them. Both their husbands are incontinent. But, Lee does not change him. He removes his own soiled diaper and puts it in the trash, he bathes himself, dresses himself with the clothes she sets out. He takes his own medicine that she has measured for him. She is keeping him as independent as possible for as long as possible, but she is overseeing everything. This keeps him going and gives her less to do. Like so many, she has been doing this for years and came here because her children insisted, they are worried about her and their father.

Lee told me up-front that she has never been to any kind of support group - but she is a natural. She is pleasant and listens intently and asks questions. She does not talk on and on and we have a few members who can talk up a storm. She just blended in and she was as comfortable with us as we were with her. Not often do we have good things to report, more often we use our time to discuss negative things - I know it is because we need the feedback when things aren't going well, and time is limited. But, it is nice when we hear happy or funny stories. I think it is important for us all to concentrate on the good things to concentrate on all that our patients can still do rather than what they can no longer do. Lee had a story to describe her husband's sense of humor and how he likes to get her. He wanted to vote, he saw so much about it on TV. So they went and he expressed to her that he wasn't sure if he could find the people he wanted to vote for. She told him they were Democrats, so he would only have to worry about line B and go straight across. When they got there she went with him to the booth and pointed to Line B and told him to just push the levers for that line. She left him. When he came out he said, "I think I made a mistake, I think I voted Republican." He then gave a huge smirk when he saw the look on her face and she knew he had gotten her again. His sense of humor is his best quality and he hasn't lost that. After I got home and read Lee's questionnaire, I saw that she is a RN. I know that has helped her as caregiver like it did for Millie, but it can also help us. She can be a useful member of the group and I am pretty sure she will return.

Ann G. came to group mainly to see Sylvia and Ann L. We all need to have contact with each other after something traumatic happens. I gave her things to make copies of. Next time we meet we will have new rosters with everyone's name on it. And we will have the 2007 schedule of meetings. When we meet December 2nd - it will be the last meeting of 2006. Hanukkah and Christmas and New Years will all use up the rest of the month. The next time we will meet after that will be January 6, 2007 five weeks later. So I hope we see you in two weeks. Esfira is not going to be with us, her grandson is having his Bar mitzvah.

We usually have a holiday party in December, but we usually have 2 meetings during the month. This time we won't and I feel that a lot is happening and we need to spend more time letting everyone talk, so we will have a regular meeting, but at some point we will have a raffle for a gift I'll bring - and I'll wear my Mrs. Santa hat. I hope to see you then. It will be a difficult Thanksgiving for some of you, for some it will be the first one without a parent, but, if you work at it you can pull this off and enjoy the day. Take care and keep in touch. And if you can watch :

Tuesday November 21st. PBS 9 PM = Frontline - Living Old

Because of all the interest and needs, I will be e mailing everyone the list of home companions.

Kathy