

October 21st Meeting

We had a very special meeting today - filled with information and catching up and happiness and tears. There were eighteen of us and we were all glad that our 6 week intermission had passed and we were together again. Eleanor joined us for the first time today. She is from RVC and I initially tried to persuade her to wait awhile till the new group opens in her town. Now I find out that it may not, but more importantly she belongs with us. She has the same problem with her mother Anne, that Annette has with her husband Gene. They can not get them to leave the house. On your first day it's nice to hear that the person you are sitting next to is in the same exact boat.

Annette has had a little break through, with the help of her aide. She has been getting Gene to sit outside and the aide walked him down the block to see his therapist without a problem. When they got home Annette felt that Gene seemed more aware and talked to her. Eleanor spoke to me weeks back and told me of an up coming doctors appointment Nov.2nd. that she didn't know how she would get her mother to attend. I suggested she bring the aide, because like Gene, Anne seems more willing to do things for her aide. Eleanor and her husband are leaving tomorrow for a one week vacation and they decided to take a test run and leave their aide of three years to care for her mother for one day. When they came home they found the aide drunk and asleep on the bed, and she had actually fallen on poor Anne. Needless to say, that aide is gone.

She was fortunate to find a new aid who is in her late 70's and who is caring for her own mother with AD. She was working for Eleanor's friends when the patient died and she became available. Her age and personal problems make her a risk, she may not be able to show up when Eleanor needs her. But she knows about the disease and is very good. Eleanor doesn't want to cancel her trip tomorrow, but she is shell shocked from her experience with the original aide who she thought she knew. This woman she doesn't know at all. Fortunately her daughter is going to look in on Anne and the aide everyday. Seeing and having talked on the phone to Eleanor, it didn't take a rocket scientist to see that she is stretched too thin, that she is going to burn out and she will be no good to anyone.

I am very happy that she was waiting for us when Esfira and I arrived and we talked, she was given time to talk to the group and she stayed after group and we talked some more. Hearing us and seeing us has made her feel better. We know what she means. It's happened to each of us in turn, walking into that room, frustrated - nervous - and not knowing what to do if this doesn't work. And that's why when someone new sits at that table, we know what they need and we embrace them. Eleanor is very fragile right now, but she spoke to the group and was grateful for the feedback. And when others spoke she listened and genuinely cared. She will fit in well with our group, I hope she continues to participate - I think she will.

Ann G's mother Ann is in Fulton Commons NH in East Meadow near the Bristol. She became sick, it turned to pneumonia, she went to Winthrop hospital and from there to the nursing home. She can no longer walk, she has been incontinent for a while now, and she has become very angry - hitting staff members. They are working on her meds and when she calms down they will begin therapy to see if they can get her walking again.

October 21st Meeting

Financially Ann and her sister have worked things out with the NH. They will sell Mom's house, using that money to pay for her care, apply for Medicaid and when that kicks in she and her sister will divide the money that is left. It's been a long rode for Ann. She has had to fight her sister through the courts for guardianship of their mother, and then while working full time she and her husband Freddie have opened their home and cared for her mother for a long time. She has brought her mother to group a few times and they were very close. Ann is sweet and patient with her mother and always careful to explain what is happening, in return her mother has told the courts how she loves her daughter and wants to be with her. Her mother was in an Assisted Living Facility years ago, but the sister got her out because it was too expensive. But, while there her mother was the belle of the ball, socializing and enjoying everyone and everything. I feel that her adjustment to the NH will be easy, and Ann's life should now be less upsetting. She can visit her mother anytime, and take her for outings if she wants. Although it is a difficult reality to have your mother put into a facility, I feel it is best for everyone. The time was right.

Ann's aide is dividing her time with Carol's mother Francis. They speak highly of the woman. Now that Ann's mother is in the NH she will be available in December. Eleanor may be able to use her if the new aide she has doesn't work out. But, more promising is Muriel. She has been having a terrible time with her husband Al. He has been having stomach trouble and with that diarrhea - Muriel is tiny and to have to change and clean her husband and the bathroom and rugs and chairs and everything else that gets in the way - has been a monumental job and an emotional torture. She found a nice aide at the hospital who said she would sleep over and bathe him at night and in the morning. Muriel called the hospital for their recommendations and they said she was excellent. So Muriel has used her a few times, but she really needs someone from say 7 am till noon. Soooooo - Ann is going to give her the name of the aide she shares with Carol, and Muriel is going to give Ann the name of the RN she has because Ann has a neighbor who needs someone overnight only. One hand washes the other. Ann asked for a complete list of the aides we have suggested to members in the last 6 months, mostly from Carol. I am sending it to everyone under the subject : Companions. We will keep adding to it. Carol said she has another name and we will try to get it soon.

Carol started this aide list for us and it has worked very well. Especially when we share. I don't speak highly enough of Carol. She is a very thoughtful member of the group. She listens and she responds to those in need. With the problems we had with the 6 week break and people showing up for meetings that were canceled, Carol asked to be included with me and Esfira in making calls if meetings were cancelled. We will each take a page, so each of you will get a personal call, especially those without computers, telling you to stay home due to weather or church conflicts, or any other reason. So I thank Carol for introducing two knew things to the group.

Carol's mother Francis was still driving when last we met, she is not now. She got a ticket for passing a school bus with the stop arm out. She kept saying she was innocent. She went to court and a policeman called Carol. She went to her mother and they appeared before the judge and when her mother proclaimed her innocense again - Carol said say guilty and told the judge she was guilty and they paid the fine. Very awkward. But, more

October 21st Meeting

than that Carol worries about her mother being thrown out of The Club. A wonderful daycare program with a terrific staff. They charge a small fee which is really a donation and waved if necessary. I went there and send people there all the time. But, I am at the end of my rope. They have always had this policy that if the patient doesn't participate or is incontinent or can't walk or anything but high functioning - they kick them out. When our patients are high functioning we usually don't need them and we keep them home with us. But, when they need more and more care - that is when we need daycare. They are there not just for the patient, but for us. We need respite and it is their job to provide it, and they don't. I was very close with the two women who created and run the program. I brought in treats for everyone and would come by and video tape - and in turn they used it to train their staff and to see where they could improve. Yet, I had to call them one day to say that my mother in law Gladys had stopped walking, and without missing a beat, the first thing they said was - don't bring her back.

I felt hurt and felt that I needed my contact with them and their feedback about Gladys. But, I had just joined this group and they became my safety net, and I sort of figured that not walking was a big problem that I should not try to push on them. But, over the years they have refused one patient from our group after another - as they declined, and I have tried to reason with them to no avail. They think of themselves as being there for the patient, keeping them high functioning and stimulated and active. Lesser patients would inhibit the others and use up too much of the staffs time. Bull Doody ! The first thing Gladys said was, _ All those people are crazy. Everyone, including the patients, knows that this is not an ordinary senior center. Their program is not that spectacular - occasionally they have piano sing alongs and they toss around a pillow. But, we don't care. The staff is warm and charming and we know our patients are safe and we have time to ourselves at a reasonable price.

The last time we met Jean she told us that her husband Arthur - who goes to The Club, was sleeping a lot and she was told that that was not acceptable. She put him on medication to perk him up (and others have had to put their patients on meds to calm them down) but he still did not participate in the program and they kicked him out. She also had Arthur in Herritts daycare and they too kicked him out because he was not high functioning enough. Unbelievable. Someone sleeping, or just sitting taking everything in - uses up no staff member, so what is the problem. Now Carol has been told that her mother Francis is not participating and may have to leave. Jean said this is how it starts. So of course Carol is concerned. In the meantime Jean is getting Arthur into Broadlawn. Elaine explained how her mother needs help and there is no problem, they will take patients in all stages. Elaine's mother Albena is back at Broadlawn after her stay for drug interactions at LIJ. Elaine was ready to place Albena in a facility, but her mother is once again functioning and non combative.

We have many heroic faithful daughters in our group - Pat is one of the best. Her father Tom is in the hospital with what they think are mini strokes. At one point they thought they lost him. The doctors are not optimistic and her mother Mary is a wreck. The aide had been staying with her during the day until Pat is off work. She only goes out to see Tom at the hospital. Pat is worried about her mother, she always has been. They are very

October 21st Meeting

close and have come to group as a team. Mary stayed home today. Pat helped her mother fight for guardianship of her own husband when another sister tried to take over. She is the one who gets things done, she gets the information and talks to people in the know and protects her mother. Now, she is so saddened by her father's failing condition, yet she has to be strong for her mother. And she has had to deal with the hospital. The plan is to get him into rehab when he is better. There is always the threat that Tom will not make it, or he will not be able to return home after rehab. Whatever happens it will be Pat who will make all the arrangements - and as I told her, she will do it well. None of her choices will feel good, nothing will make this go away, but she will consult with her mother and she will take care of everything. We all wish we had a daughter like that.

Sylvia arrived with her husband Ben. He was wound up and she was quiet. I asked her how things were and she shook her head no. I asked if Ben was still in daycare and she said it wasn't Ben, it was her. She began to cry - and she told us she just found out she has lung cancer and she never smoked. We were all shocked - Esfira leaned over and told me the hair on her arms was standing up. She said her family wanted to have Ben placed and she is not ready for that. Elaine said for her to do it and think of it as temporary until she gets better, then she can decide if she can take him home again. I told her that stress would be very harmful for her now, she needed to take care of herself and get better. But, it was when Carol said that her mother was diagnosed with lung cancer - went through therapy - and went into remission - it's been seven years now and she's doing well. Then Ann said she knew a woman with lung cancer who went for surgery to remove it from the side under the arm. She was in the hospital for 3 days and is fine now. Both Carol and Ann, who Sylvia has listened to and looked at across that table for years, were a ray of hope to a desperate woman in panic mode. Her whole being changed, she sat back, relaxed, and took a deep breath. There were no more tears, she was ready to participate in the rest of the meeting. And she did. But, we all saw Ben's reaction to all this. Ben has always been high functioning and social, over the years we have watched him decline, but he has remained sweet and friendly to all of us. As soon as Sylvia's eyes welled up with tears he reacted. He jumped up and put his finger to his mouth and when any of us talked he went shhh shhh shhh. We kept reassuring him and I called him over and held his hand, but every time he quieted down and one of us talked about cancer he jumped up and waved his hands and at one point began waving a magazine at us. He has seen Sylvia crying and somehow he knows. She is upset and therefore he is upset. She is his world and she is falling apart and he is scared. He needs to be removed from this situation, he needs to see his precious wife happy and well.

I know Allison, Sylvia's daughter. She came to group when Sylvia was not ready to attend. She and the rest of the family will help their mother and their father. Sylvia asked which of 2 hospitals we suggested - Sloan Kettering or South Nassau - SK won unanimously. They are the professional and they are also located at Mercy Hosp. I know Allison will help find placement for Ben and be at her mother's side. Whether Ben returns home again, time will tell. But, I know that Sylvia will get through this and be there for Ben, no matter where he is.

Natti brought her husband Jim again today. He just sat and seemed in his own world. He

October 21st Meeting

did say hello to me, but near the end of group he became restless. There was no problem because Natti knows how to handle him. She is one of the few members we have that is in total control, yet it is taking an emotional toll on her. Having her life turned upside down and inside out, and knowing that it will never be the way it was, is a horrible living nightmare that we all share. Ann L called me last night to help her co-ordinate her visit with us. She wanted to say good bye to Jack and Zena but could only be there for half the meeting. I told her to come for the beginning because our LTC guest would be talking later. She had to rush home to bathe her father. My husband used to bathe his mother and I can tell you it is not only difficult, but it is something you will never forget. Like burying a child - there are things we are not suppose to have to do. Yet, we do them. Later when we were talking about Medicaid and Medicare and Long Term Care, I thought to myself - look at all this garbage we have to wade through. After 5, 10, 15 years of pure hell - shouldn't some part of our country be taking us under their wing and saying, _ What do you need, we'll give it to you, no strings attached. We as caregivers for this disease are part of a huge group of people who take care of our own for longer than most of us should - we don't relinquish our Dementia patients easily - but when we ask for help, it should be there.

But, opinionated as I am, I digress. Ann and all of us were able to say good bye to Jack and Zena. It was so much easier than I thought, I thought I would get misty. But, Zena was such a doll, so full of energy and conversing with all of us and making everyone laugh. At one point Jack went to the hall for a cell phone call. Zena became a little concerned, we told her what he was doing - then we turned the spotlight on her and she shone like a shining star. She often reverts to Yiddish, Esfira said that she feels more comfortable speaking in Spanish and understands Zena's use of Yiddish. She told us Jack's name in Yiddish and then she told us her maiden name - Weiner. She said in 3rd grade we should have heard the other kids - she began singing - Zena Weiner - and told us how bad it was. That's how she created her strong personality. But, she said - later on she found that in high school kids remembered her and said - aren't you Zena Weiner from 3rd grade ? And she has been unforgettable ever since. She told us that fortunately she married and became Zena Goldfarb. We had so much fun with her. Then when Jack came back her eyes lit up, but he was wary. As we talked with him about how his daughter is coming over to help them pack up 50 years of their life and how he looked forward to the move, Zena kept jumping in and he told her to be quiet, and she started singing again and he scolded her. I told Jack that it was alright, we would tell him when she was over the top - and he said she is over the top, and I told him to behave or I would spank him - and Zena said, you would do that, and I said, I bet you would pay to see that - and she laughed and laughed and Jack kept giving her the stern paternal face.

We all understand it, we've all done it. We are trying to let people see only their good side - as we perceive it to be. We don't want our patients to embarrass themselves or us. We want people to think highly of them. But, people, especially us, understand. Jack doesn't think less of Ben or Sylvia if he walks around the room, or less of Natti and Jim when he wants to leave, yet he is always concerned about Zena's honor. We all have felt we have had to make excuses or cover up for our patients. Jack, I know you are reading this. Know one thing, Zena is a delight and nobody in their right mind would thing badly

October 21st Meeting

of her. When you go to your new home, give her a wide berth, don't inhibit her, allow her to be herself for as long as she can.

We were all able to sneak a card around the table for Jack and Zena and we all signed it. They stayed for ½ an hour and then had to be at a Bar Mitzvah, which Zena was looking forward to attending. When it was time to go I gave Jack the card and they both said good bye to all of us. They have both been a part of the group for about 5 years and we love them as much as they love us. They will keep in touch - you all have his e mail it is part of this e mail and on the roster. When I get his new address you can send them a note from time to time if you wish. And once again Jack promised that since it is only a two hour drive, they will visit once in a while and Zena wants to do that. We will share information about them and keep them in our hearts and prayers. I hope you will join me in also saying a special prayer for Sylvia, Pat's father Tom, and Ann's mother Ann, as well as keeping each other in our thoughts and prayers. Together we can make a difference.

Judy Jaross visited us today and sat and listened to us for an hour. That hour touched her very much and she was very impressed with the group - what we endure and how we help each other. We saw her as a warm, intelligent woman who would help us whether we took out a policy or not. That's what we needed and that's what this group does for us. It puts a face to the person before you make an appointment to meet. You know who will come to your door, or as she says, to her home, or a diner. She will treat us well and be fair. I told her we did not want to be pressured and become part of a list that she would try to pressure on a regular basis. She said straight out that that would not happen. She wants to get people to sign on the bottom line, but more importantly she wants to get referrals. So if we say no, or just have her look at policies we have - charge nothing - and say good bye _ well next time we talk to someone who needs LTC we will recommend her, and that is what makes the world go around. Some wrote down their names for her to call and set something up. All of us got her business card for future reference. She will not charge for her consultations. Mention our group and you, family members, friends and neighbors are in. She lives in Merrick and responds quickly. Ask her to look over your existing policy even if it is not with John Hancock, or get a policy for yourself, or just get information for future use - its a win win situation for all of us. I took notes and will send another e mail with LTC information in it. I am also sending it to Judy for her to correct any mistakes I might have made. March 31st we are having Vincent Russo visit the group and I hope he will be as informative as Judy was. He will be talking about Seven Ways You Can Protect Your Assets. November is Alzheimer's month, if something is on TV let us know. I really missed everyone, 6 weeks is a long time. It was good to be back. I want to thank all of you for participating in the process and making this an A+ meeting. We will meet again November 4th. . I hope to see all of you again and those that we missed today. Take care and keep in touch. Kathy