

Nineteen of us met this sunny but cool November 4th day. We met in the Outreach Office thanks to Nancy. I had a sign up and everyone found us. Many of you don't read your emails, this is the one I sent out last night :

WE WILL NOT BE MEETING IN OUR USUAL CONFERENCE
ROOMTOMORROW

WE WILL MEET RIGHT NEXT DOOR IN THE OUTREACH OFFICETHE FIRST
DOOR YOU COME TO WHEN YOU ENTER OUR HALLWAY

I WILL PUT A SIGN UPEVEN THOSE WHO DO NOT READ THIS MESSAGE
WILL BE ABLE TO FIND US

So what happened ? I got a call late this afternoon from a woman who works at the church. She said our room was being used, that we would have to meet in the Youth Center. I'd never heard of the Youth Center and stranger yet, neither had she. She said that someone would be in the rectory where we pick up the keys. They would be able to direct us to the Youth Center and give us the keys. So, I called our Nancy. She works at the church. She told me the Youth Center is in the front of the building we meet in - it's windows face Merrick Ave. We used to call it the Meeting Room, but that changed. Nancy said there was a mistake. The Youth Center was holding a Retreat Brunch and she was attending it. As far as she knew our conference room wasn't being used. She said she'd call and figure it out and call me back. About 10 minutes later she called to say she spoke to the woman who called me and - boy, is she confused. She told Nancy that she knew more than she did - duhhhh. Our room is being used by construction workers who are doing some work nearby. The Youth Center is being used for the Brunch Nancy is attending. And the auditorium is also being used. The woman said to send us to one of the classrooms. All the classrooms are upstairs and Nancy made it clear that that was not an option. Nancy had to make the decision and she decided to set us up in the Outreach Office where she works. It has 3 big couches and a long table and chairs. We can run to our room for more chairs if we need them. She will have everything opened up and ready for us in the morning. She also plans on popping in to say hello. She was very happy that I called her and that she was able to make our meeting happen. We are so blessed to have Nancy for emergencies, and for dear friend. We'll see you in the morning.

Kathy

Everyone who came in first crowded around the table, finding chairs from all around. Nobody wanted to sit on one of the three couches. Carol was the first to sit and she was uncomfortable until others arrived and joined her. As I always say - we are table people. We love being apart of the large circle and having a surface to write on. Couches are too impersonal and seemed to have created many side conversations. But, we managed. Hopefully we will have our room back next time.

Nancy arrived first and got us situated. She then went to her brunch. She returned at the end to say hello to everyone and to see how we were doing. She had wanted to see Sylvia, but she missed her. Ann L had laryngitis, but she joined us anyway. She is having

terrible time with her mother Ann, who has become very combative. She is now in Fulton Commons and they are trying to medicate her because she has slapped the aides. When given pills she spits them out. She yells at everyone. We have met Ann's mother, she was a sweet woman who loved her daughter and looked to her for reassurances. This behavior is a complete reversal for her. She was always very aware and able to communicate - I think that because she has always been so aware of her world, she knows what is happening to her. She understands how she is unable to do for herself, and she is frustrated and very angry, and probably scared. She is acting out her feelings. But, as we told Ann, this is a phase - she will move on - she will eventually progress in this disease and become subdued and lost in her own little world.

Ann is going under the assumption that she will not be bringing her mother home again. On her visits she is not sure if this will be the time her mother will recognize her. It's a very difficult time to watch our loved ones. Martha joined us again after a few years away. She came for one meeting, like Sylvia did, they both decided they weren't ready for this yet, and when the time came they returned. Some of you will remember Martha as an opera singer who brought a tape for us to listen to. Over the years she has read everything she could find. She has learned so much and taken good care of her husband Larry. But, she is tired and she is burning out. She needs respite. We gave her a list of aides. She may return, she says she will, but either way we are getting the information out to another AD family.

We were talking about hallucinations where the patients see people who are not there, or not knowing who we are. It's a very sad scary thing to witness. Muriel said that her husband Al thinks she is 3 different people. Jean's husband Arthur often tries to send her off to get his wife. Elaine's mother Albina sees a little girl. She points to her and doesn't understand why others don't see her. She talks with her. She also talks to her husband who is in a closet and who talks back to her like the little girl does. It is freaking out the aides. They are constantly doing the sign of the cross and grabbing for their rosary beads.

Ann G said that it was like a child's imaginary friend. It's a companion that should be encouraged. It gives her someone to talk to and keeps her mind alert. We all agreed it should be encouraged. Elaine's mother is doing well at Broadlawn and recommended it to Jean. Jean is planning on sending Arthur there since he was asked to leave from his other daycare programs, because of all things - he was nodding off and not participating. It's been a few months and Jean has noticed a decline in him. He has no routine, no reason to get up and around. She is concerned that when the time comes, she will not be able to get him up, washed, dressed, and fed in time for the bus. She has a woman who comes in from 3 till 6 and she does nothing. Jean is going to be looking at our companion list for someone to come in for 3 hours in the morning.

Muriel's husband has stopped having stomach problems and diarrhea. She still has an aide from Winthrop to fall back on, and she has a woman come in from Senior Respite every other Saturday when she comes to group. She is also going to have Al participate in a drug testing program and will report back to us about it. Elaine has 2 aides who each stay for one week on and one off. Albena only likes one of them. Since they are a team,

Elaine must keep both. The one who Mom hates, seems to be taking her nastiness for now. If she complains, Elaine will tell her she will help her by making suggestions of how to ease the tension. One thing that stands out is that the aide is loud and bubbly and Albena rolls her eyes at her. Elaine told her to tone it down, and last night she heard her talking softly to her mother. It takes time to fix these things.

We were happy to see Eleanor. She had just gotten a new aide a day before she went on a one week vacation to Florida. The aide was wonderful and she did not have to cut her vacation short. It took her a few days to relax, then she had a wonderful time, before she started dreading her return. The aide is older and is caring for her own mother, which is a concern for her reliability. But, I think the week took it's toll. She told Eleanor that her mother was very nasty. Eleanor also has the companion list if she needs it. You all do. It's a shame because this aide was good. I called to see how Eleanor was and the aide said they would be back that evening. She said she had just walked in the door with the mother. This was a huge step because like Annette, it's a battle to get them out the door. It gives her hope that this is not an impossible task.

A number of people are now going after Medicaid. Ann L says that the new law with a 5 year look back is not going into effect until 2011. They feel people need more time. So, there is still only a 36 month look back for now. Eleanor is getting everything out of her mother's name, but she has stocks in her name and her mother's name. Elaine had the same thing. She worked with a wonderful woman in Chase in RVC, who guided her in, when to cash them little by little. Eleanor got help from some man at the same bank, and he messed it up. Elaine is going to call her and give her someone who should do a better job. When trying to get these things out of the patient's name, go to the bank and have them guide you. They will tell you what you have to do.

Pat and her mother Mary came together this time. Dad, Tom is ready to be discharged. He made it through the iffy period, but he needs a lot of care. They are deciding if they should bring him home. Pat wants him placed because she feels it will too difficult for her mother. Mary wants him to come home to die in his bed. She will always regret not trying to give her husband the best final days, but it may be many years. We suggested that although it would be easier to have him placed now, they should bring him home with the aide they already have in place. Then if Mary comes to a point when she feels she can not continue to care for him at home, they can choose a facility and put him on a waiting list.

Ann G surprised me by coming to the meeting, she felt she couldn't. She sees Sylvia at rehab and found out about Ben's placement and Sylvia's surgery. She called to keep me in the loop. Ann is taking care of 3 generations, her parents, her children, and her grandchildren. Her daughter just had a little girl. Judy's son just had a little boy - her first grandchild. We are going to arrange for the kids to get together - keep it in the family. Ann's father has declined and her mother is just too frail to continue to care for him. Ann is doing more now and they are planning on getting him on Medicaid. This is why Ann doesn't come to group as often as she would like. Gilda surprised us with a visit today also. She is interested in the 5 Wishes - so is Carol. This is a pamphlet that just has to be

signed by 2 witnesses. In it you write out your end of life decisions. It is much more detailed than a living will and is recognized and legal in NY and Florida and many other states. I have some copies that I will bring in next time.

Natti brought Jim to group. Unlike Muriel she has not been able to get an aide for Jim from Senior Respite for every other Saturday morning. She needs some time for herself. She says she is not getting enough sleep. We gave her the Companion list. She is also ready for Medicaid for Jim. She has done her homework and gave us a list of three places where you can get help getting on Medicaid - free of charge to Seniors. Natti sat on the couch, but she felt a chair was better for Jim - it had no arms. Right in the middle of group Natti let out a long scream - Jim fell out of the chair and hit his head on the heater. Annette and Elaine and others jumped to help Natti get him up. The top of his head had a huge red bump on it. There was a scrambling for a better chair and everyone surrounding him was concentrating on getting him in a chair - except Carol. She got right in front of him and began stroking his arm and talking softly to him. He stayed focused on her. She asked him if he hurt himself and he said it hurt. She maintained eye contact and a physical hold on him - talking and reassuring him. When he was seated she ran out to get a first aid kit in the car, but there were no bandages. Eleanor went and got hers from the car, but by then Natti was beside herself. All she wanted to do was get Jim to the doctor. He really needed ice for the swelling and some antiseptic. We all felt terrible and everyone knew the feeling. Our patients have balance problems and we have all experienced the fear of their falling.

Usually it's like the drunk who drives the wrong way on the parkway and sends dozens of people to the hospital, but he walks away without a scratch. But. Occasionally they get hurt and we all usually get them checked out to make sure. Hopefully it looked worse than it was. I'm glad our little Florence Nightingale - Carol was with us today.

Annette exclaimed that her husband Gene was just awful. He won't leave the house and he doesn't care what anyone says or does about it. Annette is living the life of a single woman. She goes places alone and she has another surgery and coming up. This will be her 3rd hernia surgery. They don't hold - the doctor is using mesh this time. This will be her 9th surgery in little over a year. Her children are with her, not her husband. She told Gene they had two weddings coming up and she would have to go without him - he said she would have a better time without her. No, she won't. Her closest friend died a few weeks ago. Annette went to Temple for the first time without her and broke down. She hasn't cried for herself or her husband and all of a sudden she started to cry and couldn't stop. Now she cries at the drop of a hat. All that she had built up has come to the surface. I told her it wasn't a bad thing - it was a release.

Judy visits her mother in the nursing home and one day a young man and woman with an older woman slowly walked past her mother's doorway. The woman asked the young man if he was her husband, and he said no Mom - I'm your son. Looking at her mother, knowing she has lost her title of daughter, she began to cry uncontrollably. It is so necessary for us to be strong. Everything depends on us. We long to be held and protected once again, by the very person we are holding and protecting now. It's

unnatural, so much is being asked of us.

Sylvia came to group alone for the first time. She was unsettled and the tears rolled off and on. She is very upset with Sunrise Asst. Living in East Meadow. They were so eager to describe their activities - but since Monday when Ben was admitted, there have been none. The aide stays with him in the morning and Sylvia has the afternoon and evening. Allison her daughter is there before work to make sure he has breakfast. All they do is put him in front of a TV. They said they would shower him - not so far. The shower has a rusty metal bottom that would cut his feet if he used it. Sylvia spoke to them about it and was told no one has ever complained before. Sylvia said that for the money she is paying this is awful. She told them that if this was a hotel she'd leave. They said maybe she should leave then. For now Ben is in a safe place, but she only signed him in for a month. When she has gone through her surgery, she intends to either bring him home, or checkout another place. Elaine suggested she try Bristol which is right next door.

We are all proud of Sylvia. In the two weeks since she told us about this, she has gotten Ben placed, found a doctor at Sloan Kettering, scheduled surgery and completed her presurgical testing. She's meeting this head on - no hemming and hawing - just moving ahead and doing what she has to do. Her surgery is this Wednesday November 8th. She is going to have her daughter Allison call me when the surgery is over - and I will let you know. When she goes home she will call me and again I will let you know. Please pray for our special friend Sylvia. Take care and I will see you in 2 weeks November 18th. Information discussed in group will follow.

Kathy

WLIW channel 12 TV Sunday November 5th 11:30 AM Alzheimer's Disease Show Find out how cutting edge science brings researchers closer to finding a cure. And learn ways of supporting and coping with loved ones.

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5 Wishes NE Florida Community Hospice 4266 Sunbeam Rd, Jacksonville, FL 32257-800-274-6614 <http://communityhospice.com/> To get one free with booklet To buy in bulk \$5. Each or \$1. For 25 or more <http://agingwithdignity.org/>

Fred Arrendondo MD Merrick A member of our group - on our e mail list Makes house calls 516-378-4818

North Shore LIJ - The Litwin-Zucker Research Center 516-487-3492 Clinical research study for new AD drug Patient must be in moderate stage 50 years and older able to have MRI Caregiver must accompany them to all visits. Everything Free and compensation for

AD drugs they are already on

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Nassau County Dept. For Senior Citizen Affairs - in Mineola 516-571-5814

Nassau - Suffolk Law Services - in Hempstead

Free legal services to Seniors 516-292-8088

LI Center for Independent Living - in Levittown

Dr. James Puchta 516-796-0135 & 516-796-0144