

## January 20th Meeting

Eighteen of us - nineteen if you count a little baby boy, made it to group on this windy cold January 20th Saturday. Three new people called to join us and they all showed up and I believe they will return. Lucia called to ask if her mother could join us. Her parents had moved into her home, they had been living in Italy, but Maria found that she needed to be with her family to help care for her husband Antonio. Lucia brought her little baby boy, what a cutie. She left after about 15 minutes to stay with her father. Her husband picked up Maria after group. Antonio has Dementia with Lewy Bodies = Dementia and Parkinson's. Physically he is having balance problems and he must be reminded and taken to the bathroom. Maria has him in diapers to prevent accidents. She changes him while he is standing either leaning on a wall or on the bathroom sink. This is the easiest way, laying down is too difficult. She is looking for help in the home, I sent a list to them.

I am very sensitive to people's behavior in group. It helps me know who I am dealing with and I use these minutes of the meeting to share what I see. Maria is trying to cope with Antonio and recognizes that this is where she belongs. She listened to everything everyone said. She was taken a back by some of what she heard and leaned over and expressed to Carol how terrible she thought that was. It didn't frighten her as much as it amazed her that someone had that happen to them. She understood that some of these things could happen to her, and that when it did she would be better able to handle it. And I know she will.

I have been in contact with Lillian for about a week and she is the one I wanted the group to gather around and find some solutions. Her husband Chuck was diagnosed with AD about a year ago. She was diagnosed with MS about 10 years ago. She had her husband and then a dear friend, as her support system. That friend died in December. She has no family, no friends, her neighbors are not really known to her. She must depend on Chuck to drive her. He is in the early stages, very aware, in denial, and has anger issues. We talked of him sitting in at group, but we decided he would be upset hearing her talk about their private business. Linda, who is married to 57 year old Pat, volunteered to pick her up and bring her home today, but, something came up and she couldn't even come to group herself. She was very upset. Lillian got Chuck to drive her and sent him home, with the instructions that he would pick her up at noon. Carol said she would take Lillian home, so Lillian called Chuck and told him to stay home, she was getting a ride and would be home by 1 pm. At noon he showed up. Somehow he managed to find his way back, but had no recollection of her telling him to stay home because she was getting a ride back home.

We all brain stormed ways to give Lillian a way to cushion herself, a way to get places, and a way to keep herself and Chuck cared for. You all out did yourself. We are brilliant. First she is going to call the outreach office of the church she attends, explain the situation and see what they have to offer. They always have volunteers to drive people, or shop for them, or help in the house. Next she will call the MS Association. She is going to check with Able Ride and the local cab companies - sometimes when people are disabled they give discounts. She will also call Hofstra and other colleges. They have programs where students get credits for helping or adopting a family. They also would help shovel snow or rake leaves, etc. Organizations like Knights of Columbus, JASA, Catholic Charities, etc. may help or know of alternatives. The Nassau County Dept. Of Senior Citizen Affairs has a Directory of Services 516-227-8900. There are all sorts of listings and while she has them on the phone she can ask specifically for help in her particular circumstances. Since she has a computer she can do food shopping through Peapod. And I passed around a catalog for HDIS ( Home Delivery Incontinent Supplies ) for diapers, and much more. Ask for a catalog :1-800-269-4663 or go on line <http://www.hdis.com>

Right now Lillian has places to call, Linda and Carol for occasional transportation for group, and a way to reach all of us. She will stay with us and we will get her on track. The third new person we had today was Walter. Since Jack, we have been a woman's club. Walter noticed that right away and seemed to enjoy the attention that afforded him. He has a great sense of humor and is devoted and in love with his wife Jean. This couple has been dealing with this for an unbelievable 20 years. She was in daycare at Broadlawn, he didn't feel she benefitted from the medical model and in fact, felt they had given up on her. He had her in a nursing home

and felt he could do a better job for her at home. He has a home companion, and he has a therapist come to his home. Everybody, professional and friends, have told Walter that Jean will never get better. It infuriates him because he knows she can improve. His question to us was, How do I go about making her get better. The first thought is that he is in denial. But, then if you pay attention, Walter does not see his wife being cured, he sees her having more good days than bad. This is his goal. She has problems eating, she talks less and less, she can't read, she is in a wheelchair, she can no longer walk. She needs help with everything, but she responds to the therapy, one on one care, and encouragement. With a lot of effort Jean will eat. Walter wants to take her on a vacation to Florida. He feels she will be happy with the setting and social life.

Walter has faith and hope. This also will effect Jean. Our patients feed off our emotions, if we are frightened, they are frightened, if we laugh they laugh. I applaud his efforts, but I am concerned that he will try so hard that he will become frustrated when the results are not there. There are times, even with well people, that no matter what we do we can't make a difference. He tries to reason with Jean, and has told her in no uncertain terms that she knows that she has to eat. Sometimes Jean doesn't know that, most times there are a lot of things she doesn't know. The messages are just not getting through her brain. It's not her fault, it's not her being stubborn. To Walter I say, no one knows how to make her better, but we do have little handy dandy tricks that we all use. That we can share, and a safe place to visit and talk and listen - is what we can offer. Walter made a lot of friends today. He was eager to offer suggestions and help others. I know he will return, and I hope that other men will join, I know that Walter would like to be able to have that male bonding going on. At one point today he wanted to break down, but he sat quietly and composed himself. He has so much emotional pain, still he rallies himself and does what he has to do. He has been living this nightmare for a long time, with no end in sight.

Just a note to all, I volunteer my time with you. We do not judge you. We will offer you choices. You can move along at your own speed. There is always someone to talk to. If you have questions, just ask.

Paula and Barbara returned. I love their friendship and the support they give each other. Barabara's mother Lucille is now in the early stages of being tested by Dr. Mazurak, a neurologist in RVC. She feels that her mother rallied for the appointment, and when she got home she began repeating and repeating. At this point all the tests will either find or eliminate causes. It is very important to know what is wrong with her mother. The uncertainty is making Barbara fearful. She is not sure what health issues may be behind her mother's problems like her fainting one day. Knowing will be half the battle. She is so adorable. She said if her mother does not have dementia, can she stay in the group - I said that the repeating is enough of a behavioral problem to keep her with us, and the fact that she is keeping Paula going will ensure her returning. That plus the fact that she is quick to ask questions and give feedback. Paula wants to change doctors. She is now looking for a new doctor at Winthrop. Muriel goes there and said there are 2 woman and 2 men. We asked who she chose. She chose a Dr. Berger because their son in law's last name is Burger and Al reacts to knowing the name and is more comfortable visiting him. Barbara said - I love that, you are terrific. It's reactions like that, that we need in group. Paula wants to get her mother on Medicaid. Community Medicaid. She will then be able to take advantage of daycare programs that can run over \$100 a day. Help getting on Medicaid using a lawyer can be expensive, so we have three places that will help you for free :

Medicaid HelpWill talk you through it and submit paperworkFree Assistance Applying for Medicaid

Nassau County Dept. For Senior Citizen Affairs - in Mineola516-571-5814

Nassau - Suffolk Law Services - in HempsteadFree legal services to Seniors516-292-8088

LI Center for Independent Living - in LevittownDr. James Puchta516-796-0135 & 516-796-0144

Paula and her mother Catherine came by today. They had a family crisis for such a long time. Al accused his son in law of hurting him. It was untrue, but nothing could change Al's mind, and the young man was upset.

They have now decided to just drop it. They don't discuss it and if Al should start again, they will just change the subject. Excellent.

Annette was so funny, her husband's name is Gene and she was sitting next to Walter who's wife is name Jean. So when I said Jean doesn't drive anymore - they both nodded in agreement. She is very upset. She is going to a party, and once again her husband will stay at home. She repeated her phrase that she feels like a widow. Yet her husband sits in front of her, a shell of what he was, a reminder of the life they had. Annette said that Linda has not called her, and in a way I think she wants to compare notes also. Both women have husband's with early onset AD. Gene was 57 when diagnosed a few years back, and Pat is 57 now.

Linda really wanted to be with us today. She took Pat to LIJ and had his meds adjusted. Then she started him at Broadlawn and he liked it. She is feeling so good about this. And of course she wanted to be able to drive and help Lillian. Judy talked with Carol and they think they are going to finally be able to have Carol send the Christmas pictures she took and Judy will post them on our website:<http://www.jbgraphics.com/mag.htm> Ann L and Gilda visited, and both added feedback, as usual. Gilda lost her husband Ken and Ann lost her mother Ann. Ann never stopped coming to group and I thank God for that. Elaine sat next to me - I am now saving her that spot. She is a very very active participant during group and outside. She spoke with a friend of Muriel's for about an hour. She is always trying to get information to someone. She is priceless and we are blessed to have her. She is office manager for AgeWell 516-488-8808. They do Physical Therapy and Wellness. They are in Lake Success, but they will provide transportation free of charge. If you need this type of help you know that Elaine will see to it that you get the best of care.

Lee has been with us a relatively short time, Muriel found her in a parking lot, and incidently she found Lillian in the church parking lot today and brought her into us. Each meeting Lee speaks up more and more. She is a nurse and is highly intelligent. She comes up with the best feed back. She was the one who told Lillian to call the MS Assoc. And she remembered FISH which offers transportation - unfortunately not for Massapequa Park. She has given so much to this group already. I am so glad Muriel brought her to us. But, as I said before everyone was focused and contributing 100% today, and it paid off. I want to add one more #. All of our patients are entitled to Handicapped Parking Stickers. Mineola Office for the Physically Challenged 516-571-3147.

Thank you to everyone in that room today. Esfira, born and raised in Cuba, forced herself out of the house today and sat at my side. We just keep getting better. Take care, keep in touch, and we will meet again in two weeks February 3rd. Kathy