

February 3rd, 2007

It was a cold, but sunny clear day. Nineteen of us showed up on this February 3rd Saturday. We had our new women. Teresa came with her mother Susan. I was happy to see that although Teresa called me, asked the questions, and made the arrangements - Susan was very comfortable and eager to be in group. She spoke up and participated, her daughter gave her the floor as she took notes. This is the mother daughter dynamics in almost all cases. The daughters usually look at the big picture and do all the research, while Mom or Dad express their situation and their needs. They all live in the same house and get along very well. Susan's husband Gino is in the earlier stages, he takes care of himself with a little assistance. He goes to daycare a few days a week, at YOM in Levittown. Dr. Fred's mother goes there and Jean had Art there. He loves it and they would like to send him more often, so I am sending them info about Elder care Lawyers.

Gino gets up to use the bathroom at night, and goes right back to sleep. It wakes Susan and she can't fall asleep again easily. Lee and Walter told her to go back to the urologist who already said Gino had an enlarged prostate, and have him prescribe medication to help him last through the night. She is also living with the constant questions and repeating. She suffers from anxiety and so it is hard for her to try to keep calm and be patient. Her other big problem is that Gino has resorted to his original language - Italian. It is Susan's original language also, but she hasn't spoken it in decades. She now finds herself trying to interpret what he is saying. He speaks in Italian at YOM and nobody seems to care. As an Italian myself, I can tell you that it is not difficult to understand us, no matter what we say. We are Mimes - we talk with our hands. I understood everything my grandparents said for 30 years and I do not speak Italian. These are two good women and I know we can help them.

Mary came alone. Her mother Kathleen has AD and lives with her father and brother. The father has all the papers and powers, the brother does not contribute. Little at a time she tries to introduce things into the home. She made all the arrangements and got her mother in an adult daycare in Huntington where they live. Dad doesn't understand why she is going, but Mary is at least getting him to let her go 2 days a week, and that's only because she is paying for it. She has an aide that accompanies Kathleen to daycare, this way she gets there stays there and gets home safely. Dad sees nothing wrong and doesn't want to put out money. He won't see a lawyer, so the house is in jeopardy, and they can't get Mom on Medicaid so that she will be able to have access to free daycare and more. Mary is just recovering from back surgery, and has a family of her own. She is hitting her head against the wall, those in the house with Mom are doing nothing because they know the good daughter will take care of things. I suggested that she pull back, stay away. Tell the guys that when they are willing to work with her, she will do everything she can to help. Until then her visits should be limited to spending time with Mom. She loves her mother and she will be able to gather info from us that will be put to good use when the family is ready to work as a team.

Walter is 86 and I just can't break through his outer layer of being absolutely convinced that his wife Jean will get better with the proper care. Friends, family, professionals, and other caregivers - have all told him that there is no cure. He agrees. But, his belief is that he can make his wife better. With diligence and therapy, she will walk again. He is frustrating not only Jean, but himself. He gets mad and yells, she gets angry with him and then he feels she stops trying to punish him. His yelling works because after a while she will try again - it is not because she has forgotten about his yelling and everything is new again. He has it all figured out and he will not change course. It is not our place to tell each other what to do. We make suggestions, tell what we have tried, and the rest is up to each caregiver. Hopefully, hearing others will give each of us a different perspective. Walter has a goal and he doesn't want to hear anything that deviates from that goal. He wants to get Jean to do her therapy. I tried to get him to work with her until she gets tired then stop. He does, but then tries again in a few hours. I suggested her let it go for a day or two. He didn't like my ideas, he didn't want to think that perhaps Jean would never leave her wheelchair. I was getting a little frustrated myself and then dear sweet Lee raised her hand with a suggestion. He should play music that Jean likes. Then do exercises with her. The music would calm her and doing things as a team would make Jean feel comfortable. Jean played classical music and Walter liked the idea. He then said that he could take it one step farther. They still had a piano, he could get her to play

again. Noooo said Lee. Play the music, let her relax and listen to it, it will take her mind off the exercise. By the grace of God, Walter said that he felt that was worth trying.

Walter is a caregiver that I have never dealt with before. What Jean wants is not a part of the equation, all that matters is what Walter feels is necessary to handle this situation. The rest of us are just the opposite, if our patient doesn't want to do something, it doesn't happen - even if it should. Most of us have to work very hard to get a handle on Walter's tough love. Walter wants to be in the group, I don't want to confront him, I don't want to have to put him in the position of having to explain or justify his world. But, he got to me today. He said that Jean began talking to her mother who has died. She doesn't speak much, never did, but she kept up this imaginary conversation. All our patients have delusions, it is part of the disease. Jean felt comforted talking to her mother. I lost my mother and take comfort in feeling her close to me and I also talk to her, sometimes out loud. Walter's response - he was not going to let this go - back to the psychiatrist she went and he put her on medication. There is a pill for everything, but is there a need each time ? I told the group that if the patient becomes delusional and it makes them happy - let them. If they wear a coat in the summer - let them. If they want to sleep with a hat on - let them. If the wind makes the curtains move and they get scared, take them out of the room and soothe them. If they think someone is in the house, reassure them and change the subject. We are dealing with people who can hardly hold one thought, it is usually easy to distract. But, try to use your own ingenuity before you dope up your patient and eventually make them into Zombies. If they enjoy talking to an invisible person - let them have what ever little and far between pleasures they can. Walter did not respond to that, he quieted down and we moved along.

Lillian is someone that I have wanted to give special attention to, ever since she called me and told me that her husband Chuck has AD and she has MS. She can't drive so he has to. She has no family near by and her only friend who lived next door and who helped her, died in December. Now her son in NJ is helping her to help that woman's husband. She asked me if she could give my number to her son Michael in Illinois. I'm glad he called because he clarified many things for me and I was able to give him numbers to start checking out options. I did not know that MS like AD effects the brain and how Lillian processes things. All the info we gave her last time at group was not acted upon. She does not read the minutes of the meetings. She was very tired in group and nodded out a few times. She needs help as much as Chuck, and Michael is willing to give his all. The family has to decide what they want, find out how to achieve it, and then make it happen. Their main choices are to either bring the parents to Illinois to be with the family, or getting help and possibly a one story home and keeping them here. The dilemma is that Lillian's medications alone cost \$37,000. Per year. She has EPIC and AARP and pays a small co pay because their only income is social security. EPIC is only in NY. They would have to find a comparable program in Illinois where their income will allow them to qualify. Michael and I have e mailed and talked on the phone and he makes monthly trips here, we are hoping that he can visit the group and make appointments here during his visits. If the whole family works together this difficult task will be able to be done.

Lillian said that she visited Assisted Living on the Island and she doesn't want that for her future. She wants to be with her family. So the goal is to move, the question is how soon, months or years. She had a question for the group. What do you do when they argue and get mad at you. I threw that one to Annette. She said that she walked away from the situation and let things cool down. When she returns she changes the subject.

Marie returned to group without her daughter Lucia and the baby. She is confident and readily speaks up even though I can see she is frazzled and in need of respite. She is very close to Lucia and feels comfortable discussing everything with her and together they decide. She wants a live in, but only when Lucia thinks it over and agrees. It is so important to have someone you can depend on for feedback and support. She left a little early because her husband Antonio isn't feeling well. All of our caregivers are very caring loving people. Mary and her daughter Pat arrived at 11:30, but it was a good thing. Mary has been in such pain from her arthritis, therapy helps, but she doesn't drive and Pat can't make it here often enough, so she is not getting enough relief. They took down Elaine's work # 516-488-8816. AgeWell will send someone to her home or provide free transportation to their office. Pat wants her mother out of the house. They are also concerned about how many

visits Medicare will allow. Elaine will have her office work with their doctor and together they can come up with the right diagnosis that will enable her to get as much therapy as she needs. Fortunately Tom is in a facility and doing well and there is less pressure on Mary.

Barbara and Paula came together again today. I was very pleased to have Paula e mail for information about support groups for a friend who lost her mother. What we share in that room means so much more when it goes beyond our walls and ripples to anyone who needs it.

Bereavement Support Groups Good Shepherd Hospice offers free, nonsectarian bereavement support groups for all who have lost a loved one throughout Nassau and Suffolk. Register, 516-876-8485

Paula like Mary - new today - is in the position of watching her parents from afar and having no power. Paula has learned not to push, she maintains her distance and is there as a back up when her father decides that steps should be taken. Her long time friend Barbara, on the other hand, lives with her mother and finds things disturbing. She seems to dwell on every detail out of the ordinary. She has been going to Dr. Mazurak a neurologist in RVC to get a diagnosis for her mother. When they park her mother notices that the parking spaces are not in order and goes on about it - well so does Barbara. She told us three times how her mother reacted to the numbering. To put this into perspective - my mother in law Gladys would talk into a porcelain figurine as if it was a phone - hello operator, operator. We smiled to ourselves, and took her into the dining room for a cup of tea. If her mother has a real episode in which she screams in fear, or yells in anger, I feel that Barbara will be traumatized. We can not over react to anything. How we react to things is how our patients will react. If they see us calm, they will be calm. If we are frightened, they will become frightened. As far as we can tell from Dr. Mazurak's diagnosis of Mom - she has dementia and he is giving his drug of choice - Aricept. Barbara was under the impression that this would fix things. Nothing will fix this. Aricept like all AD drugs help some people for a short period of time. There are no cures and no treatments for this. Barbara's mother, like Paula's mother and all our patients will get worse. Right now Mom is living in her own home with her daughter and she wants for nothing. Aside from forgetting occasionally and being confused at times - all is well in the world. This is the time for Barbara to relax, this is the lull before the storm.

Linda has been away for so long, I only saw her for our Christmas party and I didn't even recognize her today. Her husband like Annette's has early on set Dementia. He is 57 and Gene was 57 when her was diagnosed. But, beside that he has Parkinson's Disease. When both diseases are combined it is called Dementia with Lewey Bodies. Very similar, yet subtle differences. I gave her literature on the disease. She has him in Broadlawn daycare and he likes it. But, he fell again and hit his head. He is always falling and he is always fixating on things. He decided someone had stolen their bikes, so he was out in the garage where everything is so packed in you can't walk through it. Yet he was on a mission and would not be deterred. He is at daycare while she works. Pat is very active and very aware and fighting Linda all the way. She is defiantly frustrated and has problems being friendly to someone so troublesome. Annette feels the same way. There is no reasoning with Gene either. Both men are stubborn and take lots of coaxing, which both wives are finding more and more difficult to find the energy to baby them and make nice. They are young, they are hurt, they are alone, and they have no life. This is not what they signed up for.

Jean can no longer take care of Art safely at home. He has declined to such a point that she has to physically do more and more for him. She can not lift him without hurting herself. She has decided that placement is necessary. She is applying for Medicaid. She has chosen 2 nursing homes she likes. The social workers at Broadlawn can help her with the application. She has spent the last month collecting everything she needs - bank records, receipts, IRA's, etc. The hard part is practically done. A lawyer will charge \$5,000 + just to apply for Medicaid for you. We have places that will do it for free. It seems they do not answer their phones - patients may be what is needed. I am giving the numbers anyway - if you have luck, tell us. This could be of help to Susan and Teresa also. They too could see the social worker at YOM for free help in applying for Medicaid.

Medicaid Help Will talk you through it and submit paperwork Free Assistance Applying for Medicaid

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

This is a very difficult step for Jean. She has tried so hard for so long. At one point she had Art in 2 different daycare programs, just to keep him stimulated. He was ejected because he had declined. In the time it took for her to find Broadlawn, he had gotten off schedule and went into this deep decline that has now led to her needing to have him placed. When Art was diagnosed, Jean's life was turned upside down. When he is placed, her life will take another turn. She will have to deal with visits and other patients and families and staff members that change all the time. She will be alone at home and everything will depend on how she holds herself together. She has a supportive family, and we are all here for her. We all come alive when one of us needs extra attention - remember that when you find your world in turmoil. We are with you.

Eleanor went to Florida for her getaway and time to refresh herself. Her mother is very nasty and argumentative and never appreciative. We all encounter that to some degree, but Ann gives her daughter nothing to keep her going. 36 hours after her arrival in Florida the aide called that they were taking Ann to the hospital. She had pneumonia. The hospital said to stay where she is, it's not life threatening, they would keep her for 3 days and send her home. They did. Her children got involved and all went well without interrupting her trip. With all her trouble she, like the rest of us in the group - come across others with our problems. She knows two other women dealing with AD. She has been trying to pass on information, but she knows that for herself, actually sitting with the group is what turned things around for her. She wants to tell them to come to our group - but she read how I wrote in my reminder of the meeting, that the group is almost saturated, in my opinion. We have taken in 10 new members in the last 2 months. We are nearly 30 when the average LI group is still only 7. I worry that there will not be the proper amount of time to give to ourselves. I don't want to take away from anyone in our group. We all need time to talk, ask questions, give feedback, etc.

So I put it to the group. Should we call a halt for a while. Nobody said yes. Instead it was thrown back on me - everyone trusts my judgement to let in who ever is in need. I already will not take anyone else who has placed someone. I only accept those that are new, and need a lawyer, doctor, and information. All facilities have social workers and support groups. We can't have someone sit with us who just wants to vent. It is very clear that we want to help, this is not a social group. We are here to get things done. So I will make the judgement call, Eleanor can bring her friends, anyone in the group who knows of someone who meets the criteria above - talk to me. As far as socializing goes - we have before and after meetings, slow days when a few people show _ and best of all we have Elaine. She is always getting people together for lunch or dinner out, or get together at her home. Call her. The rest of you can do the same thing. Invite others to join you. We could have a contest for The Hostess With The Mostest. But as long as we are The Merrick Alzheimer's Support Group - that is what we will give to as many as we can.

Besides Elaine giving out names and phone numbers, we have Lee giving out useful information - she is a nurse and explains things to us, as well as comes up with handy dandy hints. Wetting the bed is a problem for so many sooner or later. Her husband Harry is uncomfortable with things around his waste so he pushes his diaper down and really soaks the bed. She has the mattress in plastic, his favorite comforter in plastic, and soft sheets to make him feel better. Linda has a device for Pat that really works. Lee told us about it. It's like a condom that goes over the penis and is attached to a belt around the waste. It has a tube at the end of it that empties the urine into a container. It works really well for Linda. But, Lee feels Harry isn't ready for it yet. She is a wonderful addition to the group. She speaks calmly and everyone listens and understands. She is there for the group. Also going through this Hell, yet there for the group, are Ann G and Carol. Of course Ann L, but she wasn't with us

today. They speak very little about themselves unless they are relating a similar event as feedback for someone else. They add information and ask questions to help solve other's problems. They are the kind of members that make it possible for us to be this large. If they do not have a problem or if they don't have an experience to talk about to inform us - they are sitting at that table to make the group function. They make this group work like a fine oiled machine. We say it often and we mean it constantly, thank you for being with us. Included in this list of course is Esfira. She sits by my side and whispers little useful things during the meeting. She makes me look good. She wants no credit. She was a pharmacist in Cuba and a social worker here. She has valuable knowledge. She doesn't drive so she helps prepare me on the way to group, and gives me her impressions after. She is opinionated and never a yes man. She gets mad at me for not reminding people I don't get paid to do this, for letting the meeting go too long, for writing minutes of the meetings that are too long - I'm in trouble with this one, but above all when things go right she beams with pride at me. This group might be totally different today if Esfira didn't give me the confidence and assurance that the group is great and I am doing things right.

Muriel had some good news. Al was accepted into a drug testing program in the city. They will receive free transportation, medication, and full access to a staff of social workers, doctors, etc. - and all the technology available. They will follow Al for one year. They only have to visit once every three months, but they can get any and all kinds of help in between. Not only will Al be monitored and followed during this time, but perhaps a medication will become available that would be useful to all of us. We will follow them.

Someone asked about our Web site. Check it out and contribute pictures.<http://www.jbgraphics.com/MAG.htm>

Thank you to all of you who participated today. I hope you feel it was worth leaving your warm homes for. Enjoy the Super Bowl and stay well. We will meet again in two weeks - February 17th. I hope to see you then. Kathy