

January 6th Meeting

Thirteen of us showed up for our first 2007th meeting, January 6th. The weather was in the high 60's which may be why some of you did not join us. We talked about end of life decisions, drugs, and drug companies - all of which have been in the news since we last met. We discussed the ability to diagnose Alzheimer's Disease through spinal fluid, looking for proteins. Now we can be positive before an autopsy. Lee is a retired nurse and she was very informative. She investigated the spinal procedure and decided against it. It could be dangerous if a dementia patient moves and doesn't follow directions. As far as she knows it is only being done in the city, so it would mean a long trip, a long procedure, and an overnight stay. When all is said and done, they will only tell her what she already knows. I think the right candidates for this would be early stages or early onset patients. Those that can't get a real answer from their doctors, that satisfies them.

Like Ann L's mother Ann, Lee's husband Harry has encephalitis, which is water on the brain. Ann and Lee both rejected having a shunt surgically implanted into the brain and draining into the stomach. Ann and Harry are both in their 80's - Ann was told that the surgery is too risky at that age. Lee knew that the anesthesia could be a problem with the dementia as well as risky for Harry's age. Everything must really be checked and rechecked, and you have to decide if it is worth it. We had a man whose wife was elderly and in the final stages of dementia. He was having trouble getting her yearly mammography done. We asked what he would do if they found cancer. He decided he could not put her through that treatment and so the ordeal of the yearly check up ended.

Muriel took her husband Al to Mt. Sinai a month ago. They spend much of the day answering questions and have not heard back. Her son took them. This is a drug testing program that would provide medication, transportation and everything for free. She has not heard back. I told her that sometimes it takes them a while to get a large enough group for testing. She wants to become involved, she wants to feel she is doing something for Al and other victims. Muriel and Al are both in their 80's and we give her so much credit for her stamina. Months ago Al had diarrhea, he is in an adult diaper and it was very difficult for Muriel. She has since been to a doctor that prescribed a drug that ended the problem and the doctor feels that it will help Al stay at this level longer. Muriel took some also, but she developed stomach problems and stopped. Al is still doing well. I sent information on it in another e mail. If you would like to look it up yourself :
<http://www.nlm.nih.gov/medlineplus/druginfo/uspdi/202388.html>

With all the talk of end of life we discussed donations. Some have signed affidavits as organ donors, some on driver's licences, or in living wills. When Ann's mother died shortly before the holidays, 45 minutes later she was on the phone for over an hour discussing which organs she would be willing to donate for her mother. She was able to say yes or no, and was told what they would be used for. So it doesn't have to be put in writing before you die. As long as you don't die of a disease or cancer, they can use tissues and eyes, ears, etc. A gift that someday you or someone you know, might need from a stranger. When all is taken that can be taken, they will notify you when cremation will occur. Lee had two friends who donated their bodies to science. They made arrangements with major Universities like NYU before their deaths, notified their families, and a number was called at the time of death and all was done for them. They just had a memorial service without a casket or funeral.

All of this stresses the importance of getting your papers taken care of. Besides a Living Will, Health Care Proxy, Durable Power of Attorney, and a Last Will & Testament, Ann has done all of the work for those seeing to the final details. She has 3 folders named with her name, her mother's, and her father's. In each are full names, dates of birth, social security #'s, marriage and birth certificates, assets, insurance policies, bank accounts. She has information on funeral homes and plots or in her case cremation instructions. There are phone #'s and names of who to contact. Everything is carefully detailed and anyone can open it and easily take the final steps. This gives you the peace of mind that all will be done to your specifications and that no one will have to run around making decisions and figuring things out. Hopefully much of this will be covered when Vincent Russo visits our group March 31st.

Most everyone had a good holiday season. Some better than others. Carol and her husband were invited to a party at Phil Collins. He and her husband both worked on a Broadway play together. Her husband is a writer. Elaine invited members of the group to her home on Christmas Day. Ann L was spending her first Christmas without her mother, Gilda stopped by, and Anita and Millie had other plans. That was so sweet of Elaine, and I know she enjoyed it also. Annette had a quiet time with her husband Gene. The kids went their own way for New Years and she made a special supper of Lobster for just the two of them, plus she made up little appetizers. She was even able to get Gene out of the house and to the doctor this week. She actually reasoned with him. She said that if he didn't see these doctors regularly, they would cut off his benefit. That he understood.

Jean is somehow getting her husband Art up and on the bus to Broadlawn each day. It turns out he is on the bus when it comes to pick up Elaine's mother Albena. Art was thrown out of two daycares for sleeping, at Broadlawn they let him rest and rouse him and keep him active when things are happening. But, he has really declined and she knows she is going to need help in the home. He is gone from about 7am till after 4pm, so Jean has a nice long period to herself, but at home he needs more and more care and needs to be lifted and he is not able to follow directions as he once did. I think she has a plan, if not she can call me or better yet Elaine. Elaine has aides for her mother that know other aides. In fact she is going to help Sylvia. Ben came with her today and hardly sat still. He was up pacing up and down the hallway, and when he headed out the door, Sylvia or someone would notice and she would go after him. She kept getting up and down, and then stood in the doorway. He never stops pacing and Sylvia is always on call. She has had so many failures with aides that she has given up. She needs a push, Elaine said she was going to call her this afternoon with hopefully a lead.

As you know Sylvia had Ben placed for a short time while she underwent what she thought was lung cancer, but turned out to be breast cancer. She says she feels fine, but she needs to relax. She is going for a liver biopsy soon. She is caught in the medical maze of everyone trying to cover their butts. She'll just have to ride this to the end. Natti could also use a rest. She has an aide for Jim, but she can never give up the reins. Jim keeps complaining that this hurts and that hurts, and Natti worries and in a day or so the pain is gone. Annette has the same thing with Gene. He always has something hurting him. Natti said it is like taking care of a two year old, she always has to be alert. It is very stressful for her. Many patients complain of pains in the wrong places because they can't articulate what they feel or where it is. Stubbing their toe can translate into a terrible pain in their stomach. Other's don't understand pain and say nothing. They must be watched like a child or a pet, we can only look for behavior outside the norm, like a limp.

Carol is feeling guilty because she has such a wonderful aide for her mother Francis, that she doesn't need to be there all the time. Her father is there at night, and Carol has cut back her visits to once a week. The aide takes Francis to the doctor and sometimes forgets to tell Carol, so she is feeling out of the loop. Elaine came up with a great suggestion. All doctors are to send their notes and test results to her mother and then she should give her own fax #. This way she will be completely informed and in the loop. Elaine has a new job. She is office manager for two therapists. They are covered under Medicare and will provide transportation free as a courtesy. They will also make house calls. Elaine is having business cards made up and we will all get one.

I want to remind you to visit our web site : <http://www.jbgraphics.com/mag.htm> Sometimes these e mails of the meetings come out as one long sentence and you have to keep scrolling, or you just have problems with them. Well, Judy reprints them on the web site. She also has pictures of years past and a brand new one of Nina with her mother Ethel - beautiful. Carol took pictures at our Christmas Party and sent them to Judy. I am hoping she will put them on the web site as well.

Just to let you know. The three woman who visited us for the first time last meeting, all got in touch with me and will be with us for our next meeting. Barbara is worried about her mother's condition and she brought her college friend Paula who's mother Hazel has dementia. Today Paula had plumbing problems and Barbara spent the day with her friend, having their own little support group. Linda's husband Pat is only 57. He is in the hospital and she and other family members are visiting him today. I hope everything is okay. And Eleanor has

her mother in a facility that she is thriving in and she and her husband are in Florida right now. I hope we will see them and you in two weeks on January 20th when we meet again. Esfira is so happy with this weather. Being from Cuba she panics in snow and ice and hibernates in the winter. As long as the weather holds up we will have her with us. Keep in touch and take care, and enjoy this great weather. Kathy