

**COMMISSION ON THE AGING**

**New Fairfield, CT 06812**

**COMMUNITY FORUM**

**“THE EMOTIONAL COST OF CAREGIVING”  
WITH DR. JORGE AGUILAR-ZANATTA**

**REVISED MINUTES**

**April 8, 2017**

The Commission on the Aging hosted a Community Forum on Saturday, April 8, 2017 at the Senior Center from 10:00am-12:00pm. The topic was “The Emotional Cost of Caregiving”. Secretary, Laurie Busse, took the minutes.

**PRESENT:** Maureen Salerno, Chair, Cindy LaCour, Vice Chairman, Julia MacMillan, Kathy Hull, and Roberta Ilardo

**ABSENT:** Katy Johannssen, Jeannette Sweeney, and Janet Loya

**KEY NOTE SPEAKER:** Dr. Jorge Aguilar-Zanatta, Director of Consultation Psychiatry at Danbury Hospital

**PANELISTS:** Jessica Hughes, MSW, Danbury Manager CT Community Care Inc. Carolyn DeRocco, Vice President, Programs and Education, Alzheimer’s Assoc. CT Chapter Barbara Newlane, LPN, Director of Home Care, Ridgefield VNA

**GENERAL PUBLIC:** 38 people present

Maureen Salerno welcomed everyone and introduced the keynote speaker Dr. Jorge Aguilar-Zanatta, Director of Consultation Psychiatry at Danbury Hospital

Dr. Aguilar-Zanatta asked who in the audience is a caregiver and most of the audience raised their hands. Dr. Aguilar-Zanatta asked which of the caregivers have feelings of guilt or resentment for those they care for. Just about every caregiver raised their hand.

Dr. Aguilar-Zanatta talked about different scenarios growing up that could lead to the feelings that you have toward taking care of your parents. For example, if your parents were very strict and controlling and as a teen you were very disciplined, you may show signs of being passive aggressive by showing up late to bring your parent to the doctors, or you may

not pick up their prescriptions on time. If you grew up in a very loving house hold but lacked parental discipline and were a wild teenager, then perhaps you will have feelings of guilt and try to make up for being such a wild teenager.

Dr. Aguilar-Zanatta explained you must cope with the stressors of caregiving. If you focus on being perfect, you will set yourself up for too much pressure. No one is perfect and you shouldn't put that burden on yourself. You should focus at achieving the task at hand.

There are many stressors in caregiving and it is always best to have back up so you do not have to go it alone. Seek professional help for yourself and always remember to have "Me Time"

Changes in your mental status such as having feelings of guilt, hopelessness, demoralizing, irritable, or anxiety, are all feelings of depression. You should seek both professional help and help with taking care of your elders.

Feelings of guilt can turn into feelings of resentment. You can have anticipation anxiety such as feeling anxious prior to an event such as taking a parent to dialysis.

Often caregivers have feelings of not being appreciated by either the person they are caring for or their siblings. They may be called martyrs or controllers by their family members. Caregivers tend to take the information given them by providers and then Googling it. Thus, causing them to read too much into a specific area. For example, all medications have side effects and it is good to be wary of them, but if you scrutinize all the side effects for a medication, then you over worry.

It is important for caregivers to be mindful of their feelings then they can channel them. Many people do not know what their tipping point is until they get there. Learn your limits. Give yourself options that are realistic. The best way to deal with feelings of being overwhelmed is don't isolate yourself. Get mental health help. Ask for help. Reach out to your family members or others to help with the caregiving. Do an inventory of resources if you are no longer able to do the caregiving. Most importantly fulfill other roles that are therapeutic to you. For example if you enjoy reading, make sure you read at least ½ hour a day. If you have hobbies make sure you give yourself time to do them.

Lastly take a long hard look at the core values of the person you are caring for. Are their core values family, socializing etc. If they prefer socialization perhaps making sure they are involved in a Senior Center or in an assisted living facility may be best.

Members of the audience talked about how they feel the burden of caring for an elderly parent because their siblings stated that they are just not caregivers, and they can't do it. This leads to resentment and anger towards their siblings.

Discussion with the audience focused on it is OK for the ones you are caring for to be uncomfortable with a situation so long as they are safe. For example, you may have had to put them in an assisted living home or nursing home. If they are safe, let them get used to a

new situation. It is ok for them to complain about it so long as they are safe. Give them 3 months to adapt. Keep their existing living quarters until you know they have adapted.

It is important to allow yourself time to care for yourself. Find a caregiver's support group. If you disagree with family members about a specific situation, do your research and back up your point of view with facts. Whenever possible find a common denominator when fighting with family members. Don't undermine a situation by not talking about it. For example, many families don't talk about money. If money is an issue, then you need to discuss it.

Sometimes parents will ask their children to promise them they will never put them in a home. Children need to tell their parents, I hear what you are saying and I understand your concerns, and I will help you with that. But do not promise if you can't follow through, no matter how good your intentions are. You may offer them a choice, perhaps give them the choice of a nursing home or a live-in caregiver.

There are two very good books by author Roger Fisher. They are "Getting to Yes" and "Getting Past No"

After a brief intermission Jessica Hughes, MSW is the Danbury Manager of Connecticut Community Care Inc. The State funded service "Connecticut Home Care Program for Elders" requires financial criteria. They help coordinate all of the services people may need in their home. Do not wait until you are burned out to contact them. Contact them ASAP; even if you don't need all the services as you can be reevaluated. They do private management on short or long term care. You can call them for an assessment as well as get agency names and referrals. The State funded portion is going to be cut due to Gov. Malloy's budget cuts. Go now because if you qualify your services will carry over. If you wait, the program may no longer be available. They will also do family meetings.

Carolyn DeRocco, Vice President of Programs and Education for the Alzheimer's Association Connecticut Chapter discussed 78,000 people in Connecticut have dementia and there are 79,000 caregivers. They have a 24-hour hot line 1-800-272-3900. There is no cure or treatment for Alzheimer and it will progressively get worse. Alzheimer's patients still have emotions and if educated can still have a quality life. One of the Alzheimer's Association's goal is to decrease caregivers' anxiety. They must take care of themselves. Their website has a caregiver's center. Plan ahead; if you can't be there get a power of attorney. Visit places now and not when you have reached your tipping point.

Barbara Newlane, LPN Director of Homecare for RVNA talked about caregivers are used to their parents being in authoritative role and now that role has been reversed. Many caregivers have feelings of being unprepared or inadequate. Barbara Newlane stated you are not alone. Caregivers are secondary patients.

Barbara Newlane stated there are many resources available to caregivers. She runs a free 6-week program entitled "Powerful Tools for Caregivers". It teaches caregivers how to handle juggling, guilt, taking care of, and making time for yourself, as well as making action plans. It is imperative that caregivers take the time to do something they enjoy at least once a week.

The program also helps to identify and reduce personal stress and teaches relaxation activities.

It is important to communicate feelings, needs, and concerns as caregiving can be a challenging situation especially if the person you are caring for has memory impairment. Try sending an “I” message instead of a “You” message. For example, say “I understand what you say but I can’t promise that always”. Learn how to deal with your own emotions of anger, negativity, and guilt and learn from your own emotions.

This free 6-week program entitled “Powerful Tools for Caregivers” takes place at the Caregiver Goldstone Foundation in Danbury Hospital through May 11 from 1:30-4pm

### **Questions and Answers from the Audience**

The audience was interactive throughout the entire program. Some questions and concerns they had were their family is spread throughout the country so they feel like they are the only one to take care of their parents or they feel guilty because they are so far away and not able to help.

Do not feel guilty or feel as though you have failed if you cannot care for your family member. It is OK to use community resources. It is OK to get outside help. The same holds true for those who are caring for parents and have siblings that live far away. Use your community resources and get outside help. You don’t have to go it alone, there are support groups.

It is important to laugh. Get help, it’s OK.

How to streamline communications and care between hospitals/doctors and patient/family?

Have a list of medications that work and that the patient is taking. If you can have a digital list on your phone that is even better because it is always with you. Let the clinician know that you are part of the team. Do not say “I am in charge and you will do things my way”.

If the person you are caring for has dementia, let the clinician know what stage they were at 2-3 days before they became sick as sometimes being ill can influence their dementia. It is important the clinician know the baseline and that it is not a progression of their dementia. Go to Alzheimer’s Association CT Chapter at [www.alz.org/ct](http://www.alz.org/ct) for more information

Maureen Salerno thanked everyone for attending. The Forum was adjourned at 12:15pm.