



VAN FORUM NOTES

March 14, 2006 “Caregiving and Vital Aging”

“In one of every four households, someone is involved in providing care to a relative or friend age 50 and over.”

--*Caring With Confidence: A Self-Help Guide for Your Caregiving Journey*

Opening Remarks

Marnie Hensel, VAN Leadership Group member, welcomed participants to the forum. She posed the question of the day and asked participants to provide their first name and their answer to the question. “When you think of being a caregiver, what word would describe you?” Participants responded with the following answers:

- Anxious
- Concerned
- Impatient
- Tired
- Overwhelmed
- I’m not sure of the word but it means allowing for distance, not being an enabler but one who is able to stand back. Another participant offered the word “perspective.”
- Control
- Fearful
- Sensitive
- To be on task, to take care of things
- Safety
- Challenging
- Nurse and frustration
- Frustration
- Humble

Introduction of the Speaker

Marnie introduced the speaker, Joan Knuesel who is with FamilyMeans. Joan is the Community and Family Educator in the Caregiver Support Program at FamilyMeans. FamilyMeans is a private non-profit social service agency focusing on three main areas: Community Programs, Consumer Credit Counseling and a Mental Health Clinic. Joan has spent the last five years working as an educator in the Caregiver Support Program. She has designed and taught her workshops in a variety of arenas from worksites, faith communities, senior centers, and just about anywhere she is invited. Her personal

experience of caregiving parents and two good friends lends depth and understanding to the difficult role people play to others in need.

Setting the Stage

Joan told the group that when she started her job at FamilyMeans they sent her to the Age Odyssey Conference in St. Cloud. This is where she met Jan Hively. In her new position, Joan wanted to be proactive and to get people information before they needed it. Jan encouraged her to participate in the Vital Aging Network. Joan truly applauds the specialists in the area of caregiver support who are a part of the Vital Aging Network.

Joan asked Kari to do role playing in which Kari played the daughter and Joan played the role of wife/mother and caregiver to her spouse. Joan acted as a typical caregiver by insisting that all of her affairs were in order, that she was fine, and that financially she and “Kari’s father” were okay.

Joan explained that the presentation she will make today was developed with input from an elder women’s group. They helped her develop this training that is relevant to people of any age. Joan warned the participants that they will have a lot of homework. She encouraged participants to make copies of the documents in their packets and to share them with their children and other important people in their lives.

Prevalence of Family Caregiving

Joan noted that Rosalyn Carter identifies four different kinds of people:

1. Those who have been caregivers;
2. Those who currently are caregivers;
3. Those who feel they will be a caregiver in the future; and
4. Those who feel they will probably need care at some point in the future.

One in four households in the U.S. have caregiving issues of some kind or another. This can include helping out a neighbor, providing care through a faith community, as well as providing care to a family member such as a spouse, child, or parent. In a 2001 survey, the National Family Caregiver Alliance found that caregivers did not self identify and thus did not access available resources. People themselves said they were not caregivers only helping out family/friends in need. Caregiving from a distance, such as when the parents winter in Florida and adult children try to deal with caregiver issues at home is going to become more prevalent. Family/informal caregiving saves the federal government \$29 billion a year.

Getting Information and Key Documents Together

It is important to get the information and documents together that your family will need to access when they are providing care to you both before and after your death. You never know when this is going to happen so everyone should start now to get organized. The information in the packets that the participants received will help everyone undertake

this process. It is not an easy thing to do. Joan indicated how surprised she was about how much time it took to get everything for her family into one folder.

Gather important documents into one central location – a folder. Include a list of locations for those documents/pieces of information that you cannot include in this folder.

Joan asked the group how many of them have their financial information all organized in one place. Several participants raised their hands and shared with the group what made them go ahead and do this.

- When mother passed on and I had to get all of the information together it got very complicated. We decided we would make it easier for our kids. We started a trust and this required us to get all of our information together.
- My husband died suddenly with no will and no siblings. It was not as complicated as it might have been but I do not want anyone else to go through that experience so I put my affairs in order.
- AARP put an article in their newspaper about doing this. So, my wife and I picked a day between Christmas and New Years to get organized. It took more than one day. It took about 20 hours. It is a great feeling to have it all in one spot.
- While my husband was dying he wrote his will.

Two key pieces of paperwork are a health care directive (formerly known as a living will) and will. Early on, we all need to make sure that someone has power of attorney for us. We need to tell people we have these documents in place. We need to identify a back-up. We need to have durable powers of attorney.

- A participant noted that Joan had not talked about emotions. He has already taken care of everything financially. This is a peaceful feeling – but it has to be planned.

Key information and documents include Personal/Family (Social Security numbers, etc.), Medical (medications list, list of health care providers, etc.), Financial (retirement savings account information, real estate, etc.), and other important documents and information (names/contact info of those who should be notified, funeral/burial instructions, etc.).

Don't put your health care directive in your bank. Keep the original and give copies to your health care power of attorney and other people who are decision makers in your life. If a person has had a health care directive for 10-12 years it is important to review it and make sure you are still comfortable with what it says. Be sure to sign your name and date it after your review.

Getting Started on Your Life Story

Joan recommended the book, The Right Words at the Right Times, to participants. The author of this book interviewed every type of personality possible. One interviewee was the author Anna Quindlin. Anna's mother died when she was very young. Her mother

gave every child an index card with a handwritten bible verse. Anna kept it for a long time until she realized its importance. Over time she learned that those words were simple yet so impossible and that her mother managed to embody them. The card is proof that she had once existed.

Joan strongly recommended to participants that they sit down and write a handwritten letter to everyone that is important to them. It should be a letter that is only opened after you death. Handwritten is very important. These are not necessarily good-bye letters but letters that tell people how much you love them.

It is also important to take the time to pull out a notebook and write down some things that have happened that you want to remember. Stories, memories can be passed from one generation to another in this way.

Participants offered their insights:

- Just start with one thing and make it an ongoing process.
- My kids say that I am neither that smart nor that interesting. Joan responded by saying that's because you're still here!
- When my husband's mother died, the kids found a journal that she had started. Everyone stopped what they were doing to listen to her words.
- Be sure to capture the good stuff and some of the bad stuff.
- I hate journals so I'm wondering if this would be a good job for caregivers who can split up the job? Joan responded by saying that she was thinking of the writers as healthy people, but this can also be done for people who are dying.
- I'm the oldest of eight. My father died a year and a half ago. At the time, my nieces were asking about things related to the care being provided by the family members. I realized that there were eight different angles on these stories. I told my siblings that I thought it was time that we all jot down our angle on this family. Our family is growing and it will become increasingly important to have this history.
- My son and I took a trip and interviewed my uncle who is the oldest in my family. I learned things I never knew and never would have known.
- Use videocameras to preserve memories.

Funeral Planning

Joan described how her mother-in-law had handwritten her ideas on her funeral, made copies, and shared this with everybody in the family. Everyone followed every detail that she laid out. Participants shared their insights.

- When Carl died I had several programs from previous funerals that I used to plan his funeral. For example, I had seen in a program that a song was identified as that person's favorite song. I did this for Carl's funeral program.
- My father died suddenly after a fall and did not have a health care directive. My sisters and I had to make a life and death decision in the lobby of the hospital. Could we agree on everything? No. And should we have been deciding this at that moment in that way? No.

- It's critical to write it down.
- To identify those who should be notified upon the passing of a relative you should use their Christmas card list.

Caregiving Issues

“Are You a Caregiver?” Joan shared a self-test that individuals can take to see if they identify themselves as a caregiver. “Care for the Caregiver.” Joan shared a list of easy ways to help a caregiver. She noted that caregivers are so overlooked. Everything they are doing is on behalf of the care receiver. Outcomes of caregiver stress and deterioration are early nursing home placement and high levels of depression. Joan recommended that participants go to www.caregiver.com. There is an editorial on Dana Reeve that calls her the “Exquisite Caregiver.” Dana does speak to taking care of herself.

Joan shared her personal experience with caregiving. She described how she helped a friend of her's who was on hospice go through all of the cards that she had received as a way of letting go of everyone before she died. Another friend died a year ago. Her family and friends developed a healing circle. They organized 15 people who would come together every other week to help her or just listen to her. They did this for a year and a half before she died. And they all became caregivers in one way or another.

Joan shared an array of caregiver resources with the group such as brochures, magnets, websites and phone numbers.

- *Caring with Confidence – A Self-Help Guide for Your Caregiving Journey*. This is available free of charge and you can download it on the FamilyMeans website at www.familymeans.org.
- *In My Family We Care*. This booklet provides something for families to use to begin to talk about the caregiving situation – especially with younger family members. This can be downloaded free of charge from the FamilyMeans website at www.familymeans.org.
- FamilyMeans conducted a small study to identify how to meet GLBT-specific caregiving needs. We also helped write an edition of the “Quatrefolio.” The issue was devoted to caregiving needs in the GLBT population. For further reference go to www.qlibrary.org
- There is a health care directive form that is available for downloading at the Minnesota Board on Aging website at www.mnaging.org.
- There are lots of free education sessions available online from AARP and others.
- Brochures handed out by Joan include the “Caring for Yourself” brochure by the Minnesota Board on Aging; “Aging Caregiving with Developmental Disabilities” that highlights the Disability LinkAge Line; “Beyond Sadness” which helps caregivers with identifying depression; and a brochure about FamilyMeans’ caregiver respite program.
- Joan read an excerpt from the book by Eda LeShain called I Want More of Everything. The author never got the chance for her mother to say something to her so she wanted to write a letter to her daughter. Who among us feels that they left too much unsaid to their parents? Can we just let our children off the hook?

Joan has developed a list of helpful websites related to caregiver support.

- **FamilyMeans** - www.familymeans.org
Respite care, caregiver support groups, education programs and volunteer opportunities for caregivers and their families.
- **Administration on Aging Caregiver Resources** -www.aoa.gov
Information and support for those who are caring for older persons.
- **National Family Caregiver Association** - www.nfcacares.org
Hope page for the National Family Caregivers Association, which focuses on the needs of family caregivers.
- **AARP Webplace: Caregiving** - www.aarp.org
User-friendly site which provides information and resources for caregivers.
- **Caregiver Network, Inc.** – www.caregiver.on.ca
This is a Canadian-based site which contains useful information for caregivers anywhere. See the section of the site called “caregiver info” for good material.
- **Senior Law** – www.seniorlaw.com
An excellent source on a wide range of legal needs and issues of seniors.
- **Social Security Administration(SSA)** – www.ssa.gov
This site can answer your questions about Social Security retirement, survivor’s benefits, disability insurance and Supplemental Security Income. 1-800-772-1213
- **Veterans Administration(VA)** –www.va.gov
The federal VA system offers benefits to veterans. The web site offers a full range of benefits, eligibility and contact info, and medical services. 1-800-827-1000
- **CHID (Combined Health Information Database)** – www.chid.nih.gov
A cooperative effort among several Federal Government agencies. Use it to find consumer information and educational resources on a wide variety of health-related topics.
- **The Department of Energy** – www.hoaxbusters.ciac.org
This website has facts about Internet hoaxes. Visit the website to recognize them and know what to do about them.
- **FirstGov** – www.FirstGov.gov
This website is a one step access to all online Federal Government resources. Use it to browse a wealth of information-everything from researching resources at the library of Congress to tracking a NASA mission.
- **Senior Link** – www.seniors.gov
Provides links to government web sites relating to the needs of older people.

Jan Hively noted that one of the active members in VAN who is with the Three Rivers Community Action Program, Pat Kimble, has developed two guides: 1) “Family Meetings – A Guide for the Caregiver” and 2) “Family Meetings – A Guide for Accepting Care as You Age.” These guides are available by calling The Three Rivers agency at 1-800-277-8418 and talking with the Senior Programs Coordinators, one of whom is Pat.

Closing Remarks

Marnie thanked everyone for attending the forum and thanked Joan for a wonderful and informative presentation.

Jan announced that the next VAN forum will take place on Tuesday, April 11, 10 a.m. – 12 p.m. at the Walker Arts Center in Minneapolis. The forum will be facilitated by members of the MN Creative Arts and Aging Network. The forum will begin with tours of the Kiki Smith art exhibit and will be followed by a discussion of her art. Participants will also learn more about the MN Creative Arts and Aging Network, hear about their current efforts and see their new website.

Marnie provided participants a chance to contribute to VAN and asked everyone to fill out an evaluation form.

Sue Meyers announced that the Advocacy and Leadership in Vital Aging certificate program is accepting applications for its next class. Sue encouraged participants to apply and noted the opportunity that it affords for intensive networking with many amazing people.

The Minnesota Association of Senior Services is having a conference in April and all are welcome to attend.

Bob Gubrud announced that VAN is sponsoring a special event on March 31st on global warming. The Environmental Force group has asked J. Drake Hamilton, Science Policy Director at Minnesotans for an Energy Efficient Economy, to speak to participants about what is happening in Minnesota and what actions individuals can take. The meeting will take place at the Roseville Library at 10:30 a.m. on the 31st.

Marnie announced that there will be a program on PBS on integrative medicine on March 29 at 7 - 9 p.m.. At 9 – 10 p.m. that same evening on PBS there will be a program on what is happening in the state of Minnesota, which is at the forefront of efforts in this area.