

Notes from the Caring for the Caregivers Forum on 4/30/17
Health Care Navigation Committee
Immanuel Presbyterian Church

Rev. Susan Graceson, moderator
Forum: Helyn Hoft, Colleen Tuner, Angie Griffith

This forum is about caring for a loved one and for yourself. Books on display are from the IPC library. Also pamphlets on back table.

Helyn Hoft: Member of IPC for 22 years, cared for Harry from 2005 until he passed away last year. No nursing experience except Peace Corp when younger and raising three children.

Bless you if you are a caregiver. It is the most rewarding and frustrating job you will ever have.

My husband, Harry, was born in Iowa, raised a Presbyterian. His grandparents and all his siblings and recently a nephew, all died from Alzheimer's. It is tragic. Dealing with it requires strength and stamina.

I was born in Western Pennsylvania and raised a Lutheran. I had a Sunday School teacher who said that no matter what we were doing in life, God is with us. I have held onto this all my life.

I took Harry to Georgetown's memory clinic in 2004 because he was becoming forgetful. They did MRIs, CT scans, and all the tests for Alzheimer's and dementia. He was diagnosed with Early Onset Alzheimer's. He did well for several years. We even traveled. We had all the documents drawn up (will, trusts, POAs, Medical POAs.) I took over all the driving and decision-making.

By 2014 he couldn't walk or stand. Communication was sporadic. I was managing but it was hard. My son moved in to help. We worked hard to have a plan and to be organized. Harry continued to deteriorate. I was on call as the caregiver from when I woke up in the morning until I went to bed at night.

I realized I wasn't doing this right. It is easy to fall into a routine and see your husband as only a patient, not a person. We forget the person. It is very important to keep the person in mind all the time....

We called hospice. They evaluated him and gave us a caregiver three times a week to help with bathing plus a weekly nursing visit. Double edged sword. Never knew when they were going to show up so annoying to have a person call and say they are on their way just as you were about to get into the shower, take a nap, or make lunch. After several months they told us that Harry wasn't getting worse so no more hospice.

There is a bible passage in Genesis 36, which says that young Anah found springs in the wilderness as he was pasturing the donkeys. I have experience with donkeys from South America. They are smelly, noisy, stubborn and insect-infested. It is a terrible job to have to protect the donkeys. But this boy did it and found springs, which made the family fortune. This is what care giving is like. Not pleasant. There were days when I'd be brushing Harry's teeth and he's spit at me. Or I'd be bathing or shaving him and he'd upend the basin of water. Bad days. At those times, I'd sit down, take Harry's hand, and say Anne Lamott's prayer, "Help me, help me, help me. Thank you, God." It was calming and changed the atmosphere. It gave me the ability to see Harry as a person, not as a patient. To see the man that I married and that I loved. I'm not a praying person, but I believe that God is looking after you every day. Care giving changed me. I became a fuller person.

Colleen Turner- Fairfax County Elderlink Organization for 15 years.

Christ told us to "go and help." Being a caregiver follows his direction. Day to day challenges are physical, mental and emotional.

Pauline Voss wrote a book called "Loving Someone with Dementia." She speaks of ambiguous loss, which is what happens when the relationship with a person changes. They are still here but they aren't the same person as before. We are grieving as we lose them.

We would prefer to have things black and white, this or that. Predictable. Care giving isn't at all predictable. You have to start thinking in terms of "and." For instance, I am married and single. Married to a man I love and care for but he can't go out to dinner with me or go dancing so I'm single for those activities. Rebuild your life around the "and" word. Build a community outside of your care giving relationship.

There are lots of county resources on the public and private side. In most cases you have to exhaust your private resources before qualifying for public resources but always call the Elderlink organization to check. Some, like Veterans' Benefits, are available regardless of income.

We offer two programs, both aimed at elders or the person with disability. The first is a Self-Management Class, which is two hours long, meeting weekly for 6 weeks. We do brainstorming for things like sleep, partnering with a physician, avoiding falls, etc. The second class is called A Matter of Balance and is aimed for those with fall fears. We discuss fall-proofing the home and balance exercises. We can offer these anyplace if we have ten participants.

We also offer support groups. Care giver groups with tips and help. There is a telephone care giver group if you can't leave the person you care for. (See Q&A)

The hardest thing to overcome is accepting help. Whether old or young, no one likes to admit they need help.

Angie Griffith: Attorney Elder Law

Cared for my 68 year old father for three months as he died from cancer. Short period of time but very intense. The time was a gift but it was very hard. I was bathing and dressing my dad. I had no sleep because his sleep patterns were different from normal.

I counsel my clients to see the whole person. To recognize that this is a journey but it won't be a straight road. There will be bumps and changes along the way.

The first step is to get foundational documents in line. The power of attorney is for while a person is still alive. It is so the care giver knows what the person wants. As long as they have capacity they can draft documents even if they have a diagnosis of dementia. (See Q&A) The medical POA addresses end of life issues, feeding tubes, etc. as well as whether care giver can set up a Do Not Resuscitate request. Doctors will not do these things if they aren't in writing. If you don't have it in writing, then you have to go to court to be appointed guardian. Guardians are not always the family members. Can be an independent third party who then has to guess at what the person would have wanted. Getting guardianship takes weeks in court and lots of money.

The POA is important to have for financial reasons. It lets you step in if you see things going astray like bills being paid twice or not at all. Or if you need to navigate difficult systems like Social Security. Or if an emergency comes up and the person needs to be admitted to a nursing home. This is huge problem. Often children sign the nursing home contract themselves not realizing that they are committing themselves to pay the bill for the nursing home. Important to have the power of attorney and to sign as the attorney, not as yourself.

Virginia has something called the Medical Surrogate Decision Act, which sets up the order in which hospitals and doctors are to work with people. A guardian is listed first (POA), a spouse is listed second and children are listed third. However, if siblings can't agree, then the issue may be back in

court for weeks and a third party guardian appointed. Parents often think their children get along great but often not the case, especially when a lot of emotion is involved or money is involved.

The POA is also for understanding the level of care a person wants during their life. A nursing home in this area costs \$10K-\$14K per month and such long term care isn't covered by Medicare. What sort of care does a person want? At home? Assisted living? Nursing home? Can they afford what they want and for how long?

The POA provides the opportunity to ask questions and discuss these issues.

Another thing to be aware of is the difference between a hospital stay that is "observation" versus "admitted inpatient." If observation status then only Part B of Medicare applies, not Part A which means no nursing home coverage after discharge while recovering. Always ask to make sure you know status. Sometimes you can contest an observation status by working with a Hospital Patient Advocate. They can't change it retroactively, but they can change it going forward.

Medicare in Virginia allows community based care in the home, which may allow a spouse to continue working while someone comes in during the day. Check on these benefits.

Make sure that you, as the care giver, have your documents in order and name a successor care giver. Otherwise, the courts may be trying to figure out who will care for the person at home if you are in a car accident and hospitalized. If you are the primary care giver, make sure you indicate this in your wallet. This lets emergency personnel know that there may be someone at home who needs attention soon.

Be proactive to look out for scam situations. Angie has a woman client who lost \$700,000 to a Match.com "love of her life." Greatest danger is as a person begins to be less capable but is still managing their own affairs.

This is a journey for both the care giver and the person affected. Every situation is different. All finances are different. All illnesses are different. Try to have as much in order as possible so you don't end up spending days in court in the middle of a medical or financial crisis.

Q&A:

If you don't have a family member who can be your advocate if you are in the hospital, then hire a person. A care manager is expensive but Eldercare Organization has a grant that lets a Fairfax County resident have as much care management as needed, regardless of their income, for \$175 for the first month and \$100/month for subsequent months. A huge deal.

Helyn: Unexpected blessings caring for Harry?

It was very meaningful for my son. He had a good relationship with both of us but he'd gone his own way after leaving home. Moving back in and helping with his dad brought us all closer again. The Faith Matters group at IPC helped by providing emotional support. I took an exercise class five days a week in the early morning to help burn off stress. Little things made a difference. I held a mirror up and told him that was him so he could see himself and connect with who he was.

Angie: Are there restrictions on a POA for unmarried couples?

No. It is your document to make as you want. It is probably more important for unmarried couples to have a POA.

Are old or out of state POAs valid in Virginia?

If it is a durable POA, then even if 25 years old, it might be okay. The key is that different states require different witnessing and notarizing. The Uniform Power of Attorney Act in Virginia lets POAs from out of state be accepted IF their witnessing and notarizing is the same as Virginia. A judge can

invalidate a POA, especially if the person with POA responsibilities isn't behaving responsibly or in the case of fraud, duress, etc.

ALSO banks have their own requirements. If a POA is more than three years old, they may require a letter from the attorney stating that the POA is still valid. They can refuse to allow access to the account in the meantime. Best to go to the banks ahead of time and sign their own special POA documents so that you will have access to the money when needed.

A note about medical POAs.....talk to your doctor ahead of time to make sure that his/her views match what you want done. However, be aware that when admitted to a hospital, your care is likely to be overseen by an intensivist or hospitalist, not your own doctor. This is when it is important to have the medical POA document. Don't be alarmed if they don't ask to see it. The POA becomes important when the doctors are advocating one course of action and the family wants a different course of action or if family members are in disagreement.

If person refuses to sign a POA there is nothing you can do.

Angie: Can loved ones be protected from unknown debt left by a person dying?
If a credit card is in a single name only, then remaining spouse not responsible. If joint debt, then surviving spouse is responsible. If you are the executor you have to pay the debts from estate but you are not responsible for them.

Helyn: Was Harry resistant to care? Aggressive? How did you deal with it?
Harry was never aggressive. Sometimes he would say "no" and refuse to get out of bed. I saw that as a miracle day because I had time for myself. With Alzheimer's, each person is different. Harry was mischievous more than anything else. It was his only way to express himself. There was no way for him to be a person except by little things like refusing to have half his face shaved. If I encountered a problem, I would just walk away and come back in 15 minutes. He would have forgotten about the issue.

Resistant behavior is 90% due to anxiety. Try to quiet the anxiety. Breathe. Take a break. If you are arriving after stress of traffic, try to relax before you go in to see the person.

What about a resistant parent?

The hardest part is accepting need for help. No one wants to admit they need help. It is part of the journey. Make a suggestion. Give them some space. Walk away. Make the suggestion again. Keep talking about it until eventually accepted. If the issue is driving, be a bit sneaky. Take the distributor caps off the car so it won't run. Go to a support group to learn tips for handling all sorts of difficulties.

Angie: What does "capacity" mean for legal documents?

Medical definition of mental capacity is different from legal. If the lawyer sees the person struggling with names or with the idea of who should inherit what, that is a problem. If the person can't engage in a natural conversation, that can be a problem. If they are struggling to express themselves, that raises red flags. Each situation is individual. For legal situations it isn't based on a test although doctors can administer a test. It is also easy for people to circumvent the tests.

Sometimes I will have children leave the room so that parents can talk freely to me. Some lawyers want the children in the room privy to everything so that they know what is going to happen. No surprises. Everyone gets copies and a copy is sent to the hospital. However, attorney client privilege means that attorney can't give children information without parental approval. There is a real problem of abusive or vindictive children.

How do agencies like SS get notified after a death?

Sometimes the funeral home will notify some agencies. Sometimes filing the death certificate with the state will generate notification. Best to make a list of all agencies and places of business and notify them yourself.

Helyn: Specific tips for care giving?

Have a plan...I had plastic desk chair cutouts on the carpet around the bed so I could roll the wheel chair easily. I had a table with baskets that had everything I needed. Depends diapers, skin lotions, thermometer, even toys. It was easier than running around the house for things. Keep supplies refilled. Harry liked classical music so we played that. He liked nature shows so we watched a lot of those. I was happier knowing he was occupied. It relieved some of my stress. In addition, the family played a big role. Grandchildren visits were great. He didn't know names but he knew these children were special. Family parties were at our house. Neighbors visited. All of that helped.

NOTE:

Care Givers' Support Group at Chesterbrook Residence 2nd Thursday of every month in the dining room at 7 pm. An LCSW/geriatric facilitator leads the groups. Mostly adult children of elders.