

C CAREGIVER CHRONICLE

Connections for Caregivers

Caregiving: It Comes in All Shapes and Sizes

By David Greenberg

There is no certainty in how and when you become a caregiver. If there is any certainty about assuming the caregiver role it's that it comes when you're least ready for it.

That doesn't necessarily mean you don't know it is coming. The most common form of caregiving is for an older parent or loved one. So while you usually see the changes in front of you, and you intellectually understand that you are getting closer and closer to reversing roles, when it happens, it is always a challenge.

The other thing that is most common, and at the same time difficult, for caregivers to understand is that they can't do it alone.

Carolyn Ascencios, LCSW, is a case manager at the Senior Healthcare Center at Crown Pointe. In that role she helps both patients and caregivers in this transition to the next phase of their lives. She brings to that role all the education and experience one needs to have. But she brings something else as well – she is a caregiver.

For Ascencios it started less than two years ago, and it

came with a unique challenge. While she lives and works here in Gainesville, the people who needed her support – her parents – were in Texas. And while she has three siblings, none of them lived in Texas either.

“Things were starting to get worse with my father's heart condition,” she said. “Mom was his full-time caregiver. But as they were aging, it became more complicated. Mom had a hard time reaching out for help. Neighbors and their church family could do only so much. We started using a private-duty, licensed caregiving agency in the area.”

She and her siblings also started taking regular trips to Texas when they could on a rotating basis and provided as much financial support as they could to give their mom some respite.

“It allowed my mom to go out a few times a week and attend to some simple but critical things,” said Ascencios. “It meant the world for her. And it was a transition for my dad to have a stranger there. It was very challenging but it ended up working.”

Another thing she and her siblings did before her father passed away was set up a twice-

a-month tele-conference to talk about their parents' needs.

Those conversations helped alleviate another problem that was looming on the horizon.

“Because of what we learned with my father, we became better prepared,” she said. “We did not have the necessary legal documents in place when he became ill. But we prepared all that for mom.”

And now, with her mother's health an issue, the family can handle things a little better.

“Her health has declined,” said Ascencios. “Her short-term memory is failing. She is staying with us temporarily until we can decide on her next step.”

She says the tele-conferences were a major factor in being able to deal with these issues. “You put any personal conflicts aside to focus on the parents,” she said. “The conversations help us plan and talk about what to expect. We stay on the same page, and we all understand each other's limits. And a side benefit was that we have all become closer through those conversations.”

Peter Wilson came at caregiving in a very different

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way. He and his wife had a limited role in dealing with older parents. His mother lives in Pensacola, and while he helps out with her, he has a brother who lives there. His wife's mother passed away five years ago, and she has siblings who help with her father.

But for Peter and his wife life changed dramatically in 2016, when she was diagnosed with cancer.

"From one day to the next, you become a caregiver," he said. "There are a lot of adjustments to make and very little time to make them. There are physical and emotional adjustments to make but first we both just had to get over the shock. When she was getting care, we both remembered realizing how special the moments were. It brought us together more."

When thinking back, Wilson says it's hard to remember now how things changed as he assumed the caregiver role.

"It was interesting because I didn't even think about the things I had to do," he said. "I just went into it almost on automatic. I had to suddenly put all my attention on her and her needs. I guess I went into self-less mode."

"But that was not without difficulty," he added. "There were very tiring moments – and sorrowful moments. It hits you emotionally. But you just did what was needed to be done. You see a lot of doctors, get a lot of information and move on from treatment to treatment. And we have had some very intense situations, especially with hospitalizations. It makes it harder for the caregiver to go get some rest."

As difficult as it has been, Wilson and his wife understand there are times he needs to take that break.

"Especially during periods when things are stable, she has honored my space and time. It's a different kind of caregiving than it would be for an older parent. She is younger and, at different points in time, she can take care of herself more. You have to set boundaries by saying 'I can do this much and no more.' The significance of taking care of yourself is monumental. It truly is a marathon."

Community Coalition for Older Adults
Second Friday of the month, Senior Recreation Center, 5701 NW 34 St.
Contact Shirley Bloodworth at sgblood@bellsouth.net for information.



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Caregiver Chronicle is published every other month
Published and produced by Greenberg Communications
www.greenbergcommunications.com
Editorial Advisor: Cheryl Robinson, L.C.S.W.

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From the Desk of Sam W. Boone, Jr.:

The Best Books for Seniors Published in 2016

By Sam W. Boone, Jr.

Editor's Note: This is part of a series of columns that will be presented in this newsletter by Sam W. Boone, Jr., a local attorney whose primary practice areas include elder law, estate planning, probate and trust administration. It is hoped that the information will be valuable for caregivers and family members dealing with issues related to elder law.

2016 was a banner year for reading if you are in your 60s or older.

I ran across an article written by Diane Cole that appeared in *The Wall Street Journal* which highlighted some of the outstanding reading material for what she refers to in the headline as books for *People of a Certain Age*.

And as I read the article, I realized that 2016 was indeed a banner year in literature for those of a certain age.

The first book she highlights is *Life Reimagined: The Science, Art and Opportunity of Midlife* by Barbara Bradley Hagerty. The book focuses on a series of challenges faced by Hagerty in her early 50s. A journalist, she lost her job at National Public Radio as a result of a paralyzed vocal cord. That was followed almost immediately by the death of her mother. She shares the challenges of facing a new career while dealing with the devastating emotional loss. The book also includes current research and information about healthy aging.

Next, author Ian Brown examines turning 60 in his unique book, *Sixty: A Diary of My Sixty-First Year*. Described by Cole as witty and poignant, Brown shares how he deals with memory lapses, not writing a long-promised novel, even hair loss. It is an emotional and amusing tale of getting older. But it is also prescription for being open and ready for life's changes.

Did you know that the National Park Service was 100 years old in 2016? It was created on August 25, 1916 by an act of Congress. *A Thinking Person's Guide to America's National Parks*, edited by Robert Manning and others, offers a series of essays and spectacular photography of the more than 400 historical and beautiful sites which make up our national park system. If your travels around the country have not taken you to these beautiful locations, this book may be just

the thing to motivate you, according to Cole.

If you are older than 60, you lived through one of the most unique periods in our nation's history – the 1960s. *The 60s: The Story of a Decade* is a book of essays published by *The New Yorker* about this most tumultuous time. It is the third installment of a fascinating decade-by-decade series. Whether you were too young to remember the 60s or want to clarify things for yourself a half century later, this anthology is a group of works written for *The New Yorker* by



some of the most prolific writers and artists of the period. The pieces range from the serious – articles about the assassinations of President Kennedy and Martin Luther King Jr. – to the lighthearted – famed sports writer Roger Angell's article on the improbable

1969 World Series victory by the New York Mets.

Two more books from 2016 are more focused for our older clients. *The Art and Science of Aging Well: A Physician's Guide to a Healthy Body, Mind and Spirit* by Dr. Mark E. Williams suggests that aging isn't something that just happens. We can do things to fight off the effects of aging. *Your Best Health Care Now: Get Doctor Discounts, Save with Better Health Insurance, Find Affordable Prescriptions* by Frank Lalli serves as a blueprint to how to work your way through the financial obstacles to good health. Lalli, a journalist and editor, draws from his own experience as he was facing a \$204,000 bill for drugs needed after being diagnosed with cancer, walking the readers through how to find the best insurance and dealing with Medicare.

So happy new year, but don't close the book on 2016 until you have examined these great reads.

Sam W. Boone, Jr. is a Gainesville-based attorney practicing elder law and estate planning. He is past-president of the Academy of Florida Elder Law Attorneys and is accredited by the Veterans Administration. To learn more about elder-law issues, go online to [www. http://boonelaw.com](http://boonelaw.com), or call (352)-374-8308.

Savvy Caregiver Training

Savvy Caregiver Training is a multi-session training dedicated to people who care for family members and friends with dementias (like Alzheimer's). Our goal is to reduce caregiver stress by offering easy-to-understand information about progressive dementias, related medicines, and diagnostic tools. In the program we help caregivers build skills on relating to persons of dementia when they behave in ways that baffle, embarrass or irritate you and others.

Here is an introduction to our New Year schedule. In 2017, all Savvy Trainings will be 7 weeks in length. Choose whichever series works for your schedule and call Tom Rinkoski at (352) 692-5226 to register. Or e-mail him at rinkoskit@agingresources.org.

- Starting 01/18/2017; Wednesdays; 1:00 – 3:00 pm; Melrose Senior Center, Melrose
- Starting 01/31/2017; Tuesdays; 1:00 – 3:00 pm; Lifestyle Enrichment Center, Lake City
- Starting 02/01/2017; Wednesdays; 2:00 – 4:00 pm; Haven Hospice, E.T. York Center, Gainesville
- Starting 02/06/2017; Mondays; 1:00 – 3:00 pm; Serenades ALF, The Villages
- Starting 02/02/2017; Thursdays; 2:00 – 4:00 pm; Hospice of Marion County, Ocala
- Starting 04/04/2017; Tuesdays; 1:00 – 3:00 pm; Buffalo Crossing, The Villages
- Starting 04/05/2017; Wednesdays; 10:00 am – 12 noon; Live Oak/Suwanee County Library, Live Oak
- Starting 04/06/2017; Thursdays; 2:00 – 4:00 pm; Mt. Carmel Baptist Church, Gainesville
- Starting 05/02/2017; Tuesdays; 1:00 – 3:00 pm; Cross City Rehab, Cross City

More dates of upcoming Savvy Caregiver Trainings can be found at our Web Page (<http://www.agingresources.org/savvy-caregiver-for-families>). Or, go to our Facebook Page (<https://www.facebook.com/SavvyCaregiverNorthCentralFlorida>) for other information, tips and techniques about caregiving and dementia.



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Dealing With Stress

By David Huckabee

Wouldn't it be nice if once we were dealing with one large stress in life, all the other stressors simply disappeared or at least waited their turn? Unfortunately, this isn't the case. For caregivers, the stresses associated with caring for a loved one who is dealing with any serious illness does not happen in a vacuum. The stress associated with work, finances, family relationships, traffic, and life in general keep coming. Not only that, but they can often seem magnified in the face of our already difficult caregiving responsibilities.

While I do not know of any magic spell that can eliminate the stress from a caregiver's life, we at the Alzheimer's Association do offer some tips that have been shown to work at making the stress level manageable. Here are a few tips for your consideration.

1. Ask for help. It sounds so simple and yet it is often one of the most difficult things for adults to do. Pride, fear, and a host of other factors keep us from asking for help when we need it. The result of this is that we wait until we are so overburdened that help becomes much more difficult to give.

2. Get organized and stay organized. If we don't know exactly what needs to be done, then the smallest tasks can feel overwhelming. Make to-do lists. Check off tasks as they are complete. What tasks can someone else do for you to lessen your own stress? Your neighbor keeps asking what she can do to help. Give her something concrete to do. She will feel better and you will have one fewer thing to do before you can rest.

3. Take care of yourself. Too many of us (I count myself among the guilty) put off our own needs while we are engaged as caregivers. We skip our own doctor's appointments, we eat on the run, and we go without quality sleep. Unfortunately, what seems like a noble use of our time and resources can have serious consequences. Ask yourself the hard question. Who could (or would) step in if I got so sick that I could no longer function as a caregiver? Then do whatever you can to prevent that from happening.

4. Taking care of you also means taking time for you. Try to carve at least a few minutes out of each day to do something you know relaxes you. Yoga, tai chi, listening to music, going for a walk... the list of possibilities goes on and on. The important thing is to make sure it happens.

5. Watch for signs that your stress level is getting too high. Being a caregiver is stressful. As already mentioned, there is no way to eliminate that reality. However, managing your stress is crucial for your own well-being and that of your care partner. I often find that having someone else you trust is important. We often do not recognize the signs of stress in ourselves. A trusted friend or family member can let us know that we appear to be reaching the breaking point.

If you would like more information about the work of the Alzheimer's Association Central and North Florida, please call (800) 272-3900 or contact David Huckabee at dhuckabee@alz.org.

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Are You Prepared for Just in Case

By Tom Rinkoski,
Caregiver Coach at Elder Options

There is so much in life that can happen unbidden. Most of us never anticipated investing so much time, money and energy as caregivers. But at this moment, I am thinking, especially as we look into a new year, about stuff that easily upsets the applecart, increases stress, and sometimes pushes us over the edge. For caregivers, this can be precipitated with a case of the flu and wondering who to call to take over caregiving duties. Stress builds when my children call from across the states asking for help. I want to fiercely believe I would do anything for my children but now I am balancing new responsibilities as well. Or, taking it a step further, I remember when I had to be hospitalized and was out of action for several months. Imagine that. The caregiver becomes the one who needs care.

This is more than simply talking about caregivers being flexible. I don't wish anyone flu or surgery or any form of additional stress, but I urge you to begin building a caregiver team. We don't know when and how we might be sidelined and become incapable of being the solitary cornerstone of caregiving. We do know from the statistics that caregivers are more prone to being sidelined with illness because of their constant stress. It is wise to build a caregiver team you can count on as early as possible.

I am not just talking about hiring people, although that is one strategy. I am suggesting we need to build a collaborative network of folk who might join us in small but meaningful ways. Start simply. These are folks who might offer to bring a meal, take my person for a walk, play a game and/or go shopping. These are the building blocks of a caregiver collaboration that not only makes our task easier, but helps me to face unknowns with a bit more grace and style. Some of these folk might

be family members, some neighbors, others from a local church – there are many different sources. Ask for ideas at your caregiver support group meeting. In addition to building a collaborative care network, we need to invest in significant self-care – which includes some time for attitude adjustment occasionally.

Develop a well-rounded caregiving plan that not only takes care of immediate needs, but also is open to future possibilities. This requires some investment in planning, which I know sounds like extra work. But, the payoff comes in knowing you are well prepared – just in case something happens.

I recommend the two following videos as places to brainstorm your advance thinking on building a care team. They are free on line. Check them out: (1) Who is in Your Caring Circle? <http://savvycaregiver.info/who-is-in-your-caring-circle/>; (2) Creating A Family Care Plan. <http://savvycaregiver.info/step-by-step/>.

Veteran Benefits

If you are a veteran or widow of a veteran please note that you may be eligible for benefits under the Veteran's Administration. These benefits may be able to help with the cost of additional care in the home or assisted living facility. There are income and asset eligibility criteria to be met. However rules of financial benefits can change at any time so it is important to speak with a Veteran Service Officer. It helps to have discharge papers available. Locally, the Alachua County Veteran Service office holds free workshops for those interested in applying. On Tuesdays there is a Pension Workshop and a Compensation Workshop on Wednesdays. On Thursdays there is a General Informational Workshop. For more details about these, please contact the Alachua County Veteran Service Office at **264-6740**.

Caregiver Support Groups

Al'z Place/Harbor Chase
3rd Thursday of the month at 9am
Open to all caregivers
Contact Nancy at 352-375-3000 for address

Alterra Clare Bridge
3rd Thursday of the month- 6pm
4607 NW 53rd Ave, Gainesville, FL 32653
Contact Gail at 376-5151

The Cancer Center at NFRMC
Heart of Healing Support Group/Meditation
Tuesdays 12-12:30pm
Call Joanie at 386-853-0162

Community Cancer Center
Living With Cancer Supports
www.cccnf.com for more information

Community Cancer Center
Lake City Support Group
2nd Wednesday every month 11am - 1pm
4520 W.US Hwy. 90, Lake City, FL 32055 For more
information call 386-755-0601

Haven Hospice
Bereavement Supports
Call 692-5123 for more information

Hospice of Marion County
Transitions Caregiver Support Group
Usually the 2nd Tuesday of each month 11am - 1 pm
The Elliott Center, 3231 SW 34th Ave. Ocala
Call for information 352-854-5200

Hospice of the Nature Coast
Wings Community Education Center
Grief Support Group- High Springs
Call 386-454-1338 for more information

Lake Area Caregiver Support Group
4th Tuesday of the month from 1-2:00pm
Trinity Episcopal Church
204 SR 26, Melrose, FL 32666
Call 352-475-3792 for more information

Park Meadows Health and Rehab Center
3250 SW 41 Pl, GV
Call the Alz Helpline at 1-800-272-3900 for more
information

Senior Healthcare Center at Springhill
3rd Tuesday of the month- 2:30-4:00pm
3720 NW 83rd Street, Gainesville, FL 32606
Contact Flory at 336-3050

NF Mind Matters Stroke Support Group
4th Thursday of the month from 1-2 pm
South Tower, 4th floor Conference Room-NFRMC
Call 1-800-611-6913 for more information

The Village
(for Village residents only)
2nd Thursday of the month from 1:30-3 pm
8000 NW 27th Blvd., Gainesville, FL 32606
Call 872-5332 for more information

United Church of Gainesville
1624 NW 5th Ave, GV
3rd Tuesday of the month from 7-8pm
Open to caregivers of persons with dementia
Contact Lynda at 352-219-3023

VA Caregiver Support
Mon-Fri- 8am- 11pm, Sat. 10:30-6pm
Call 1-855-260-3274

Useful Resources

Seniors vs. Crime: www.seniorsvscrime.com

Alzheimer's Association – www.alz.org/cnfl/index.asp

Elder Affairs – www.elderaffairs.state.fl.us/index.php

Elder Helpline – 1-800-963-5337, options@agingresources.org

Elder Options – Savvy Caregiver Classes – www.agingresources.org

Florida Silver Alert – www.floridasilveralert.com

SHINE (Serving Health Insurance Needs of Elders) www.floridashine.org

Driving – www.independencedrive.php.ufl.edu

Medicare – www.medicare.org

State of Florida – www.myflorida.com

National Institute on Aging (free publications) – www.nig.nih.gov

United Way – Alachua, Bradford & Putnam counties – www.unitedwaycnfl.org

National Association of Professional Geriatric Care Management – www.caremanager.org

U.S. Department of Veterans Affairs – www.va.gov