

CAREGIVER CHRONICLE

Connections for Caregivers
Dedicated to the memory of Cheryl Robinson, M.S.W., L.C.S.W.

March/April 2019

Having the Talk: Facing the Reality of a Changing Life

By David Greenberg

There may be no bigger challenge for adult children than having the talk with their senior parents about having to change their living situation.

It's likely that if you are the caregiver for an older parent or family member who is struggling to function independently, you are already assuming additional responsibilities that you never dreamed would be yours. And it's also likely this is a conversation that, at the very least, you are not looking forward to. In fact, you're probably dreading it.

This talk can range from a suggestion that it is time to bring in some help for a senior family member, to the more extreme alternative of having to change their living situation. If you are thinking about this conversation then, in all likelihood, it is a talk that should have already happened, according to Jennifer Fitterman, co-owner of Next Steps Senior Solutions, a company that helps guide families and individuals through this process.

"Starting the conversation



is not easy," said Fitterman. "And most people put it off. But no one ever just goes to long-term care too soon. In every case we have dealt with they end up not believing they did it too soon. Often, they just don't know what to do, so they don't do anything. And then tragedy strikes. We help them see the problem before it becomes a tragedy."

There are many different ways to start the conversation.

"It often depends on the personality and what's going on," she said. "One of the best ways to start is to talk about how much it will help you (the caregiver). They don't want to be a burden. That often works. It's the benefit of being a senior. They spent a lifetime taking care of family and their community. Now it's time for

the community to take care of them. We have all these services in our community ready to give back for all they did for us."

Flory Antiga-Stephens, LCSW, case manager at the Senior Health-care Center at Springhill, agrees, suggesting that it is often a crisis that gets people to finally act.

"Often, it takes too long to figure out, and then there's the crisis," she said. "Maybe their parent had a fall, or broke something, or is diagnosed with dementia for the first time. They simply can't live by themselves anymore. People don't want to deal with it. It is a difficult conversation that they certainly don't want to have with their parents."

Jeffery Linville, Fitterman's partner at Next Steps Senior Solutions, says the crisis conversation is all too common.

"Ninety percent of the people we deal with are emergency situations," he said. "Or their dementia has reached a point that they can't take care of themselves. They can't even plan or prepare

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meals. We can help take them to the next step. When we must deal with people in emergency situations, they have done zero research and have no idea what the best solution is.”

At this point, people are generally dealing with inaccurate information they receive from friends or colleagues.

“That does more damage than good. We can help with all the necessary research. It’s not only about what living situation you might love, or who is coming in to your home to help you but also how you pay for it. Families look at the obstacle right in front of them but not the next obstacle.”

Frequently it takes the crisis to see what must happen. It is often after crisis that family members – especially those that don’t live nearby – discover changes in their parents. Those changes can include finding spoiled food in the refrigerator, a messy house or car accidents. Those may be signs of your family member no longer being able to take care of day-to-day activities.

Antiga-Stephens points out the essential conversations that must happen at that point – financial, health care, aging, end-of-life decisions and family legacy. And it will take more than one conversation.

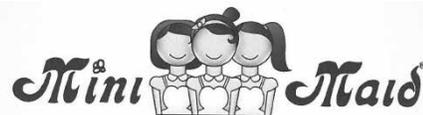
“One of the most important things is be patient,” she said. “Usually, the older generation feels strongly about individualism and taking care of themselves. They don’t want to leave their homes, and they certainly don’t want their kids telling them what to do.”

So it may be the most challenging set of conversations you ever have as a family, but it also may be the most important.

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.

For more information and class dates, go to the website (<http://agingresources.org/savvy-caregiver-for-families>) or Facebook page (<https://www.facebook.com/savvycaregivertraining>). Contact Johnnie Jones at jonesj@agingresources.org or 352-692-5277 to register.



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and her vision

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

People with Disabilities and Their Families Earn a Lifetime Pass to National Parks

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.

As we all know, caregivers face some of the biggest challenges. Not the least of which is finding appropriate activities for those in their care.

That varies, in part, based on the issues they are dealing with. The person they are caring for may be a senior suffering from dementia or another age-related ailment. They could be a younger person with a critical disease. Or they could be a person of any age dealing with a permanent disability of some kind.

If the person for whom you are caring falls into the second or third category, traveling for activities and entertainment may be an easier option. And while finances may often be an issue, here's a great idea for those who care for a family member with a permanent disability.

Having a permanent disability may be limiting in some ways but it opens many other doors as well – including visits to our national parks and federal recreational lands.

The pass is available for anyone with a qualifying disability – physical, mental or sensory – and all their family members.

Included in the pass privileges are more than 2,000 federal recreation sites across the country – national parks, national wildlife refuges, national forests and other federal recreation lands. And the offer extends to everyone in the vehicle with the pass holder. That means if one person in the family qualifies, you are all entitled to visit the park at no charge.

In Florida alone, there are 12 locations where the free pass can be used.

There are some steps you need to take to obtain the free pass. It starts with one of the two following documents.

You can use a statement signed by a

licensed physician that says you have a permanent physical, mental or sensory impairment that substantially limits one or more major life activities. The document must include the nature of the impairment. Or you can use a document issued by a federal agency, such as the U.S. Department of Veterans Administration, saying it has been medically determined that the person is eligible to receive federal benefits as a result of blindness or permanent disability. In lieu of either of those, you can use proof of receipt of Social Security Disability Income (SSDI) or Supplemental Security Income (SSI), or a document for a state vocational-rehabilitation agency benefits or services as a result



of blindness or permanent disability.

Once you have one of these documents, you simply need to fill out a form that can be found on the passes page of the National Park Service website: www.nps.gov. You can either mail it in with a \$10 processing fee or go to a federal recreation site in person with proof of disability and residency. If you do it in person, the \$10 fee is not required.

So don't let a family member's disability keep you and them from being active. Just take these few simple steps, and then go enjoy nature's beauty.

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.boonelaw.com, or call (352) 374-8308.

When Home is No Longer an Option

By Johnnie Jones III

As a Caregiver Support Specialist, one of the most popular and pressing questions that I receive is “How will I know when it is time?”

Most spouses, children and family members innately know that they will, at some point, be unable to fully provide the direct-care that their care-recipient needs in the current caregiving arrangement. They know that they will not have the physical, medical or even emotional strength and wherewithal to continue to do the massive amount of work that comes as the diagnosed condition progresses.

Many caregivers begin to prepare themselves early for the stress that separation and a new living arrangement will cause. Well trained and prepared caregivers know what their limits are, and many have set red-lines or milestones to help them more easily identify the changes that will necessitate a skilled nursing or other community living placement.

It is important for caregivers and others to realize that a care placement is not a failure. It is simply a next step in the caregiving continuum. As many as 70-80% of people living with dementia are

being cared for in private settings by family caregivers. The majority of the work is being done at home.

It is reasonable to expect that prolonged periods of care provision with limited support will eventually wear on caregivers and require a change. As caregivers struggle with guilt, they simply need to consider that the role has limitations and an expiration date that might come long before their person’s demise.

The caregiving role will evolve and take many unexpected turns and will, undoubtedly be the proverbial roller-coaster ride. When home is no longer the best option, caregivers should be prepared to release the good and bad stress that comes with that ride and move to the next phase as a remote caregiver. Placement is not failure. It is the next phase..

Johnnie Jones III is the Caregiver Support Coordinator for Elder Options/Savvy Caregiver Training Program.

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Downsizing Your Home While Keeping the Memories

By Leilani Doty, PhD

When your adult children become independent tax-paying, homeowners, when it becomes too much work to keep up with housework and yardwork and when it becomes difficult to get to the grocery, drugstore, library, place of worship, barbershop/beauty salon, etc., it may be time to downsize to a smaller home.

Changes in health, such as difficulties with balance, movement, memory or other thinking functions, may indicate that it is time to move to an efficiency apartment, a retirement community, an assisted living facility, etc., that offers services to residents such as meals, housekeeping, transportation, blood pressure/health checks, or help dispensing medicine.

To move from a home of many years and filled with precious memories is difficult. The furniture, wall hangings of places visited, books, a favorite jacket/coat/suit, etc., decorative doodads and even the broken lawnmower sitting in the garage hold memories of the past. Discarding such items because they will not fit into a smaller home may feel as if you are tossing away a piece of yourself. Sometimes the items may be donated to an organization that serves people in need and offers a new life of usefulness to the items and a tax benefit to the donor.

Downsizing in steps may help. Choosing items to pass onto children and grandchildren may provide a sense of the family history “living on” through the younger generations. Over the years, asking visiting family members to think about selecting items for their own home may help with slow downsizing. Sometimes these “treasures” are highly valued by other family members, other times not so much or not at all!

Prioritizing items that have the least emotional value to give away (or discard if they are broken, rusted, frayed or moth-eaten) first and then slowly working one weekend a month to go through rooms or closets to pick out items that carry less of an emotional tug to give away may relieve the sadness of separating from loved items. Talking about the process with loved ones, trusted friends, clergy or a professional helper such as a care manager may help ease the process.

Taking a photo of an item for a scrapbook may be a way to keep the memories. Sharing the scrapbook photos while taping the related stories for grandchildren may help Grandma and Grandpa to keep the emotional connections to their memories which will live on in their future generations.

Leilani Doty, PhD. is a local community expert in aging issues. She can be reached by email at leilani@mangerian.com.



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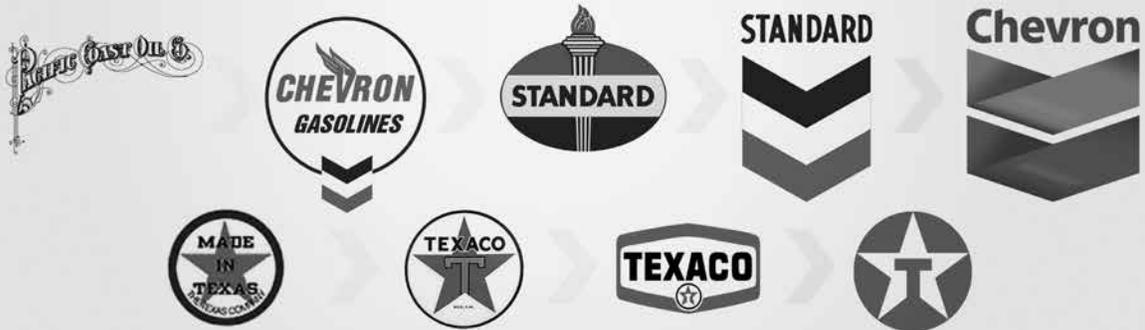
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The Toughest Conversations: How to Talk to Your Parents About Assisted Living

By Ruth Brunner

Some of the most meaningful conversations you'll ever have are with your parents. They're there for you for all the toughest times in your life – when you scraped your knee, when you needed a shoulder to cry on, your first date, and especially when you needed some life advice. While these were all hard conversations to have, they all had meaningful impacts on your life. The same is true about the conversation to move your parents into assisted living communities.

Choosing to move out of the comforts of home and routine is not an easy decision. Obviously, safety is of the utmost importance, and so is the overall wellness of your loved ones. You also want to be confident you and your loved ones are happy with the decisions being made. At Legend Senior Living® our goal is to help those in need find the care they deserve while maintaining respect, independence and dignity.

Below are some tips we have learned directly from families like yours who have gone through this process:

Be Sympathetic and Speak from the Heart

Moving is hard! Especially encouraging your parents to move away from a home where they've had meaningful relationships and raised their kids, in to start a new chapter of life. Help your parents by being sensitive to their needs, wants and fears. Include them in the conversation about their life. They have a voice too! Invite your siblings. Sometimes it's also advantageous to bring in a trusted third party for advice such as your parent's primary care physician or spiritual leader.

Make Collaborative Choices

People are more willing to make choices when they feel involved, especially when it comes to living arrangements. This is why it's so important to get your parent involved in picking the community they prefer, with the right combination of their favorite things. On the other hand, when people feel forced to make changes, they typically resist them (even if the changes are in their best interests). You should structure your conversation in a way that shows you aren't trying to run their lives; rather focus on keeping them safe, happy and healthy.

Set Up Visits to Tour Senior Living Communities

Sometimes senior living communities get a reputation as being boring or dull, but this is far from the case. At Legend Senior Living, we pride ourselves on providing engaging, enriching, modern, and luxurious residences that give seniors a wide variety of physical, mental and spiritual activities, games and hobbies, new friends, great tasting/healthy meals and snacks and above all safety and security.

A tour of an assisted living community is often the easiest way to show how comfortable, and innovative senior living communities are. With var-

ied services tailored to the individual and a focus on family and independence, finding the right home for your parents can be an exciting experience (like moving into your first apartment).

Assess the situation

Some signs it's time for assisted living can include:

- Weight Loss Due to Malnutrition or an Inability to Feed Oneself
- Frailty of Strength or Stature
- Weight Gain (Potentially Due to Illness or Inactivity)
- Changes in Behavior, Appearance, or Bathing Habits
- A Loss of Friendships, Activities, or Interests
- Unopened Bills, Personal Mail or Past-Due Notices
- When Daily Living Activities and Independent Living Activities Wane
- Chronic, Persistent Health Conditions or Conditions that Require Daily Monitoring
- Slower Recovery for Small Injuries or Illnesses
- Recent Accidents or Incidents

Assisted living means not worrying about your parent getting a nutritious meal, not having to worry about your parents forgetting to turn off the stove or forgetting to take their medications. Be open and honest regarding your concerns about your loved one living on their own. They'll appreciate how much you value their safety, happiness, health and independence! Senior living ensures your parents will have the assistance in the case of an emergency or accident.

Ready to Make the Move?

It's important to realize feelings, emotions, and stress affect everyone differently. Obviously, the decision to get extra care for your parents isn't just about you -- but it is hard on your health (and can wear anyone out). That's why we're here to help! If your loved one is showing signs that living alone is becoming a strain or is dangerous to their health, find out what we can do for you! It's never too early to be proactive about your loved one's well-being.

Ruth Brunner is the Sales Director for The Windsor of Gainesville. She has worked in the senior care market for over a decade and currently serves on the Board of Directors for ElderCare of Alachua

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ASSISTED LIVING & MEMORY CARE

Caregiver Support Groups

Al'z Place

3rd Thursday of the month at 9am
Open to all caregivers
1610 NW 23rd Ave. Gainesville
Contact Nancy at 352-265-9200

Alzheimer's Association

Caregiver Support Group
2nd Thursday of each month - 1:30 p.m.
Edward Jones conference room,
220 North Main Street, Suite 2, Chiefland
Contact Kathryn at 352-493-4949

Cancer Center at NFRMC

Breast Cancer Support Group
2nd Tuesday of the month - 6pm - 7:30 pm
Call Susie at 352-333-5849

Caregiver Connection by Senior Healthcare Center

3rd Tuesday of the month- 2:30-4:00pm
Senior Healthcare Center at Springhill
3720 NW 83rd Street, Gainesville, FL 32606
Contact Flory at 352-336-3050

Caregiver Connection by Senior Healthcare Center

4th Tuesday of the month from 1-2:00pm
Trinity Episcopal Church
204 SR 26, Melrose, FL 32666
Call 352-475-3792

Caregiver Connection by Senior Healthcare Center

(for Village residents and their families only)
2nd Thursday of the month from 1:30-3 pm
8000 NW 27th Blvd., Gainesville, FL 32606
Call 352-872-5332

Community Coalition for Older Adults

Second Friday of the month, Senior Recreation
Center, 5701 NW 34 St.
Contact Shirley Bloodworth at
sgblood@bellsouth.net

Elder Options

Fourth Wednesday of the month, 1:30 pm – 3:30 pm
100 SW 75th Street, Gainesville
Contact Renee Horne at 352-692-5226

Haven

Bereavement Supports
Call 352-378-2121

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 352-854-5200

Lake Area Caregiver Support Group

4th Tuesday of the month from 1-2:00 pm
Trinity Episcopal Church
204 SR 26, Melrose, FL 32666
Call 352-475-3792

Park Meadows Health and Rehab Center

3250 SW 41 Pl, Gainesville
Call 352-378-1558

United Church of Gainesville

1624 NW 5th Ave, Gainesville
3rd Tuesday of the month from 7-8pm
Open to caregivers of persons with dementia
Call 800-272-3900 to RSVP

VA Caregiver Support

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

VITAS Healthcare

Grief Support Group- High Springs
Contact Joy at 386-201-1070

Useful Resources

Seniors vs. Crime: www.seniorsvscrime.com

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

Doggie Styles: Mobile Pet Grooming – www.doggiestyles.org

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

Elder Helpline – Florida hotline 1-800-963-5337

Elder Helpline – Alachua County hotline 1-800-262-2243

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

Florida Silver Alert – www.elderaffairs.state.fl.us/doea/silver_alert.html

SHINE (Serving Health Insurance Needs of Elders)

www.floridashine.org

Driving – www.ufhealth.org/uf-smartdrive-driver-rehabilitation

Medicare – www.medicare.org

State of Florida – www.myflorida.com

National Institute on Aging (free publications) – <https://order.nia.nih.gov>

United Way – Alachua, Bradford & Putnam counties –

www.unitedwayncfl.org

Aging Life Care Association – www.aginglifecare.org

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

Uber Guide for Seniors – <https://www.uber.com/blog/gainesville/freedom-in-motion>