

C CAREGIVER CHRONICLE

Connections for Caregivers

**How does a “Whisper” Turn into a Cure?
How does a “Stigma” become a Treatment?
When Will We Meet the First Survivor of Alzheimer’s?**

By Michelle Branham

Nobody survives Alzheimer’s. No one walks away from the disease having beaten anything. There are no winners; no one to claim victory. That’s the stark reality of today, and the harsh certainty for families given the diagnosis of Alzheimer’s or another form of dementia. We don’t have to imagine a healthcare epidemic that has no known cure. We are facing it now, amidst a flurry of anxious thoughts that come when mom can’t remember how to make that chicken soup she’s made for over 30 years. We face the depth and breadth of it in the sinking moment our sister tells us she got lost going to her daughter’s house that’s been just down the street for a long, long time. We are “slapped” with it the day our husband can’t think of his secre-

tary’s name – the one that’s worked with him for over ten years...

To-day, the “A” word accounts for the same terrible whispers the “C” word had when we were younger – the days when

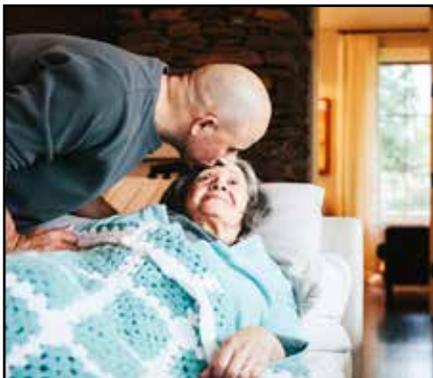
our parents, friends and neighbors couldn’t even say the actual word, “cancer” at the dinner table. Now, like it was then, there are murmurs in the church pews; there are knowing, sympathetic glances from others when our loved ones forget who they are talking to, or where they are. There are nights when we finally recognize we’ve been so overcome by Alzheimer’s disease, for so long that people have stopped asking if they can help. There’s no need to imagine what Alzheimer’s and its affects looks like...we can see it in our loved ones’ faces. It’s there, insidiously weaving plaques and tangles through memories we’ve taken a



lifetime to make.

But, that is our present; and tomorrow’s prospect is where we cast our hope. The first person to survive Alzheimer’s is out there. They’re going to hold onto everything the disease steals away. That smile they can’t hide – that dance class they love... every single piece of them is going to make it through because research and science is beginning to catch up to the disease. Our government is starting to listen. Our communities, and our families, aren’t whispering the “A” word any more. We are living painful moments without a cure; now... But, what if we could imagine a

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future that survived Alzheimer's?

How does a "whisper" turn into a cure? How does a "stigma" become a treatment? It happens when our neighborhoods, our schools, our government, our families, our caregivers start beating the drum – the reverberation of voices multiplied, "Enough. We've had enough." The present tells us that Alzheimer's disease is the only top-ten leading cause of death in our country that has no prevention, treatment or cure. Currently, science can't even slow it down.

Our future tells us that by funding research, advancing public policy and spurring scientific breakthroughs...and by providing local support to those living with the disease and their caregivers – the Alzheimer's Association will continue to ease the burden for all those facing it until we accomplish our collective goal. The goal we share with every family who has to hear the word "Alzheimer's" delivered in a diagnosis. And, this goal we share isn't elaborate. We just want what every family who faces Alzheimer's wants – a survivor – a glimmer of hope. But, we won't know any kind of

victory without challenging our awareness and our actions as a collective community of hopefuls. We need to start considering participation in clinical trials, so we have more research and data in the pipeline. We need to ask questions and start exacting answers from our elected officials when it comes to funding important research and support services in our country and our state. Florida has the 2nd highest prevalence in the country. And, we don't want to be a state known for this kind of human casualty. Alzheimer's disease has devastated millions of lives; half-a-million of them here, in the Sunshine State. But that can and will change when we reach the first survivor. Don't just hope for a cure, help find one.

Trial Match Clinical Trials: trialmatch.alz.org
Alzheimer's Advocacy: alz.org/advocacy
Education Services and Support: alz.org/care
24.7 Helpline: 1.800.272.3900

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

Top Scams Against Seniors

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.

We have written before about the need to be on the alert for deceptive or fraudulent ways used to try to take advantage of our senior (and not so senior) clients. These are excerpts from a recent USA Today article about the most common tricks used in 2016. To read the full article, go to <http://www.usatoday.com/story/money/2017/02/15/here-top-scams-targeting-senior-citizens/97913682/>

2016's Top Scams Against Seniors

An IRS impersonation fraud that has victimized thousands of Americans leads a 2017 U.S. Senate ranking of the Top 10 scams targeting senior citizens. Dubbed by the Treasury Inspector General for Tax Administration as the most pervasive impersonation fraud in IRS history, the swindle involves suspected scammers based in the U.S. and India who telephone Americans and threaten arrests unless purported tax debts aren't paid immediately. At least 1.97 million people have been targeted, with as many as 200 victimized per week during the scam's peak last year, according to the inspector general. Other frauds that made the Senate Aging Committee's rankings include:

- Sweepstakes scams, run by perpetrators who contact victims by phone, tell them they've won a financial prize, and then require advance payment of a fee to collect the purported winnings.
- Robocalls, using advanced electronic technology that enable would-be scammers to maximize the number of potential victims reached.

- Computer scams, a fraud in which callers impersonate representatives of well-known technology companies and convince victims to allow remote access to their home computers to check for problems. The scammers then charge fees to remove purported electronic viruses.

- Elder financial abuse, in some cases involving relatives or friends who gain access to victims' identification data, bank accounts or other records.



- Grandparent scams, a con game in which fraudsters phone with phony claims that a grandchild is in trouble and needs help paying a hospital bill, returning home from overseas or gaining release from jail.

The IRS, Social Security Administration, and the Centers for Medicare & Medicaid Services never make phone calls asking for bank information or Social Security numbers.

The Senate report advised seniors and other Americans to never give out personal information by phone and always keep personal and financial documents secure.

People who suspect they have become victims of identity theft should call companies where the fraud occurred, place a fraud alert with national credit reporting agencies, notify the Federal Trade Commission and file a report with local police departments.

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 spring/early summer 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 04/04: Tuesdays; 1:00 – 3:00 pm; Buffalo Crossing, The Villages
- Starting 04/05 Wednesdays; 10:00 am – 12 noon; Live Oak/Suwanee County Library, Live Oak
- Starting 04/06; Thursdays; 2:00 – 4:00 pm; Mt. Carmel Baptist Church, Gainesville
- Starting 05/02; Tuesdays; 1:00 – 3:00 pm; Cross City Rehab, Cross City
- Starting 05/04; Thursdays; 1:00 – 3:00 pm; Hospice of Citrus and the Nature Coast, Palatka
- Starting 05/16; Tuesdays; 2:00 – 4:00 pm; Santa Fe Davis Center, Archer
- Starting 6/1; Thursdays; 2:00 - 4:00 pm; Marion Oaks Community Center, Ocala
- Starting 07/03; Thursdays; 2:00 - 4:00 pm; Cone Park Library; Gainesville
- Starting 07/11; Tuesdays; 2:00 – 4:00 pm; Marion Senior Services, Ocala

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

We at the Alzheimer's Association often get questions from caregivers regarding expected and unexpected hospitalizations for the person with dementia. While not every situation is the same, there are some general tips and guidelines that should help you as a caregiver if you find yourself in this situation.

First, make sure that everyone who will be involved in the person's care knows about the person's dementia. Be honest with doctors, nurses, etc. about the stage of dementia, behaviors that the person exhibits and any specific facts that might help them in their care of the patient. If the person is at risk of wandering, it is very important to alert the hospital staff to this so that they can ensure the person's safety.

Second, ask all the questions you need to ask and don't be afraid to ask them again if you do not understand the answer. Make sure that everyone who is involved in your loved one's care knows that you are the caregiver and that you want to understand everything that is happening. Doctors and nurses have a responsibility to inform patients and/or responsible parties (caregivers) as to the progress of care, risks involved, medications administered, etc. However, they cannot answer a question that hasn't been asked. Ask for written copies of everything if possible or write the answers down yourself. The

hospital experience is stressful for everyone. Don't trust that you will remember everything that is said to you. Take the time to write things down so that you can refer to them later.

If it is possible, request a private room for your loved one. Ask hospital staff about bringing familiar items (photos, blankets, robe and plants) from home to make the setting more familiar. This will help lower the patient's stress during their hospital stay.

You may want to be with your loved one at every moment during his/her hospital stay. However, this might not be possible. This is the time to enlist the help of family members, friends, or companion services to sit with the patient when you need to attend to other matters...or you just need a break.

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.

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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**We will publish every other month around
the 15th, January, March, May, July,
September and November.
Deadline for each issue is the 5th of the
month of publication.**

Farewell Dr. Goldblatt!

Good luck on your next adventure.

***Thanks for everything you have done
for our senior community!***



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A Caregiver Emergency Survivor Kit

By Tom Rinkoski,
Caregiver Coach at Elder Options

Until the cure for dementia arrives, caregivers need to prepare themselves. I am aware that every caregiver's situation is different: some are minimalists, some hesitate to appear whiny or in need, while others will take advantage of every electronic gizmo available. Scan this list for items that you think will compliment what you have already have in your pockets.

1. **Patience.** "I need patience!" is a repeated clarion cry of caregivers. I am daring to suggest you need to dig a little deeper into the rucksack. You probably wouldn't have gotten as far as you have without patience. You feel impatient because you allow the same old "buttons" to be pushed all too often. What you may really need is an attitude adjustment. In an alternate reality, it used to be said that "Happy Hour" at the local tavern was really an attitude adjustment time. I am suggesting you create a daily ritual of decompression, of relaxation, or meditation. It doesn't really matter what you call it, but it does matter than you practice this discipline daily. Play piano, garden, read a book, it can take a variety of shapes.

2. **Pixie Dust.** Remember, when we were kids we used to believe there was some hidden dust that could make you fly, hide you from the meanies, or make the trolls disappear? We'd like to think that as adults we no longer believe in fantasy, but lots of doctors report to me people still are desiring magic pills to take away the pain. As adults, we have to accept the creation of magic pixie dust is our own job. It is a super power we all have (and frequently disown.) Infuse your dark chocolate with magic. Take time to watch fantasy movies on Netflix in which the good guys triumph in the end. Breathe deeply. Listen to Mozart and dance!

3. **Bandages.** You are going to get hurt and need care. Find people that not only have bandages, but who know how to apply them with love and care. Sometimes the best bandage for the wounded soul is a massage. Always carry gift certificates for a massage! Whenever I got my flu shot at the local pharmacy they gave me a bright red bandage and it

immediately improved my temperament. I wore it like a badge of honor that whole day. Don't just get regular bandages, find ones that protect the wound and brighten your disposition.

4. **Journal.** Every night before you go to bed (whenever that may be) make notes in your journal about the day! Scrawl out your feelings. Use a crayon if it helps! Get them out of your head and on to paper. Use your journal like a detective's notebook to give perspective to behavior patterns (yours as well as your person's). This is a gift you can give yourself. Most do it using a simple composition book, but I know a few who keep a video journal as well (modern cell phones are gifts from heaven – see pixie dust above. Date each page. Look back often, and occasionally dream about the future. Perhaps you can use this to write a book later on.

This list is by no means exhaustive. Send me your thoughts on what you've added.

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

Alz Place

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

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.ccnf.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

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

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.phhp.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