

C CAREGIVER CHRONICLE

Connections for Caregivers

When to Bring in a Professional Caregiver?

By David Greenberg

This is one of the most difficult questions for a family caregiver to answer. But maybe there's a better way to ask the question: when is it bad to bring in a professional caregiver for the first time?

Because the answer to that question is not only simpler,

it is also easier for most family caregivers to accept.

Sally Dahlem is a co-owner at Home by Choice, a locally owned home health care agency that provides private-duty homecare services. She has 25 years of experience in the field and just a few months ago was recognized for her work by the



A Message From Cheryl Robinson

I've been thinking about an article my intern presented this week on the role of coping patterns in successful aging and the difference between a reactive versus a proactive response to a situation. As it implies, the proactive response entails planning ahead, thinking of preferences, considering potential challenges and researching resources and supports in preparation



for a care crisis. A reactive response implies living in the moment, going with the flow and then dealing with the care crisis when it occurs. The research suggests that there are pros and cons for both coping strategies. Both responses carry a fair degree of anxiety. Planning for potential crises can cause anxiety when thinking about the inevitable. Reacting in the moment to a crisis leaves one vulnerable in a time of need. And both responses are influenced by one's

ability to adapt and the strength of the social support system in place.

It appears to me that our goal is to find that balance between the two. The proactive approach appears to be beneficial as long as we keep the inevitable in perspective. And we can still savor the moments and enjoy the days for what they bring with the understanding and acceptance of those things that may come and cannot be changed. The well-known Serenity Prayer comes to mind.

In our newsletter we usually focus on the proactive approach. We present information on planning ahead like knowing the difference between inpatient and observational hospitalization status and how to ask for help. We provide contact information for the VA, professional caregivers and caregiver classes. Today, I'd like to remind us as well to savor the moments, to enjoy the gifts of today and to know that we are sharing so much. Thanks again for allowing us to be a part of your team.

Cheryl Robinson, LCSW

Gainesville-Ocala Unit of the National Association of Social Workers. She is certainly one of the leading experts in the community on caregiving.

Sally's message is don't wait. If you are a family caregiver then you are in a stressful situation 24-7, but there's stress and there's even more stress.

"It's important to arrange for caregivers before that stress becomes overwhelming," she said. "You need to do it before the client and family are under so much physical and mental stress that you can't even begin to bring another person into the picture."

Planning in advance is critical. If you are caring for a loved one, and it is starting to become the primary function in your life, you should be planning for help right now. The result, if you don't, is over time you will no longer be able to function as an effective caregiver. Then there are two people in crisis.

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Professional caregivers

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Let's assume you have some outside help already in the form of adult daycare. And let's say your loved one is sick and can't go to that daycare for a week. If you have not planned in advance, you are now locked in with that person for the duration of that illness.

This community is blessed with a wide variety of support programs for caregivers and experts who can share their knowledge on caregiving. But if you are locked in with the person for whom you are giving care, those resources are beyond your reach.

Additionally, the caregiver may have their own medical issue and may not be able to care for their loved one. These are all reasons to have introduced them to an outside home care agency.

"Reach out to an agency like Home by Choice and schedule an appointment," Sally said. "It takes time to find a good match with a professional caregiver."

Start with a few hours two or three days a week, so both you and your loved one can get accustomed to this new person.

"If you both are familiar with this person over time, it's more likely that when there is some sort of increasing crisis, they will be more effective for you," she said. "And as the caregiver, you will be more comfortable leaving your loved one with this

professional, so you can take care of yourself."

As a side note, when you do get to the point where you are using a professional caregiver, it's important that your loved one understand they are here to help.

Try to make sure they understand that the caregiver is there to help you with household activities," she said. "They will be more accepting if they don't think the person is there to help them, but to help you."

And the professional caregiver should start with the simple things.

"Don't have them do all the tasks right up front," she said. "Something like shower assistance should wait until they get to know you better. Once you all get used to each other, you can introduce more challenging tasks."

But that is issue #2. The first issue is to reach out for professional help. That's what it's there for.

Community Coalition for Older Adults

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Center, 5701 NW 34 St.
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sgblood@bellsouth.net for
information.

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

Observation Status: What is it and what does it mean for patients?

By Sam Boone

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.

Sometimes going to the hospital is necessary but what happens when you get there changes based on the medical need.

When the medical need is serious enough your doctor or the hospital attending physician will decide to admit you to the hospital on an inpatient basis. In some cases you may be treated, and when the treatment is done – generally in a few hours – you are released.

Another status is becoming increasingly common – observation admission status – sometimes referred to as outpatient. Initially devised to monitor patients for a longer period of time, observation status is generally used when a patient can be treated within 24 hours, or if the conditions causing the problem have not been determined and the hospital medical staff wants to observe the patient for a longer period.

After the 24-hour period your doctor will generally decide whether you can be released or admitted as an inpatient.

However it is becoming increasingly common for patients to stay in observation status for longer periods if the medical condition requires it, and that creates a financial issue.

Patients are often designated as being in observation status or outpatient even though they are staying in the hospital for several days. During this time they stay in hospital beds, receive medical and nursing care, diagnostic tests, treatments, medications and food, just as they would if they were inpatients. The problem is that under the Medicare statute patients must have an inpatient hospital stay of three or more consecutive days, not counting the day of discharge, in order to meet Medicare criteria for coverage of post-acute care in a skilled nursing center.

Also as a result of the observation designation, outpatient co-pay will apply, and routine or self-administered drugs and medications are not covered. And depending on the hospital, you may not be able to bring your medications from home.

While the cost of those medications could impact an older person on limited income, the bigger problem is what happens if there is post-hospital rehab care in a skilled nursing facility – something that is very common with older patients. They must either pay the full bill or forgo treatment. A recent Florida law, which took effect July 1, requires notice be given to the patient or the patient's proxy through the discharge papers. But notice of observation status is not required at the time



of admission.

So it is important for you or your caregiver to understand under what status you are in the hospital. The best person to talk to is the hospital's discharge planner. If you are going to be there for an extended period of time, and you anticipate rehabilitation in a skilled nursing home after you are released, try to get the hospital to admit you as inpatient.

Beyond that there needs to be a solution that protects the patient and recognizes the financial implications for hospitals. Legislation being considered in Washington may do just that. It would amend the Social Security Act to count the time of outpatient observation status toward the three-day period needed to meet Medicare criteria for coverage while in the nursing home. While it doesn't fix everything, it goes a long way to help relieve the financial and emotional stress experienced by our elder community and their caregivers.

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. To learn more about elder-law issues, go online to [www. http://boonelaw.com](http://boonelaw.com), or call (352)-374-8308.

Asking for Help!

By Tom Rinkoski

Even though often living lives of quiet desperation, caregivers are ordinarily reluctant to ask for help. They have probably even turned away a polite offer by a neighbor or someone from the church. We are hard pressed to confess need and accept dependence. Maybe the caregiver has been burned by a family member who questioned their judgements.

Nonetheless, every single caregiver needs to build a network of support. This may include hiring temporary help from an agency to enjoy some well-deserved respite. It usually begins with accepting a dinner gifted from your church on a day of the week. It expands when someone goes for a walk with your person in the neighborhood. You're really cooking when you let someone do your laundry for you. We caregivers need to think out a better way to ask for help, so it is not random, but a collaborative plan of action that improves the overall care of our person and lessens our stress.

This begins with clearly identifying your needs. What are the opportunities in your patterns of care that others easily can plug into? I've created a volunteer handbook that not only names the activities, but suggests the best times to do them, and a couple of notes describing the best path to pursue. For instance, I was asked by a friend if they could come over and spend time with my dad who had beginning Alzheimer's. When they told me they had early afternoons on Tuesdays I was happy as a clam. I asked them if they could play poker with my dad at the kitchen table! They said, yes, and dad had companionship and fun and I an extra hour off.

Plus, when you ask you need to be realistic about what it is people can do. My mom, whom I now care for, loves getting cards and letters from the grandkids, but frankly cards and letters are not the thing for this e-generation. Nor can I expect my brother who lives 900 miles away to slip down for the weekend to come and give me some time off. We only build in our own stress when we ask the impossible. There are ways everyone can participate, we just need to be unafraid to be creative and ask with respect.

Caregivers also need to provide helpers brief recipe cards, bulleted with suggestions on how to successfully spend time with our person. This may be the first time they've ever been with someone with dementia, and you want it to be a positive experience for both parties. When folks take my mom shopping, I remind them she is deaf and blind on the left side, and that cuts out a lot of problems.

There is an art and a science to asking for help in such a way that you are building a collaborative network of help, as well as a network you can count on. You will remain the primary caregiver, but you and your person need the socialization and refreshment that company can provide. In Savvy Caregiver Training we teach these skills in the 6th class in the series. We have handouts to help you ease into this process. Savvy Caregiver Training is free. Trainings are scheduled throughout North Central Florida. Please consider joining us in this very special caregiver training. To find out dates and places trainings are scheduled call Tom Rinkoski at **(352) 692-5226** or e-mail him at **rinkoskit@agin-gresources.org**.

Upcoming Savvy Caregiver Trainings

- Thursdays, 1:30 – 3:30 pm beginning July 30, in Gainesville at the offices of Elder Options 100 SW 75th Street, Suite #301
- Tuesdays, 1:30 – 3:30 pm beginning September 1, in Tavares, FL, at the offices of IFAS Lake County Extension
- Wednesdays, 1:30 – 3:30 pm, beginning September 2, in Oxford, FL at Mission Oaks
- Thursdays, 1:00 – 3:00 pm, beginning September 10, in Chiefland, FL at the Career Source Offices
- Thursdays, 1:30 – 3:30 pm, beginning September 10, in Starke, FL at the Bradford County Senior Center
- Mondays, 1:00 – 3:00 pm, Beginning October 5, in Melrose, FL at the Melrose Senior Center

Get Information Easily with the Elder Helpline

By Damaris Lopez

Assistance is just a phone call away with Elder Helpline. This Elder Options program gives seniors and their caretakers the opportunity to gather information about various topics in one place.

“It’s a starting point for information about resources available to seniors, their caregivers or anyone really,” Vidya Hogan, Elder Options Director of Consumer Services, said. “There is no age restriction for the Elder Helpline.”

Specially trained and certified professionals operate the Elder Helpline. They provide callers with information about referrals and services available to seniors, persons with disabilities and their caretakers.

Examples of some specific things callers can get help with are transportation, recreation, Meals on Wheels, job placement and testing, legal assistance, emergency alert systems, disaster resources, prescription drug assistance and more.

The program also helps callers with applying for other programs such as Medicare Savings Program, state and federally funded in-home services and others.

Assistance with Medicare and in-home care services are the primary reasons people call the helpline, according to Hogan.

“Seniors want to remain in their homes, but they are unable to do their everyday tasks, so they

call the Elder Helpline,” she said.

The Elder Helpline is a division of Florida’s Aging and Disability Resource Center. It is available Monday through Friday from 8 a.m. to 5 p.m. by calling 800-963-5337. Voicemail is available for after hour calls, and those messages will be responded to the next business day.

More information on this can be found by calling the Elder Helpline at 1-800-963-5337.

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**.

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Alzheimer's News

The text below is from a June 17 email from the Alzheimer's Association:

Today, the chairman of the House Labor, Health and Human Services (Labor-HHS) Appropriations Subcommittee took an historic step by proposing a \$300 million increase for Alzheimer's research at the National Institutes of Health (NIH). If this increase becomes law, it will be the largest annual increase EVER in federal Alzheimer's research funding.

This development would not have occurred without the efforts of the Alzheimer's Association, the Alzheimer's Impact Movement (AIM) and advocates like you. Thank you!

From the Alzheimer's Association Advocacy Forum in March when over 1,000 advocates from all 50 states went to Capitol Hill to ask for a \$300 million increase for Alzheimer's research activities, to the Association being selected to testify before members of this same subcommittee this spring, advocates from the Alzheimer's Association and AIM have driven these developments. Your call for a \$300 million increase for Alzheimer's research activities was heard loud and clear.

This very exciting development is a critical step in a year long appropriations process. This funding increase will not actually occur until it is included in a bill passed by Congress and signed into law. For the last two years this has happened near the end of the calendar year.

The appropriations process is not a sprint; it's a marathon, and we are committed to continuing to call for the robust funding needed to change the trajectory of Alzheimer's disease. We expect more important developments in the House and Senate in the coming weeks. Keep an eye on your inbox. We will keep you posted on this historic legislation as it moves through the process and again, thanks for all you do to ensure that Alzheimer's is a national priority.

Continuing the process week later, the Senate Labor-HHS Appropriations Subcommittee approved a \$350 million increase for Alzheimer's research.

To learn more about the work of the Alzheimer's Association, go online to <http://www.alz.org/cnfl/> or call 1-800-272-3900.

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John Markham and Sally Dahlem

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Caregiver Support Groups

Al'z Place/Harbor Chase
3rd Thursday of the month at 9am
Open to all caregivers
Contact Robyn 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 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 of the Palms

2nd Monday at 2pm in the Library
Contact: Gail Haynes RNC - 352-246-5601

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 Monday of the month from 1-2:30 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

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

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

Medicare – www.medicare.org

State of Florida – www.myflorida.com

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

Caregiving – www.rosalynncarter.org

Driving – www.thehartford.com/talkwitholderdrivers/driversatrisk.htm

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

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