

# CAREGIVER CHRONICLE

*Connections for Caregivers*

## National Healthcare Decision Day Reminds Public to Plan Before It's Too Late

By Damaris Lopez

The mission is simple. Encourage all Americans to consider, discuss, and document their advance healthcare wishes, and encourage healthcare providers to honor those wishes better.

Since 2008 people nationwide have been encouraged to set aside April 16 and recognized it as National Healthcare Decision Day (NHDD). The effort is spearheaded by a



national nonprofit foundation and supported by the National Hospice Foundation, as well as many other organizations nationally and locally.

The NHDD initiative is a collaborative effort designed to ensure all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions.

While the stated purpose of this day is to educate and inform the public about the healthcare process and inspire them to participate in advanced care planning, it is really a day about taking action.

Advance care planning is something people often avoid as it may be uncomfortable to talk about what a loved one's wishes would be if they became severely ill, but NHDD is in place to remind everyone that it's better to know these wishes now before it is too late. And knowing those wishes is just the first step. You need to take the time to prepare a living will and create a healthcare surrogate designation.

In fact, this year's theme is

### A Message From David Greenberg

Normally Cheryl Robinson writes in this space but she is taking some well-deserved time off. If she were writing her column, she would be talking from her own professional experience of the importance of National Healthcare Decision Day and our feature story in this issue of the *Caregiver Chronicle*.

As the cover story says, it is both a time for education and action. It is important that you take the time for both.

In his column, Sam Boone talks about the legal aspects of advance directives. It is a perfect companion piece for the cover story. And because of the importance of this issue, some of our other pieces also highlight aspects of this critical issue with contributing writers Tom Rinkoski and David Huckabee adding their own perspectives.

But while there is no question that this is a significant issue, we are, after all, a publication designed to give support to caregivers. So in her column, Sal-

ly Dahlem offers insight on how to create a comfortable environment for your loved ones.

As we add a new supporter of the *Caregiver Chronicle*

in this issue – Randy Sperring Medical Supply – I want to take a moment to thank all of them. Cheryl, especially,



screens all these advertisers to make sure they are quality individuals and businesses. They support the *Caregiver Chronicle* not because it is the wisest advertising decision but because it is a valuable tool for caregivers. Please use these advertisers, and do it with the utmost assurance of their quality and professionalism.

We hope, as always, you find this issue of the *Caregiver Chronicle* to be of value to you.

David Greenberg

(continued on next page)

## National Healthcare Decision Day

(continued from previous page)

*It Always Seems Too Early, Until It's Too Late.* It is critical that you sit down with loved ones and have a conversation about your wishes. This way no one has to guess what you would want in case of a medical emergency. This should also involve completing your advanced directives forms to do all you can to guarantee your wishes will be followed.

Elder Options Executive Director Kristen Griffis recently saw the importance of taking these steps on a surprising and personal level.

“People think this is a conversation that you need to have with older relatives, but we discovered that’s not always the case. You’re never too young to have the conversation,” she said. “Recently, a very good friend in their early 50s suffered a massive heart attack and was in a coma. He never had the conversation with his significant other, who, as a result, did not know how to handle the situation.

“To me, the importance of this day is the need for education,” she said. “When we’re talking about advance directives people just don’t understand. I know when I bring it up with my family, it is a very uncomfortable conversation for many reasons. The tragedy is people wait until it’s too late, and then you are in crisis mode. Everyone has to have this conversation and act on the results, and if this day serves as a reminder, that’s great. We appreciate any type of movement or education initiative that increases awareness about this issue and gets people to take action.”

So by talking about these topics ahead of time, no one will be forced to make tough medical

decisions on your behalf – assuming they will even be able to. Celebrate National Healthcare Decision Day this year by making sure your wishes are in order.

### An Opportunity to Learn More

The Conversation Project:

Advance Directives

March 31

Senior Recreation Center

5701 NW 34th St.

<https://ufhealth.org/events/conversation-project-advance-directives>



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### Caregiver Chronicle is published every other month

Published and produced by  
Greenberg Communications  
[www.greenbergcommunications.com](http://www.greenbergcommunications.com)  
Editorial Advisor: Cheryl Robinson, L.C.S.W.

Find us online at [www.caregiverchronicle.com](http://www.caregiverchronicle.com).  
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Like the page to get notices about events and activities between our print issues.

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

### The Importance of Advance Directives

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 all have our own thoughts and wishes about how we want to live and die. But more often than not, people do not make those wishes known to loved ones until it is too late. The two-part tragedy when that occurs is your desires are not known, and those who are making decisions for you are faced with the challenge of doing so without direction.

If you read this issue's cover story, you know that April 16 is National Healthcare Decision Day. So what does that mean from a legal standpoint? At the very least it means make your wishes known to your loved ones. Beyond that it should mean putting those wishes in writing in a legal, binding form.

Under Florida law you have the right to make decisions concerning your health, including the right to choose or refuse medical treatment. But when you reach a point when you are unable to make those decisions due to medical reasons, you should have in place advance directives that will determine your medical treatment. Without those documents those who are treating you have no guidance, and will, in most cases, treat the way they have been trained to do.

So what are advance directives? Simply put they are written statements about how you want medical decisions made should you not be able to make them yourself. They can also serve to express your interest in making an anatomical donation after death. There is no right time to create advance directives. It can be done when you are healthy or later after you may be diagnosed

with a life-threatening illness. Generally, there are three types of advance directives: a living will, a health care surrogate designation and an anatomical donation.

A living will is defined as a written or oral statement explaining the type of medical care you want or do not want if you become unable to make your own decisions. A health care surrogate



designation is a document naming another person as your representative to make medical decisions for you if you are unable to make them yourself. You can include instructions about any treatment you want or do not want, similar to a

living will. A recent significant change in Florida law allows health care surrogates to take effect immediately. This can be particularly important if you want someone to accompany you to a doctor's appointment or in the hospital. Of course you can revoke these at any time.

Again if there are other family members involved, this should be part of a conversation with them. Additionally, a qualified elder law attorney can help you with any of these documents. There are many online sources for information about advance directives. This link will take you to information specifically dealing with Florida advance directives: <http://www.caringinfo.org/files/public/ad/Florida.pdf>.

*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://www.boonelaw.com), or call (352)-374-8308.*

## End-of-Life Decisions with Alzheimer's Patients

By David Huckabee

Nobody I know looks forward to planning for the difficult decisions that may need to be made as a person reaches the end of his or her life. When the planning involves a person with Alzheimer's disease or another form of dementia, the process is even more difficult. As caregivers, we want to make sure that we honor our care partner's wishes, especially when it comes to decisions regarding end of life care, legal and financial matters and advance directives.

While each situation is unique, there is one maxim that works in every circumstance. This maxim has been stated in slightly different forms everywhere from the Book of Proverbs to the sayings of Benjamin Franklin and of Pablo Picasso. In its simplest form, it reads "Don't put off until tomorrow what you can do today."

End of life planning does not become easier if it is delayed. At the Alzheimer's Association, we see many cases where it becomes much more difficult. Because plans were not put in place earlier, seemingly impossible decisions have to be made by caregivers in the most emotionally draining

circumstances. Or family members who have not agreed on decisions previously now come forward with multiple opinions regarding medical, legal and financial matters.

It is impossible to plan for every eventual-ity. Some decisions have to be made in the moment. However, the more decisions and documents that are in place, the better. Living wills, advance direc-tives and other necessary legal documents can all be drawn up and ready if and when they are needed. Of course, the best scenario occurs when the person with dementia has made all these decisions. That may not always be possible. But even if the care partner can no longer actively participate in the decision making process, delay serves no useful purpose.

If you have questions regarding end of life decisions for persons with dementia, please feel free to contact the Alzheimer's Association at (800) 272-3900. Be sure to ask if we have any free educational programs in your area to help with these issues.

*David Huckabee is the Associate Director of Pro-grams for the North Central Florida Regional Office of the Alzheimer's Association.*



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## The Basics of Making Healthcare Decisions

By Tom Rinkoski,  
Caregiver Coach at Elder Options

Whether seeming small or large, there are basic components that are a part of every healthcare decision. It doesn't matter if this is a decision about surgery, moving a person into a new residence or beginning a new therapy. It is difficult enough to make these decisions for ourselves, let alone when we are making them on behalf of those we care about. I came up with the following list.

**Quality of Life:** How will this decision affect the quality of life desired by the person directly affected? Do you know what they would consider quality of life?

**Capacity:** Will the person be able to carry out the suggested surgery/therapy/action to its logical conclusion on his or her own without any major difficulties? Will they be able to take pills on schedule? Can they do the therapy exercises as prescribed? If the person has dementia will the procedure aggravate the condition such the person's cognitive changes will lessen their existing abilities and increase losses?

**Finances:** Can the person afford this surgery/therapy? Will paying for this adversely affect them and their lifestyle in other ways that would also be detrimental? How much may be covered by insurance, Medicare or Medicaid?

**Caregiver Health:** How will this decision affect you as primary caregiver? Will you be able to accept and carry out all related after care to your already existing duties? This takes into consideration the physical, social,

mental, spiritual and inancial health of the caregiver.  
**Family Involvement:** Especially if this is a major decision regarding hospitalization, change in residence or moving into hospice care. What is the extent of the family support in this decision?

**Other Input:** Have you asked opinions of others in your support group? Perhaps a minister or priest? A trusted friend? Maybe you need a second medical opinion? Maybe this decision requires input from a lawyer? Have you checked out the agency, hospital, doctor against public records? The more significant the procedure, the more important is to have help in making the decision.

Because every person's decision is located within unique circumstances and woven in personal stories and relationships there is no one simple answer to any problem. Sometime you can go through the list quickly because of your preparation, but often we need to give ourselves time for careful consideration. What I have outlined above is a simple list to assure you have checked out the basics in health care decision making.

### 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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## Upcoming Savvy Caregiver Trainings

Savvy Caregiver Training is a six 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 into our New Year schedule. In 2016, we are making Savvy available in 6 or 7 week versions. 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](mailto:rinkoskit@agingresources.org).

- Mondays: 1:00 – 3:00 pm. Beginning March 7, 2016 @ Lifestyle Enrichment Center in Lake City, FL (six week version)
- Tuesdays: 2:00 – 4:00pm. Beginning March 22, 2016 @ Church of the Advent in Dunnellon, FL (six weeks version)
- Wednesdays: 1:00 – 3:00 pm. Beginning May 11, 2016 @ Hospice of Citrus and the Nature Coast in High Springs, FL (six week version)
- Thursdays: 2:00 – 4:00 pm. Beginning June 6, 2016 @ The Willows at Wildwood in Oxford, FL (seven week version)
- Thursdays: 1:00 – 3:00 pm. Beginning June 23, 2016 @ Haven Hospice, E. T. York Center in Gainesville, FL. (six week version)
- Thursdays: 1:00 – 3:00 pm. Beginning August 18, 2016 @ Hospice of Citrus and The Nature Coast in Chiefland, FL. (six week version)

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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## Creating a Comfortable Setting

By Sally Dahlem

Ensuring that caregivers are assisting their loved ones in a positive way is extremely important. Ensuring your loved one is comfortable, creating a calm environment and offering your loved one options will allow them to enjoy a sense of independence.

Make sure they are comfortable. Help them to participate in activities that they enjoy. This could include painting or reading a book. Other activities that you can do with your loved one include going for a leisurely walk or going for a picnic. These activities can also help your loved ones relax. Home by Choice offers companion care. Companion care often involves playing card games or engaging in friendly conversation.

Create a calm environment for the person under your care. When you create a calm environment for them think of calming music and calming colors. Calming music can be just instrumental music or music featuring a singer with a calming voice. Maybe implement earth tones on the walls of their room and even in your other home décor.

Offer your loved one options when asking them questions. You can give them options when asking about

which activities they want to do, what they would like to eat and when they would like to shower. Asking instead of telling allows them to feel as if they have some control and an acknowledged opinion in the situation.

The above ways will allow you to assist your loved ones to stay happy during the aging process. Look to home health care agencies, such as Home by Choice, to assist in these activities and more. Professional caregivers at Home by Choice treat your loved ones with respect and dignity. Services offered by Home by Choice include personal care, sitter services, and companion care, medication assistance, transportation services and shopping, meal planning and preparation, light housekeeping and laundry and respite care.

*Sally Dahlem is a partner at Home by Choice, which provides private-duty homecare services. She and her business partner, John Markham, have more than 35 years of experience in home healthcare, assisted living, long-term care and the medical equipment industries.*

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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 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](http://www.seniorsvscrime.com)

Alzheimer's Association – [www.alz.org/cnfl/index.asp](http://www.alz.org/cnfl/index.asp)

Elder Affairs – [www.elderaffairs.state.fl.us/index.php](http://www.elderaffairs.state.fl.us/index.php)

Elder Helpline – 1-800-963-5337, [email@agingresources.org](mailto:email@agingresources.org)

Elder Options – Savvy Caregiver Classes – [www.agingresources.org](http://www.agingresources.org)

Florida Silver Alert – [www.floridasilveralert.com](http://www.floridasilveralert.com)

SHINE (Serving Health Insurance Needs of Elders) [www.floridashine.org](http://www.floridashine.org)

Driving – [www.independencedrive.phhp.ufl.edu](http://www.independencedrive.phhp.ufl.edu)

Medicare – [www.medicare.org](http://www.medicare.org)

State of Florida – [www.myflorida.com](http://www.myflorida.com)

National Institute on Aging (free publications) – [www.nig.nih.gov](http://www.nig.nih.gov)

United Way – Alachua, Bradford & Putnam counties – [www.unitedwaycnfl.org](http://www.unitedwaycnfl.org)

National Association of Professional Geriatric Care Management – [www.caremanager.org](http://www.caremanager.org)

U.S. Department of Veterans Affairs – [www.va.gov](http://www.va.gov)