

BAI BEACON

*The Newsletter from Family and Community Services
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Lessons Learned from the Rhinestone Cowboy

Country legend Glen Campbell and his family openly share his life with Alzheimer's disease (AD) in the recently released movie, "Glen Campbell... I'll Be Me." This movie is not only an honest portrayal of one person's journey with Alzheimer's disease, but the many challenges that a family must navigate over the course of this chronic illness. Outlined below are some important lessons this talented singer and his family teach us all when living with dementia.

Disclosure of the diagnosis – When Glen Campbell was diagnosed with AD in 2011, he and his family decided not to hide from it, but to go public and give this illness a face. His wife, Kim, wanted people to know that "this is not your grandmother's Alzheimer's disease." Their honesty and courage to make this diagnosis public was received with love and warmth from family, friends, and fans. His dignity was essential in the disclosure and public appearances; and he used his fame to go before the US Congress in order to raise awareness and lobby for increased funding for Alzheimer's research. *Lesson learned:* There is no shame in a diagnosis of Alzheimer's disease/dementia. We don't need to hide it from others. We may lose some friends along the way, but will also learn who our real friends are and benefit from their love and support.

Plan A, B, C... - Planning ahead is essential when living with AD, but imagine going on a national "good-bye" tour when living with memory loss. In the movie, we see his family, band members, bus driver, publicist and long-time friends always looking ahead and anticipating all of the things that could go wrong and then making plans

to ensure that the performances could go as smoothly as possible. When one plan didn't work, they quickly shifted to another plan to ensure success. *Lesson learned:* Family caregivers and friends must be flexible especially when routines are changing. For some, the changing nature of the day and its impact on memory and thinking, calls for different plans and strategies throughout the day. Travel is another example of when families must have multiple "what if" plans ready to go. Thinking through alternate plans is more likely to lead to success for the person with dementia and the family alike.

Build upon strengths – It is often easy to focus on losses in AD versus remaining strengths. The Campbell family built success on the singer's remaining abilities and also used additional tools to bring success during his yearlong 2011-2012 farewell tour. While he is a gifted singer and guitar player, his family made sure he had a teleprompter to assist with remembering the lyrics; his daughter was there to help him get back on key; and he drew upon his strong social self in front of an audience to do what was so natural – perform! Yes, we see that Glen forget his lyrics at times or occasionally become confused; but we also witness his charm, humor, beautiful voice and unbelievable motor memory for playing the guitar. *Lesson learned:* Each person with dementia has remaining strengths and a sense of self. When we play to the person's overlearned and innate abilities, we are still able to tap into the possibilities that often seem lost. When we witness the person "acting like they don't have AD," we see the beauty of that person's spirit shining through and celebrate their sense of self.

Our Mission

To end Alzheimer's disease without losing a generation, to set a new standard of care for patients and their families, and to forge a model of collaboration in biomedical research.

Did you know, Banner Alzheimer's Institute is a not-for-profit and relies on financial contributions of the community to support programs and services offered to our patients and families? Make a gift and join our community of friends, call 602-747-GIVE (4483) or visit www.banneralz.org/waystogive.

Partners in care – Treating AD can be a challenge as each person is different and will respond to medical treatment in a different way. There is not a “cookbook” approach when using the four FDA approved treatments for AD (Aricept, Exelon, Razadyne and Namenda) which can provide modest benefit in slowing progression and managing symptoms. We learn in the film that Glen along with his wife routinely sees a dementia specialist to manage his ongoing care. At one point the physician increases one of the medications in hopes that it will benefit him; but in fact, there are some unwanted side effects that his wife quickly reports to the doctor. *Lesson learned:* It is essential to partner with a medical provider who listens carefully to the patient and caregiver and provides education and ongoing ideas and options for care, including clinical trials if appropriate.

Live in the moment – People living with AD suffer from significant short-term memory loss and subsequently “live in that moment” before the moment and its memories get lost. However, when family and friends can join that person in good moments, it can be joyful, fun, satisfying... a real gift. While those precious moments may be quickly lost by the person with AD, they still matter and create precious moments for those around them to treasure. We witness many beautiful moments as Glen Campbell’s adult children accompany him as part of his tour band and hear their thanks for being able to create such rich moments for them to remember for years to come. While Glen may quickly forget a performance, the family was able to enjoy the “now” of his presence and joy and remember these precious moments for years to come. *Lesson learned:* Rather than looking back at what was, or being focused on what will be, we all need to focus on the now and appreciate the beauty of the good moments.

Don’t argue – We often use the phrase, “no one has ever won an argument with a person with AD.” It is natural for all of us to want to correct a wrong, explain or reason something that is not understood, or coerce someone into something that we know is good/right for that person. However, this just doesn’t work in a person with AD and will likely lead to an argument. We see this technique work very well in this movie as Glen’s family avoids arguments often by going along with what he is saying – even when it is incorrect. His wife, Kim, demonstrates how a warm smile and gentle approach can often diffuse a difficult moment rather than trying to explain, reason, correct or coerce. *Lesson learned:* A calm, gentle and warm approach creates success in all types of communication. There is no need to be right and we must learn to live in the person’s world as this is all s/he understands to be true.

Create a care team – No one can go at this illness alone. The demands are too great and the length of the illness is much too long. Glen’s family demonstrates the power of a wonderful team that included family members, friends and paid staff. Each played an important role in his life providing support, friendship, supervision and hands on care. While each person’s network is different and may not have the wide array of players we saw in this situation, we must draw upon those around us and ask for their gift of time and presence. *Lesson learned:* We must ask family and friends for help and be clear and specific in the needs we have. We may get “no” for an answer but may be surprised with all the “yes” responses as well. And, we must all come to understand that we are likely to draw upon paid help at some point as we think about using Adult Day Health Care or companion care. There is no shame in asking for help – we need one another in this lifetime.

Transitioning care – As AD/dementia progresses, most families find that they needed added help either in or outside of the home. Even celebrities can succumb to a chronic illness and need care. We learn that Glen needed care beyond what his team of family, friends, and hired help could manage at home. Once again we learn some valuable lessons from Glen’s wife, Kim, as she did her homework and found a facility that would feel familiar and comfortable for him. She began by taking him to stay at the facility for the day and quickly learned that he adapted and was having fun with the staff. A short respite stay led to a longer respite stay and understanding that this new “home” could better meet his needs and keep him comfortable. While transitions can be difficult, they can be successful when the person’s comfort guides us. *Lesson learned:* As dementia progresses, it is important to begin to explore options for in home care, Adult Day Health Care, and/or residential care. People with dementia can adapt to new people (caregivers) and surroundings. If/when transitions occur; they are more likely to be successful when careful planning takes place.

Perhaps beyond the legacy of Glen Campbell’s music, we can all be reminded of a bigger role he and his family played; that of our humanness, the love and compassion of family, friends and strangers; the ability to adapt in difficult times; and the ability to teach lessons in the most fragile of states. Thank you Campbell family for your transparency as you share your story.

Have a Question?

To submit your question for future consideration email us at: baiinfo@bannerhealth.com



Ask The Expert

Jan Dougherty, MS, RN, FAAN
Director, Family and Community Services

Dear Jan:

I am confused. I've been attending a support group where they keep talking about the stages of dementia. I've heard them use different terms like "mild, moderate, severe" and Stages 3 - 7. My husband has Alzheimer's disease and when they ask me what stage he is in, I don't know what to say. Can you help me understand what it means and why it matters?

Signed,
Marilyn

Dear Marilyn:

This is a great question that you have asked and often creates a lot of confusion for families and professionals alike. The progression of Alzheimer's disease (AD) has been studied the most and is probably best understood. Developmental changes are more consistent in AD than in other dementias such as Lewy Body Dementia and Frontotemporal Dementia and consequently, observed stages are better summarized.

The Global Deterioration Scale (GDS) was developed to outline changes in cognitive and functional abilities from normal cognition, to mild cognitive impairment, to the end stages of Alzheimer's disease. This scale has 7 stages with stage 1 being "normal" and stage 7 as "severe" dementia. Stage 4 is often called "Early Stage AD" or "mild dementia." During this 1-3 year stage we see that short-term memory loss leads to forgetfulness, repetitiveness, losing things, and having more difficulty managing finances, meals, household affairs and medications. Stages 5 -6 is frequently referred to as "Middle Stage AD" or "moderate dementia." Over some 2- 5 years (on average) we see increased short-term and long-term memory loss leading to increased dependency in personal care activities including grooming, dressing, bathing, and eating. Time relationships are lost, and problem solving is next to impossible as language skills are also diminished. Stage 7 is called "Late Stage AD" or "severe or advanced dementia." During this 1-3 year stage, we see loss of mobility, bladder and bowel control, and very limited language skills as the person becomes dependent for all aspects of care.

It is important to keep in mind that the GDS is generally only helpful in AD type dementias; therefore using mild-moderate-advanced dementia may better define a given stage. Knowing the stage is helpful as care providers can better predict care needs for the affected person and resources that are likely to help the caregiver. I encourage you, as you consider the stage, that you also "inventory" remaining strengths in your husband and continue to tap into his overlearned abilities. Even in the advanced stages of AD/dementia, we see a person's ability to enjoy good music, favorite foods, spiritual practices and being with people who care for him/her.

I invite you to learn more about planning for the stages at the next "Dementia Dialogue" webinar as we discuss "Planning for Care across the Stages of Dementia."

Clinical Trials Announcement

Now is the time... If you are a healthy older adult with normal memory, this could be the right time for you to join the fight to prevent the memory loss of Alzheimer's disease.

What is the A4 Study?

The Anti-Amyloid Treatment in Asymptomatic Alzheimer's study (the "A4 study" for short) is a clinical study for older individuals (65 to 85 years of age) who may be at risk for memory loss due to Alzheimer's disease (AD). The A4 study is investigating a new drug intervention that may reduce the impact of a protein known as "amyloid" or "beta amyloid" forming plaques in the brain. Scientists believe that accumulation of amyloid in the brain may play a key role in the eventual development of AD-related memory loss. The A4 anti-amyloid investigational drug targets amyloid build-up in the brain with the aim of slowing memory loss associated with the development of AD. To learn more call 602-839-6500 or visit a4study.org.



Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

BEACON BITS

Clinical Trials at Banner Alzheimer's Institute and Banner Sun Health Research Institute

This month we will discuss what people must consider before participating in a clinical trial.

Participation in a clinical trial is a highly personal decision. Most individuals who enroll in a clinical trial do so to help others – particularly family members who may someday also be at risk for developing Alzheimer's disease (AD). Others may wish to test new treatments that may be more effective than current treatments of AD. While people participating in clinical trials get regular medical monitoring by medical professionals and often learn more about the illness and resources, there are both risks and other factors that should be considered.

Risk of unwanted side effects may be the most concerning. While researchers take steps to ensure safety, all clinical trials carry some degree of risk. Most trials will have an experimental group and a placebo (or control) group and neither the research team nor participant may know the results for a period of time. Location and time are other factors as many studies can last months to years and will require multiple visits to the study site. Finally, having a study partner (family member or friend) is generally a requirement so the study team can learn important insights from that person over time.

The risks and benefits of all studies, including compensation for time and travel, will be discussed in detail before joining

a clinical trial. The research team will explain what you can expect, including possible side effects or other risks so that you (and your study partner) can make an informed decision about joining the trial.

TELE-SAVVY: A Dementia Family Caregiver Education Program Offered at a Distance is sponsored by Emory University and will help you to gain knowledge and skills, and a savvy outlook—to help you provide care more effectively. Most of TELE-SAVVY is done on your own schedule. You can view daily instructional videos and participate in one weekly teleconference with 5-7 other participants and an instructor. Caregivers interested in taking part in this pilot research study can obtain more information by phoning 404-480-2426 or emailing adrctelesavvy@gmail.com.

Caregiver FOCUS Series: Zentangle

Experience an easy-to-learn, relaxing art and fun way to create beautiful images by drawing structured, repetitive patterns. The Zentangle Method increases focus and creativity, and sense of personal well-being. Thursday, March 19; 12:30 – 2 p.m. at Banner Alzheimer's Institute, Third Floor conference room. Free but registration is required. To register, call 602-839-6850.

March 2015 Program Schedule

CAREGIVER EDUCATION PROGRAMS

MESA

Communication Tips to Avoid Arguments

Learn about changes in communication as dementia progresses and a variety of alternative strategies that will be practiced during class so that caregivers can walk away with new techniques to immediately put into place.

Tuesday, March 17, 10 - 11:30 a.m.

Mesa Library Red Mountain Branch

635 N. Power Road, Mesa

Free but registration is required.

To register, call 602-839-6850

New Support Group for care partners in the East Valley! Circle of Friends - East

This group is designed to help care partners solve problems and discuss concerns in a supportive setting. Discussions are initiated by care partners and supplemented with occasional formal presentations on relevant topics. This is a "drop-in" group.

Tuesday, March 17; 12:30 - 2:00 p.m.

Fellowship Square

6945 East Main Street, Mesa

Building 4, Acacia Room (take elevator to 2nd floor)

No registration required.

For questions, call 602-839-6850



PHOENIX

COMPASS: Directions for Caregivers after the Dementia Diagnosis

Learn the basics of Alzheimer's disease/related dementia and how to implement 8 practical strategies to avoid many of the common problems that arise.

Tuesday, March 3; 10 - 11:30 a.m. and

Monday, March 23; 4 - 5:30 p.m.

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

Free but registration is required.

To register, call 602-839-6850

Planning Ahead Class for Caregivers

Learn how to plan for legal, financial and medical decisions for someone with Alzheimer's disease/related dementia.

Tuesday, March 10; 4 - 6 p.m.

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

Free but registration is required.

To register, call 602-839-6850

Problem Behaviors: Solutions that Work

Learn about the most common types of behavior problems in dementia and a variety of solutions to minimize them.

Wednesday, March 11; 10 a.m. - noon

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

Free but registration is required.

To register, call 602-839-6850

Please turn over for more classes →

These programs are made possible by the generous support of the Banner Alzheimer's Foundation.

March 2015 Program Schedule

CAREGIVER EDUCATION PROGRAMS

PHOENIX (CON'T)

GPS Lecture for Caregiving: Staying Me

Caregiving can result in loss of health, relationships and interests. This lecture will provide a variety of ideas and solutions to restore balance while maintaining a sense of self during caregiving.

*Friday, March 13; 10:30 a.m. - noon
Musical Instrument Museum
4725 E. Mayo Blvd., Phoenix
Free but registration is required.
To register, call 602-230-CARE (2273)*

Caregiver FOCUS: Zentangle

Experience an easy-to-learn, relaxing art and fun way to create beautiful images by drawing structured, repetitive patterns. The Zentangle Method increases focus and creativity, and sense of personal well-being.

*Thursday, March 19; 12:30 - 2 p.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
Free but registration is required.
To register, call 602-839-6850*

Transitioning Care from Home to a Residential Setting

Learn the importance of planning and considerations when making the transition from one level of care to another.

*Tuesday, March 24; 10 a.m. - noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
Free but registration is required.
To register, call 602-839-6850*

Brain G.Y.M. (Grow Your Mind)

*Friday, March 27; 9:30 a.m. - noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
Free but registration is required.
To register, call 602-230-CARE (2273)*

SUN CITY

COMPASS: Directions for Caregivers after the Dementia Diagnosis

Learn the basics of Alzheimer's disease/related dementia and how to implement 8 practical strategies to avoid many of the common problems that arise.

*Friday, March 6; 12:30 p.m. - 2:00 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive, Sun City
Free but registration is required.
To register, call 623-832-3248*

Brain G.Y.M. (Grow Your Mind)

*Monday, March 2; 2:00 p.m. - 4:30 p.m.
Banner Boswell Hospital, Juniper Room inside the
Support Services Building Memorial Hall
13180 North 103rd Drive, Sun City
Free but registration is required.
To register, call 602-230-CARE (2273)*

WEBINAR

Dementia Dialogues: Planning for Care across the Stages of Dementia

*Wednesday, March 18; 12:00 p.m. - 1:00 p.m. MST
Online Education. Registration is required and must be done online at www.bannershri.org under events and education and online education.*

To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit www.banneralz.org and click on "Events Calendar" icon or call Deidra Colvin, Events Coordinator at 602-839-6850
- Banner Sun Health Research Institute, visit www.bannershri.org and click on "Events and Education" or call Veronica Flores, Events Coordinator at 623-832-3248