

SUPPORT

ADVOCATE

Caregiver Communiqué Supporting Arkansas Families since 1984

Volume 31 Issue 2

February 2016

CARE

My Third Husband Karen Hayes

Corcura

After 25 years, my marriage was a little rocky. Then this guy started showing up. I didn't like him much, but he kept dropping by anyway. He would run errands, cook, do household chores. But he kept missing the mark. He put the garbage in the recycle bin. He cooked big butter beans with chili powder. He made a milk run and came home with eggs. If he put away the laundry, I was lucky to find it again. And he was mad about it. Mad, as if I had hidden the socks.

One Tuesday Bob and I got up to a dark house. A spring storm had knocked out the power. I stumbled off to work. Mid-morning the guy called me. He had gone to the store. "Are the lights back on?"

"No."



"But the refrigerator doesn't have electricity," I said.

"YOU put the bags out," he said.

I put out the bags. I did. I made the list and I put the grocery bags out.

I told my boss that I needed to go home. Now. When I got there, our neighbor James was hooking up a portable generator on the car port. I fixed an early lunch on the gas stovetop. We didn't talk about the groceries again, and the electricity came back on that night.

Things went back to normal, except when they weren't. We saw a neurologist. Bob had an MRI and a battery of tests. He was having some problems with his memory. I started going to Arkansas Alzheimer's Support group twice a month. I read. A lot. The books had plain paper covers, or decorative labels pasted over the word. Alzheimer's.

The guy didn't know how to get to the River Market downtown. The guy lost his money and we turned the house upside down to look for it. The guy kept his prescription medicines in 17 weekly pill reminders and lined them up in a complicated ritual. There were a lot of pills left over. When I tried to take charge of the prescriptions, he threatened to call the police. Do it, I said.



He couldn't work the TV remote. He asked me if the VA had his truck. He wore all of Bob's jewelry at once. He carried 5 pairs of sunglasses, and his reading glasses littered the house.

I was learning to live with the guy, but I didn't like him. And he didn't like me. Except when he did. He started asking me to marry him. Five, six, seven times a day. One day I woke up and I was married to him.

To be continued in 2016 March Caregiver Communique



February 2016

			February				
Sunday	Monday	Tuesday	Wednesday	Thursda	y Friday	Saturday	
	1 1st Monday S/G @ Alz Ark Office 12 pm	2	3		HOPE is coming to you! April sellville HOPE for the Future inton HOPE for the Future		
7	8 Jacksonville S/G @ Ester D. Nixon Library, 703 Main Street at 7 pm	9 Parkinson S/G with Guest Speaker James Dailey @ Alz Ark at 11:30 am	10	Spr	May Mt. Home HOPE for the Future June Springdale HOPE for the Future Hot Springs HOPE for the Future		
14 Halppy Valentines	15 Alz Ark Office Closed	16	17 Memory Café @ Alz Ark at 10 am - 12 pm Free Starbucks Coffee	18	19 Normal Aging with Priscilla Pittman - Breakfast at LRAFB at 8 am	20 Chilirhea @ Fayetteville Town Center	
21	22	23 4th Tues S/G @ Alz Ark Office at 6 pm	24	25	26	27	
28	29 Leap Year!	Mont	h	March 4, 2016 Little Rock Hope for the Future The Crowne Plaza 7:30 am - 4:30 pm			

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Generous Donor who will pay to have our two memory walls recovered. We take them all over the state and display photos and stories about loved ones past and present. Please call Stuart at (501) 224 - 0021 for details if you are interested in helping!

We are here for you 24/7! After hours, weekends and holidays caregiver help line

Toll Free: (800) 689-6090

ADVOCATE

Community Partner Spotlight: Arkansas Hospice



The son of one of our patients said it best: "Arkansas Hospice was such a relief for me and my family. I only wish I had called sooner."

What is hospice exactly? Hospice is a specialized service for those with a life-limiting illness. It focuses on compassion and comfort so the patient and family may make the most of their time together.

A common misconception is that hospice is a place. Instead, most of our patients are cared for in the comfort of their own home or a residential facility. We serve a 33-county area. Arkansas Hospice also has inpatient facilities in Russellville, Hot Springs and Little Rock.

We offer a full spectrum of services based on an individualized plan of care. The care plan is designed to meet the unique needs of each patient and family. You are never alone; on-call services are available around the clock. In addition to our clinical team of physicians, nurses and hospice aides, we have social workers and chaplains to provide spiritual and emotional care for the patient and family. Grief support is also available to the patient's family for 13 months after the patient dies.

Hospice is paid for by Medicare, Medicaid and most private health insurances. You may contact us at any time and get to know us before you need us, toll free (877) 713-2348, or visit our website at <u>www.arkansashospice.org</u>. We can discuss the specific services we offer, your circumstances, and determine if hospice will be right for you and your family member. As a community-based, not-for-profit organization, we also welcome your involvement and support through volunteering or donating. Thank you for allowing us to serve you.

Judy Wooten, Arkansas Hospice President and CEO



People will forget what you said, people will forget what you did, but people will never forget the way you made them feel. ~Maya Angelou~

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SUPPORT

Caregiver Conversations - It's Time To Talk

Q: During the holidays I visited with many of my extended family members. My uncle seemed to looked less plump and a little disheveled. I wanted to ask my cousin about his health, but I felt embarrassed because I hadn't seen them in so long. When is a good time to talk to family members about their declining health and end-of-life desires?

A: Everyone's life is fragile, and you never know what will happen when you get up in the morning. "Families who avoid talking about these issues often misrepresent a relative's wishes during a time of crisis," says Alan Carver, MD, and an attending neurologist at Kettering Cancer Center in New York. Parents don't want to upset their adult children, adult children don't want their parents to think they want them to die, and so the conversation never gets started. The best gift you can give your spouse and adult children are your written advanced directives; intubation, resuscitation, hospice, living will, palliative care and physicians orders for life-sustaining treatment will help make the decision a less painful one down the road.



Call us toll free at 800-689-6090, 501-224-0021 or 24/7 after-hours emergency number, 501-913-1878.



Volunteer of the month



Lois at her 29th birthday with the Alzheimer's Arkansas staff. We love you Lois!

February

Lois Looney

Started Volunteering: 11/8/2007 (That's 9 years ago! WOW)

Loves: Snicker's & Sonic Drinks

Betcha' ya didn't know: Lois was a friendly face from the beginning and always entrusted with proofing anything we were to use. She had given up a good job to move in and care for her mother. By the way, she was an excellent caregiver. She consistently went above and beyond to provide care. She also makes some lovely preserves every year!

CARF

Res-pite What is that?

Priscilla Pittman, MSW, MA

Respite is a short period of rest and relief. (www.thefreedictionary.com/respite)

Too many caregivers wait to use respite care until late in the disease process; their health is improved when breaks are taken before they are drained. Guilt is usually responsible for the reluctance to take a break. But when caregivers become ill due to stress, no one wins. We must remind ourselves that reality is always changing and a new normal is just around the corner.

Early in the disease the caregiver and care partner can enjoy some separate activities with special precautions, as well as activities together. The separation provides freedom and independence when illness can be very eroding to self-esteem.

The use of respite needs to occur regularly. Two days a week of scheduled care in planned segments of time may enable the caregiver to relax and participate in social activities. Being able to look forward to a break can improve one's outlook when care becomes exhausting.

Respite is best used for things longed for and enjoyed. What did you do prior to your role as a caregiver? Were you involved in a club; did you participate in a sport, fish, or hunt? Was art, music or reading enjoyed previously? Include friends in the project and schedule these breaks consistently.

Now, how do you get away? Some caregivers have a family member, neighbor or friend known by their care partner and willing to provide them a break. Home care agencies have trained and bonded individuals who can be hired to provide consistent care. Many will send the same person each time to reduce confusion. Adult day programs are good and most provide activities and a meal; care partners reluctant to attend can be assured they are going as volunteers to help provide care.





Word of the PSP - Progressive Supranuclear Palsy Progressive supranuclear palsy, also called Steele-Richardson-Olszewski syndrome, is an uncommon brain disorder that causes serious problems with walking, balance and eye movements. The disorder results from deterioration of cells in areas of your brain that control body movement and thinking. http://www.mayoclinic.org/diseases-conditions/progressive-

supranuclear-palsy/basics/definition/con-20029502





Randi's group is unique because it is the only Cure PSP support group in Arkansas. After her father's diagnosis, she noticed there was not a support group for families dealing with the lesser known neurodegenerative diseases, and knew this had to change. Most of their members are people living with PSP, MSA and CBD, and their families, but Randi reminds us that everyone is welcomed with open arms. No one should feel alone in their journey with these difficult neurological diseases. Another feature of the group is how important awareness is to everyone. Since these diseases are so unknown by the general public, and even doctors, one goal of the group has become to raise awareness. Members have been brainstorming and are excited about education and making more people aware of these diseases; they intend to make a difference. The friendships that have formed, conversations shared in and out of the group meetings, and the people who have touched her heart are blessings.

Randi and her siblings assist her mother as much as possible in caring for her father, but he is reluctant to let them help with much. She describes her mother as, "the most amazing caregiver I know...I will never understand how she does everything she does. Our parents are the strongest and best team there will ever be, even with this disease."

Alzheimer's Arkansas and Cure PSP have been her best sources of referrals since the group's beginning almost a year and a half ago. We list them in our newsletter and on our website; PSP sends email awareness information frequently. The group meets at our office and quickly out-grew the room they began meeting in and moved into a larger one.

The group has helped members learn of clinical trials. Since there are no medications that will really help with these diseases, clinical trials have regained some hope for families that are willing to participate. Some couples have participated in the same studies increasing the friendships that had formed in the group.

For Randi, the most difficult thing about being a facilitator is making sure everyone is given an opportunity to say all that they need to say. She said they have always had plenty to say and have never experienced "awkward silence" moments. Since the group is so large, carving time for everyone is more difficult, but she wants to make certain that no one leaves feeling like the meeting was a waste of time. "Whether they take home more resources on how to make things easier or extra smile and uplifted spirit, we never want anyone to be empty handed when they leave. Time is extremely valuable, especially for these patients and caregivers who are running on fumes as it is!"

"Age is just a number" describes the wide spread of ages involved the group; the average age would probably be 55-60, but the age range can include some in their 20's and 30's.

Randi and her two babies are enjoying Dr Seuss books, dancing and singing to Christian music and the "good ole country songs on the radio." Yummy, southern cooking and of course anything chocolate are favorites of hers. If you have met Randi you know the three words she uses to describe her personal interests ring true, "Faith, Family and Friends!"



Good Nutrition: Improving dementia care

Priscilla Pittman, MSW MA

The basic goal for those with dementia is to avoid unintended weight loss because the loss increases the risk for skin tears, poor wound healing, falls and, agitation. The normal weight loss for those with dementia is slow and subtle, usually only 1 to 2 pounds per year. Occasionally, there are periods of "exercise like" physical activity that will require additional calories to keep body weight stable. Increasing intake by 200 calories a day or 34 additional calories for every 2 pounds of body weight is recommended.

In reference to the numerous challenges facing an assessment of nutrition challenges for persons with dementia, Laura Hilliard reminds us, "There are no one-size-fits-all solutions." A good analysis can include diagnosis, self-feeding skills, environment, preferences, and eating habits. Good care is individualized care.

In the early stage of Alzheimer's disease, the person may not remember to eat. They may have problems shopping and preparing meals or adopt unusual menu ideas and consume high levels of sugar and salt. By mid-stage, they may have difficulty using a fork or spoon, developed a tendency to hide food, or they may have problems pocketing food in mouth or forgetting to swallow.

As we age our ability to smell and taste foods dissipates. Learning to season with juices and herbs improves taste without raising sodium levels. Too many of the frozen meals have excessive sodium to improve the taste destroyed by processing the ingredients.

Some studies have referred to fiber as a wonder food. In addition to preventing constipation, fiber improves the immune system, deters inflammation, and protects individuals from many diseases and conditions.

Some individuals may not be able to detect thirst and, as we age we lose muscle mass which decreases our storage capacity. Drinking water decreases constipation problems. But we lose fluids when we exhale, speak, move, etc. The loss is a constant process, thus our intake of fluids must compensate.

"The doctor of the future will no longer treat the human frame with drugs, but will rather cure and prevent disease with nutrition."

-Thomas Edison

Medications must be monitored for nutrition challenges. Persons living with Parkinson's disease need to take Sinemet medications 30-60 minutes before eating a meal. Consuming them with foods containing protein will interfere with the absorption of the medication. Other medications may have food limitations; read the fine print.

Good nutrition can improve quality of life.



DEVELOPMENT NEWS 2016 Save The Dates

2/20 - Chilirhea Chili Cook-off in Fayetteville www.chilirhea.net or www.facebook.com/ChilirheaCharity

3/24 - Advocate of the Year Awards & Dinner www.alzark.org or www.facebook.com/AdvocateOfTheYear

4/9 - AMP OUT ALZ 5 in Little Rock www.ampoutalz.com or www.facebook.com/AMP.OUT.ALZ

- 4/19 Advocates for Care Volunteer Appreciation Luncheon 2nd Presbyterian Church 11:30 am -1 pm (Free to our Volunteers)
- TBD River Valley Alzheimer's Walk www.alzark.org or www.facebook.com/alzarkwalks
- 9/10 Faulkner County Alzheimer's Walk www.facebook.com/AlzArkConway
- 9/17 Hot Springs Alzheimer's Walk www.alzark.org or www.facebook.com/alzarkwalks
- 9/24 Little Rock Alzheimer's Walk at the Zoo www.alzark.org or www.facebook.com/alzarkwalks

10/8 - Van Buren County Alzheimer's Walk www.memorystroll.com or www.facebook.com/alzarkwalks

We are always looking for ways to partner with local communities. If you are interested in hosting a Walk or another fundraising activity, please download our **"Fundraising Policies and Guidelines"** from our website or contact Barbara Jensen at <u>barbara.jensen@alzark.org</u> or 501-224-0021.

CHILIRHEA

A PARTY WITH A PURPOSE

Chilirhea is an event for all ages. Bring the family and experience over 30 different types of chili, live music, a silent auction, and a lot of fun!



This year is our 11th annual event, now located at the Fayetteville Town Center.

Join us on February 20, 2016 12 pm till 6 pm. For vendor and entry information contact <u>chilirhea@gmail.com</u> and for ticket information go to their website at www.chilirhea.net.

2016 Advocates of the Year March 24th at 6:00 to 9:00 pm Metroplex/Team Summit

Celebrate our 2016 Outstanding Advocates!

The Outstanding Advocate for 2016 is Sissy Clinton. The Outstanding Volunteer Advocate is Dr. Mark Pippenger with UAMS and The Outstanding Support Group Facilitator is Amy Thomason, with Arkansas Hospice in Hot



for

Springs. See our website for sponsorship and ticket information.



The Rosemary Society will allow you to combine your charitable giving goals with your estate and financial planning goals. Your gift will provide lasting benefits

through our programs and services caregivers.

We offer planned giving arrangements that are feasible for donors of all income levels. To become a member of the Rosemary Society, contact Elise or Barbara at 501-224-0021.



How is your **Fitbit Challenge** going? Send us an email and let us know how you are doing. For information on doing a Fitbit Challenge go to www.alzark.org to find instructions and forms you will need to start your Challenge.

SUPPORT GROUPS AND CONTACT PERSONS THROUGHOUT ARKANSAS

Support groups are free to attend and confidential. Financial Assistance is available if needed.

- *****BATESVILLE** 2nd Thurs @ 5:30 pmKen Harper(870) 751-9002Deanna Greene
- ***BEEBE 3rd Thurs. @ 3:00 pm Sandra Garrett (501) 882-3969
- ***BENTON 3rd Tues. @ 7:00 pm Richard Mills (501) 315-0087
- **BENTON 3rd Thurs. @ 2:00 pm Azy Crabb (501) 778-6260 Diana Ferrell (501) 315- 0160
- ****BERRYVILLE** 3rd Thurs. @ 10:00 am

 Rebecca Davis
 (870) 423-6114

 Renee Gonzales
 (870) 423-6114
- ***CAMDEN 3rd Wed. @ 1:00 pm Nancy Bailey (870) 234-7410
- *CHEROKEE VILLAGE 3rd Wed. @1:30 Misty French (870) 994-2341
- *CLARKSVILLE 4th Thurs. @ 5:30 pm Nicholle Dorn (479) 264-5833
- *CLINTON 1st Wed. @ 2:00 pm DK Olmstead (501) 745-9495
- **CONWAY 1st Tues. @ 7:00 pm Kathy Jette (501) 450-7528
- ****CONWAY** 2nd Thurs. @ 7:00 pm Kenneth Priest (501) 730-3582
- ***DARDENELLE 3rd Thurs. @ 2:00 pm

 Billie Holsomback
 (501) 321-2811

 Lori Kamerling
 (501) 321-2811
- ***EL DORADO 3rd Thurs. @ 12:00 pm Nancy Bailey (870) 234-7410
- *FAIRFIELD BAY 3rd Wed. @ 2:00 pm

 Ron Henson
 (501) 745-7004 X2

 Lise Neave
 (501) 253-4698
- ** FORREST CITY 2nd Thurs. @12:00 pm Felisa Stewart (870) 270-6219 Janis Waddy (494) 870-3300
- ***HARRISON 1st Wed. @ 11:30 am Michelle Byler (870) 743-1623
- ***HEBER SPRINGS 4th Tues @ 3:30 Nicki Stacy (501) 362-3185
- **HENSLEY 1st Thurs @ 7 pm Tereasa Holmes (501) 626-4529
- *HOT SPRINGS 2nd Mon. @ 2:00 pm Dian Masingill (501) 623-2881
- *HOT SPRINGS 3rd Tues. @ 4:00 pm Amy Thomason (501) 209-1950
- ****H.S.V.** 4th Thurs. @ 3:00 pm Amy Thomason (501) 209-1950

- ****JACKSONVILLE** 2nd Mon. @ 7:00 pm Priscilla Pittman (501) 224-0021
- *JONESBORO 2nd Tues. @ 10:00 am Cheryl Hamm (870) 930-2226 Shirley Crawford (870) 935-4672
- *LITTLE ROCK 1st Mon. @ 12:00 noon Priscilla Pittman (501) 224-0021 Lynn Akdamar (501) 224-0021
- *LITTLE ROCK 4th Mon. @ 6:00 pm Janet Nelson (501) 412-5683
- **LITTLE ROCK 1st Tues. @ 10:30 am Beth Allen (501) 686-6219
- *LITTLE ROCK 1st Tues. @ 6:00 pm Debbie Rawn (501) 952-4182
- *LITTLE ROCK 2nd Tues. @ 5:30 pm Beverly Villines (501) 350-5053
- *LITTLE ROCK 3rd Tues. @ 1:00 pm Beverly Villines (501) 350-5053
- **LITTLE ROCK 4th Tues. @ 7:00 pm Priscilla Pittman (501) 224-0021
- **LITTLE ROCK 2nd Wed. @ 12:30 pm Rene Simmons (501) 256-1461
- **LITTLE ROCK 3rd Wed. @ 10:00 am MEMORY CAFÉ Priscilla Pittman (501) 224-0021 Lynn Akdamar (501) 224-0021
- ***LITTLE ROCK 1st Thurs. @ 1:00 pm Janet Nelson (501) 412-5683 Rev. Karen Akin (501) 227-0000
- *LITTLE ROCK 3rd Thurs. @ 1:00 pm Janet Nelson (501) 412-5683
- ***MONTICELLO 3rd Tues. @ 1:00 pm Pam Leeper (870) 367-6852
- **MT. HOME 4th Fri. @ 3:00 pm Debbie Love (870) 508-3880
- ****MT. VIEW** 1st Monday @ 6:00 pm Teresa Cheatham (870) 368-4522
- ** NEWPORT 1st Wed. @ 5:30pm Courtney Snow (870) 219-3745
- **N. LITTLE ROCK 1st Wed. @ 9:30 am Ashley Meggers (501) 257-3335
- ***N. LITTLE ROCK 3rd Thurs. @ 11:30 C.J. Shane (501) 681-3531
- *SHERWOOD 2nd & 4th Mon @ 6:00 pm Kathey Green (501) 864-7452
- **PARAGOULD 2nd Thurs. @ 1:00 pm MEMORY CAFE Jana Wineland (870) 565-5033

- **PARAGOULD 3rd Thurs. @ 2:00 pm Caregiver Support Group Jana Wineland (870) 565-5033
- **PINE BLUFF 3rd Mon. @ 11:00 am Carolyn Ferguson (870) 543-6300
- **Rison 1st Friday @ 5:00 pm Nadia Owen (870) 220-1152
- ***RUSSELLVILLE** 4th Tues. @ 6:30 pm Shelly Jones (479) 498-2050 Jerry England (479) 498-2050
- *SEARCY 2nd Tues. @ 3:00 pm Marjorie Ryan (501) 268-6490
- **SEARCY 1st & 3rd Mon. @ 6:30 pm Martha Vendetti (501) 266-8613
- ***SPRINGDALE Last Tues. @ 6:30 pm Melissa Northington (479) 288-5951 Teshema Woodfork (479) 288-5951
- **STUTTGART 2nd Thurs. @ 12 Noon Charles Proctor (870) 830-1170
- *** Elise Siegler, Support Group Liaison
- ** Priscilla Pittman, Support Group Liaison
- * Lynn Akdamar, Support Group Liaison

**CURE PSP SUPPORT GROUP - LR 4th Thursday @ 1:00 pm Randi Haley (870) 703-6417

***New Caregiver Support Group Meeting!!

Friday, February 5th at 5:00 pm The Green House Cottages of Southern Hills RSVP by 1/29 Nadia Owen nowen@southernadmin.com or (870) 220 -1152

**PARKINSON'S SUPPORT GROUP ALZHEIMER'S ARKANSAS TAYLOR CENTER

2nd Tuesday @ 11:00 am Priscilla Pittman (501) 224-0021

****YOUNG PARKINSON'S S/G** 2nd Tuesday @ 11:00 am Kathy Rayburn (501) 663-3900

The newsletter is a monthly publication of Alzheimer's Arkansas Programs and Services, 201 Markham Center Drive, Little Rock, AR 72205. All members and donors receive the newsletter. Contact the office for membership or other information. Alzheimer's Arkansas cannot endorse or recommend any provider, program or product.



14th Annual HOPE for the Future Caregiver Registration

Please register by February 26, 2016

Seating is limited. Please register early! No refunds after registration deadline.

No charge for family caregivers, unless requesting CEUs. ALL professional and family caregivers please enclose payment or credit card payment.

Name:					
	y:				
Phone:	Email:				
Check as appropriate:	Family Caregiver				
	Caregiver Funds Requested				
	CEUs/Certificate Requested - \$ 80				
	Professional - \$80 (Includes 6 CEUs/Certificate)				
	Student - \$65 (Includes 6 CEUs/Certificate; Must present Student ID)				
	Vendor Booth- \$200				
Method of payment:					
Check (Make payable	to Alzheimer's Arkansas) Credit Card: 🔲 V 🔲 MC 🔲 DSCV 🔤 AMEX				
Credit Card #:					
	CVC:				
Signature of Card Hold					