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# The Caregiver

Newsletter of the Duke Family Support Program

Volume 27: No. 1

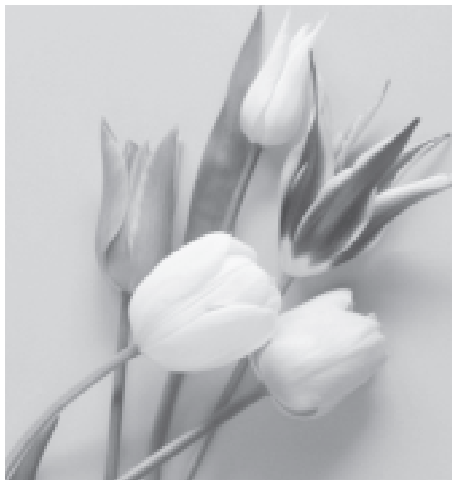
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An optimist is the human personification of spring.  
—Susan J. Bissonette

### Duke Family Support Program

Lisa Gwyther, MSW  
Edna Ballard, MSW  
Cheryl Copeland

The newsletter is co-sponsored by the

- **Joseph and Kathleen Bryan Alzheimer's Disease Research Center**
- **Duke University Center for the Study of Aging and Human Development**

The newsletter is funded by the North Carolina Division of Aging and Adult Services.

Subscriptions to *The Caregiver* are free to North Carolina residents. Call 800.672.4213. View this newsletter online at [www.dukefamilysupport.org](http://www.dukefamilysupport.org)

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**Caregiver Education Conferences**

**Fayetteville**—June 12  
**Raleigh**—August 12  
**Goldsboro**—August 18

**Mountain Regional Office**

31 College Place, Suite D320  
Asheville, NC 28801-2644  
828.254.7363 800.522.2451

**Triangle Memory Walk**  
October 4

**Foothills Area Office**

260 1st Avenue NW, #218  
Hickory, NC 28601-4757  
828.267.7100

**Triad Area Office**

1315 Ashleybrook Lane  
Winston-Salem, NC 27103  
336.725.3085

**New Early Stage Support Groups**

**Triad:** July 2008 336-725-3085

**Mountain Area:** Sept. 2008 828-254-7363

**Memory Walks**

Rowan-Cabarrus County Sept. 20

Iredell County Oct. 4

Randolph County Nov. 8

**Bryan  
ADRC  
Education Core News  
Welcome Cheryl Copeland**

Cheryl started in March, 2008 as the Program Coordinator for the Duke Aging Center Family Support Program and Conference Coordinator for the Bryan ADRC. She is usually the first voice you will hear when you call. She comes to us from the Duke Center for Human Genetics.

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## Exercise Theme Pervades Bryan Alzheimer's Disease Research Center Conference

**Move for Life and Mind: Applying Exercise Guidelines to People with Alzheimer's Disease and Their Caregivers.** *Jama Purser, PT, PhD, Duke University Medical Center Division of Geriatrics, Department of Medicine and Division of Physical Therapy; Department of Community and Family Medicine; Salli Benedict, MPH, University of North Carolina at Chapel Hill, Center for Health Promotion and Disease Prevention*

Dear Friends and Colleagues,

At this year's annual Bryan Alzheimer's Disease Research Conference, we were excited to have the opportunity to present the new exercise guidelines for older adults recently published by the American Heart Association and the American College of Sports Medicine: (<http://circ.ahajournals.org/cgi/reprint/CIRCULATIONAHA.107.185650> [accessed 5/13/08]). We especially appreciated your overwhelmingly positive response and your enthusiastic participation in the group exercise demonstration. A few of you worked up quite a sweat! For us, it was empowering to see hundreds of you on your feet and engaging in the types of exercise that might help us all delay chronic disease and disabilities, including, but not limited to cognitive decline and dementia.

The new exercise guidelines suggest that regardless of the physical, cognitive or behavioral limitations we might have, all of us should be engaging in **endurance-related physical activities** (such as brisk walking, biking, or swimming) for at least 30 minutes on 5 days of the week (at a "moderate" intensity of 5-6 on a scale where 0 is sitting still and 10 is maximum effort). If the intensity of our exercise is "vigorous" (i.e., an intensity of 7-8 on the same scale) we should exercise at least 3 days per week.

For older adults, aerobic exercise is not all that's needed. The new guidelines state that all older adults should participate in regular activities that **strengthen** their major muscle groups three times weekly, and which also incorporate regular **balance exercises** and those that **promote flexibility**. Most older adults will best be able to meet the minimum standards for different types of exercise if they develop a written **activity plan** which details how they will meet each suggested component of exercise.

Many of us will find it beneficial to join a regular exercise class (check your local senior centers, for example, where there are often low-cost or even free exercises classes available). Some of you may prefer exercising regularly at home with an exercise video workout (for example, see ordering information below for "Salli's Senior Workout" video).<sup>1</sup> Many of you will also benefit from a discussion with an exercise specialist, and for some, special assistance will be needed to help you deal with physical, mental or social barriers to exercise and physical activity. For the most challenging problems, a referral can be made by the primary care physician to a skilled therapist to help develop an appropriate plan for regular physical activity. For people who use wheelchairs, many of the health professionals and caregivers who attended the conference offered suggestions for encouraging group games and activities that work on upper body postural control, strength and endurance (such as seated volleyball with a balloon or light ball), even when lower body activities are an impediment to unassisted physical activity.

We reviewed exciting new evidence that regular exercise can decrease the incidence of dementia,<sup>2</sup> and animal studies suggesting that dementia in mice could be partially reversed by regular treadmill exercise.<sup>3</sup> If an intervention with a similar magnitude of positive treatment results were available in an expensive pill that we could just swallow daily, we'd all be lined up at our physicians' offices demanding a prescription. Instead, how many of us will accept the challenge to seek whatever assistance is needed to develop a plan for incorporating regular physical activity into our lives and into the lives of those we care for?

**Materials available at the National Institute on Aging to help you get started:**

Exercise: A Guide From the National Institute on Aging:

<http://www.nia.nih.gov/HealthInformation/Publications/ExerciseGuide/> (Updated version with new guidelines will be out in the Fall, 2008).

**Our colleague, Dr. Barbara Resnick, PhD, CRNP, FAAN, FAANP, Professor of Nursing, University of Maryland School of Nursing, suggests the following web resources on exercise programs and their health benefits for older adults. (See [infoaging.org](http://infoaging.org), The American Federation for Aging Research, Ask the Expert column by Dr. Resnick).**

**General Exercise:**

American Heart Association

<http://www.americanheart.org/presenter.jhtml?identifier=1200013>

International Council on Active Aging

<http://www.icaa.cc/PressInfo/onehouradayrelease.htm>

International Society for Aging and Physical Activity

[http://www.isapa.org/ISAPA\\_Newsletter](http://www.isapa.org/ISAPA_Newsletter)

National Blueprint: Increasing Physical Activity Among Adults Age 50 and Older

<http://www.agingblueprint.org/tips.cfm>

NIH SeniorHealth

<http://www.nihseniorhealth.gov/exercise/toc.html>

President's Council on Physical Fitness and Sports

<http://www.fitness.gov/>

The Canadian Centre for Activity and Aging's Home Support Exercise Program. Geriatrics and Aging

<http://www.geriatricsandaging.ca/PDF/PDFJuly2003/0607homesupport.pdf>

**Links for Exercises for Dizziness or Lightheadedness:**

Association of Otolaryngology: Balance exercises for chronic dizziness

<http://www.umm.edu/otolaryngology/balance.html>

London Health Sciences Center: Balance Exercise

<http://www.lhsc.on.ca/programs/msclinic/exercise/groupd1.htm>

National Institute on Aging Balance Exercises

[http://www.niapublications.org/exercisebook/chapter4\\_balance.htm](http://www.niapublications.org/exercisebook/chapter4_balance.htm)

Pennsylvania Neurological Society: Understanding Vertigo and recommended exercise programs

<http://www.pneuro.com/publications/dizzy>

**Links for Cardiovascular Specific Exercise Programs/Information:**

American College Sports Medicine: Exercise and the Older Adult <http://www.acsm.org/pdf/EOA.pdf>

Cardiovascular Institute and Center for Cardiovascular Health  
<http://www.mssm.edu/cvi/exercise.shtml>

Centers for Disease Control: Strength Training for Older Adults: Why Strength Training?  
[http://www.cdc.gov/nccdphp/dnpa/physical/growing\\_stronger/why.htm](http://www.cdc.gov/nccdphp/dnpa/physical/growing_stronger/why.htm)

- .....
1. To obtain a copy of Salli Benedict's 55-minute workout video "Salli's Senior Workout," a limited number of VHS videos can be purchased through the Duke Family Support Program for \$10.00 (includes shipping).
  2. Larson EB et al. Exercise is associated with reduced risk for incident dementia among persons age 65 years and older. *Annals of Internal Medicine* 2006, 144:73-81.
  3. Nichol KE, Parachikova AI, Cotman CW. Three weeks of running wheel exposure improves cognitive performance in the aged Tg2576 mouse. *Behavioral Brain Research* 2007, 184(2):124-32.

**Bryan Alzheimer's Disease Research Center  
2008 Annual Conference Highlights**

- Dr. Welsh-Bohmer's provocative promise to broaden the scope of the Bryan ADRC research to encompass Memory, Health and Aging
- Dr. Burke's insider look at future disease-modifying treatment targets
- Dr. Logsdon's materials promoting quality of life programs for people with early stage dementias
- Dr. Eric Reiman's fascinating look inside "lit up" brain PET scans
- Dr. Carl Cotman's persuasive scientific rationale for the cognitive benefits of exercise (Remember the picture of the mouse on the couch?)
- Chuck and Linda Hollinshead and Terri Payne's powerful personal testimonies about the personal benefits of participating in research. (See Chuck's blog report on the conference in the [Asheville Citizen Times](#))
- Dr. Joanne Rader's inspirational call to action to change our future of long-term care
- Dr. Anne Basting's over-the-top ideas for storytelling
- "You are Here", a powerful film preview and discussion with producer, Tim Jeffrey

"This annual shot-in-the-arm invigorates and recharges me. I leave here with more choices for my toolbox. I relish the practical proactive energy and hope that fills the whole two days." "This is the best conference I have attended in my entire life, and the best Bryan ADRC conference in the past fourteen years."

– Participant quotes

**SAVE THE DATES:** Bryan ADRC 23<sup>rd</sup> Annual Conference  
Thursday-Friday, **February 19-20, 2009**  
Sheraton Imperial Hotel & Conference Center  
Research Triangle Park, NC



## News and Notes

### **One in Three People Over 70 Have Memory Impairment**

More than a third of people over age 70 have some form of memory loss according to a national study by the team of researchers at Duke University Medical Center, the University of Michigan, the University of Iowa, the University of Southern California, and the RAND Corporation. The group performed the first population-based study to determine the number of people who have some form of cognitive impairment, with and without dementia. The researchers estimate that 5.4 million people over age 70 have memory loss that disrupts their regular routine but is not severe enough to affect their ability to complete daily activities.

“These findings illustrate that nearly every family will be faced with the challenges of caring for a family member with some form of memory impairment,” said Brenda Plassman, Ph.D., associate research professor of psychiatry at Duke and the study’s lead author. Even among the people 71-79, a sizeable number had cognitive impairment. *Annals of Internal Medicine* 2008;18:148(6) 427-434).

### **Project C.A.R.E. (Caregiver Alternatives to Running on Empty)**

A series of Regional Forums held this spring encouraged NC General Assembly funding for continuation and expansion of the NC Project C.A.R.E. Alzheimer’s Respite Program. These Forums were sponsored by the NC Senior Tar Heel Legislature and co-sponsored by the Alzheimer’s Association – Western and Eastern Carolina Chapters and the Duke Aging Center Family Support Program. As a result of these very effective regional forums, House Bill 2245 “Funds for Project C.A.R.E.” was introduced by Representatives Ray Rapp, Phil Haire and Bruce Goforth. Special thanks to these Representatives who attended and spoke at the Haywood County Regional Forum in support of Project C.A.R.E. For current information, call the Mountain Area Office of the Alzheimer’s Association – Western Carolina Chapter at 828-254-7363.

### **Duke Medical Programs Remain High in U.S. New Rankings**

Duke University’s School of Medicine ranks among the top institutions according to the latest *U.S. News & World Report* rankings of the best graduate and professional schools in the country. The medical school tied for sixth for research. Among medical specialties, Duke was acknowledged in geriatrics (third), internal medicine (fifth), tied for ninth in clinical psychology and tied 13<sup>th</sup> for physical therapy.

### **The Alzheimer’s Action Plan**

**The Alzheimer’s Action Plan**, by Duke authors P. Murali Doraiswamy, MD and Lisa Gwyther, MSW, with science writer, Tina Adler, hit the bookstores in April, 2008. This book for people with memory concerns and their families received a star rating and a glowing review from the National Library Journal.

### **Resilience in An Aging Society: Risks and Opportunities**

Lisa Gwyther, MSW, Education Director for the Bryan Alzheimer's Disease Research Center and Director of the Duke Aging Center Family Support Program is the 2008 President of the Gerontological Society of America (GSA), the leading US aging research and education professional association. Ms. Gwyther is the sixth Duke Aging Center faculty member to serve as GSA president in its 61-year history, sealing Duke's record as home to more GSA presidents than any other academic research center. Ms. Gwyther will convene the 61st annual GSA meeting in November, 2008, in National Harbor, MD. She chose the meeting theme, "**Resilience in an Aging Society: Risks and Opportunities**". For more information, see [www.agingconference.com](http://www.agingconference.com).

### **Remarkable Double Grad**

Susan Moore, a social work intern with the Duke Family Support Program graduated in May, 2008, with dual Master's degrees in Social Work from UNC-Chapel Hill and in Divinity from Duke Divinity School. Ms. Moore will be returning to her native Georgia to marry and to seek ordination in the United Methodist Church. She will lead a senior services ministry.

### **Pre-med Duke Intern to Enter Medical School**

Margaret Walters, a Duke pre-med undergraduate, spent the summer of 2007 as a Duke Leadership in an Aging Society intern with the Family Support Program and the Bryan ADRC at Duke. She enters medical school at UNC-Chapel Hill with a Navy scholarship in the Fall, 2008.

### **Scam Jam Dates 2008**

**Editor's Note:** We are all vulnerable to increasingly sophisticated scam, fraud, and even financial abuse, but people with early to moderate memory impairments are especially vulnerable. Scam Jams are very successful, fun and popular free community education days sponsored by NC AARP. Take advantage of these local opportunities to learn how to protect yourself and/or those you care for and about.

<b>June 24</b>	Union County Agricultural Ctr. 3230 D Presson Road Monroe, NC 28112	8:30 am Registration 9:00-12:00 Scam Jam
<b>June 25</b>	McDowell Senior Ctr. 100 Spaulding Rd. Marion, NC 28752	8:30 am Registration 9:00-12:00 Scam Jam
<b>July 15</b>	Harvest Baptist Church 3741 S. Church St. Burlington, NC 28752	8:30 am Registration 9:00-12:00 Scam Jam
<b>July 17</b>	Oxford	8:30 am Registration 9:00-12:00 Scam Jam
<b>Sept 18</b>	LJVM Coliseum 2825 University Parkway Winston-Salem, NC	1:00 pm Registration 1:30-4:30 Scam Jam

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"The only thing to do with good advice is to pass it on. It is never any use to oneself."  
– Oscar Wilde

## Offering Sanctuary: What Faith Communities Can Do To Help

Susan Moore, Duke Family Support Program Intern  
UNC School of Social Work and Duke Divinity School



I recently had the opportunity to witness a delightful sight. A man came to visit his aging mother in a nursing home. She has Alzheimer's disease and barely recognized her son when he arrived to take her to the weekly church worship service. As we began to sing the opening hymn, I watched miraculously as this sweet woman's eyes lit up. For a fleeting moment, her memory raced back to years past. She smiled at her son and loudly proclaimed, "I'm so glad we're in church!"

As a future social worker and minister, I have reflected on the importance of the faith community's support of families facing Alzheimer's disease. One of the most interesting things I have learned about Alzheimer's and dementia during my studies and internship is that research suggests that best retained memories are often related to rituals and music.

These areas are helpful to remember for our faith communities. Our churches, synagogues, temples, and other places of worship must be safe havens offering the peace and joy of religious ritual and music, while providing non-judgmental support to individuals and families who may no longer be on their best "church behavior."

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What will it take for every congregation to become such a welcoming haven for persons with Alzheimer's, other dementias, and their caregivers? With the 'Baby Boomer' generation aging, faith communities must respond with programs and resources to meet the physical, emotional, and spiritual needs of this growing population of older adults. Focusing on awareness, education, and ministries with older adults is a vital need for the "graying" church today. Laity and clergy alike must recognize that current American culture—including churches—are biased toward youthfulness. Intentional efforts are needed to engage in holistic ministries that emphasize that all of life is holy—including life after disability. Ensuring the dignity and worth of older adults must be a premise for ministries of faith communities. Persons with Alzheimer's, other dementias, and family caregivers are at risk for isolation from their community and church.

If you or a loved one is facing the challenges of Alzheimer's or other dementias – talk to your ministers and religious leaders about what they can do to help you. For families, *the key is to ask for support*. If you are a minister, religious leader, or concerned church member – talk to the families facing the challenges of Alzheimer's or other dementias about what you can do to help. *If others need help, offer your support.*

Here are a few ideas for you to share with your ministers or other religious leaders:

- Organize volunteers from the congregation to provide transportation assistance for worship services, doctor's appointments, grocery shopping, etc.
- Use volunteers to provide assistance with sitting/standing, reading, and participating in worship. For example, have a "buddy system" of partnering a person with Alzheimer's or other dementia with someone who can be an escort to enjoy church activities together.



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- Present an Alzheimer's disease seminar to share information and resources with your congregation and the community (consider providing respite care for caregivers who would not be able to attend otherwise).
  - Offer a caregiver support group or offer facilities where support groups can meet.
  - Use volunteers to provide caregiver respite in the homes of church families.
  - Provide volunteer opportunities for persons with Alzheimer's or other dementias. There are all ways to use helping hands – from folding napkins to activities with children.
  - Visit, telephone, and send cards of encouragement regularly. (Families report that this is always welcome. Be generous and understanding of what is best for family members and caregivers.)
  - Remember the keys of communication with someone with Alzheimer's/ dementia: A calm approach, eye contact, reassuring touch, a low tone of voice, and *patience*.
  - Host a daytime respite program at the church.
- Provide a scholarship fund for older adult day programs, in-home care, etc.
  - Have a lending library of books, videos, and other resources.
  - Provide a rotation of meals/visitors/chores, etc. for families in their homes. (When providing meals, share them in containers that do not need to be returned.)
  - Provide a special Sunday School class or fellowship group for persons with Alzheimer's or other dementias.
  - Recite familiar passages, prayers, and sing favorite hymns together. People with Alzheimer's or other dementias can often remember old hymns and prayers they learned long ago.

Do you suffer from Alzheimer's Disease or have a family member who suffers?



If you are interested in learning about research studies that are currently being conducted at the Duke Memory Disorders Clinic, please contact:

Dr. James Burke 919-684-5650  
or Deb Heydt, Study Coordinator,  
919-668-2843

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The only kind of dignity which is genuine is that which is not diminished by the indifference of others.

– Dag Hammarskjold

After the verb 'to Love,' 'to Help' is the most beautiful verb in the world.

– Bertha von Suttner

The moments of happiness we enjoy take us by surprise. It is not that we seize them, but that they seize us.

– Ashley Montagu

## A Wife-Family Caregiver-Survivor Speaks

By Eileen Abramson, Durham, NC

**Editor's Note:** Ms. Abramson led a discussion in three consecutive monthly meetings of the Durham Evening Support Group of the Alzheimer's Association, Eastern NC Chapter. The focus of the first night's discussion was her first experiences with life with a husband with Alzheimer's disease.

My husband has been gone ten years, five years in the nursing home, ten years at home and "they" say that you have Alzheimer's 5 to 7 years before diagnosis. I remember when our disease; Alzheimer's, started. I say ours because I lived through it. Of course, at the time, I did not know it was Alzheimer's. Looking back, I can snap my fingers and say, "Yes -- Alzheimer's, but I certainly could not say it then."

Let me start at the beginning. I had not met Gus until we had our first date. My future mother-in-law and her girlfriends fixed us up. He came to our house on our first date. I remember so well what he was wearing and how he looked. He was dressed very stern-looking - business suit, tie, and me in slacks. He was so old looking, or should I say, mature-looking. I was 18 and he was in his early 30's. He was so funny, but quiet. We played scrabble that night with my mother and stepfather. I liked him, but that was all. I really didn't see us having a future. Well, obviously he thought otherwise. He called me everyday. He chased after me. I was dragging my feet.

As time went on, I was falling in love with him. He was so strong, tall, funny and a very take-charge type of guy. I was a very dependent type of person. He would tell me what to do, because I really didn't know what to do. A lot of the time, instead of telling me what to do, he would just do it himself. He was not a controlling man, but whatever he was, I loved it and loved him so very much.

Here is how strong and sure of himself he was – we met on October 6, 1961, got engaged February 21, 1962 and got married February 24, 1963. Why the long wait? My

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family was afraid of him being older. They tried to break us up, but I would not hear of it.

After we got married, we moved into an apartment. We had a lot of friends and family visiting and we visited them. Gus told me I didn't have to work unless I wanted to, but I wanted to work. I remember when I found out I was pregnant with our first child. I told my boss. Instead of being happy for me, he fired me. My boss said I would be leaving soon so he was going to hire someone now to take my place. You have to remember this was about 43 years ago when pregnant women were not welcome in the workplace. I was crying when Gus came home. He held me and was protecting me and told me not to worry because he will always be there for me. He wasn't always there for me. He left me when the disease took over him. Not left me like leaving the house, but left me in mind, which was so painful.

We had our first child – a beautiful nine-pound baby boy. My grandmother, mother, Gus, baby and I were all in the car coming home from the hospital. When we got out of the car at home, my grandmother said she would carry the baby, my mother said she would carry the baby, and I said I would carry the baby. Then big strong Gus spoke and said he was going to carry the baby, and he did. In my eyes, he was the greatest!

Not too long after that we bought a home, and we had another beautiful son. Soon after and now looking back I saw some little changes in Gus that were not very noticeable at first. There were long naps, temper tantrums, moodiness, and depression. The very independent Gus became a very dependent Gus. Personally, I use to joke that he was going through male menopause. Then I said nah-----! I tried to put it out of my mind, but I guess all the time it was in the back of my mind. His indifference was affecting our marriage. I decided I needed to go home. We were living in New Jersey, his home state, and my home was Durham. He followed me three months later.

His personality was off the wall. He wasn't acting the same. In fact I didn't know him anymore. Strange things were happening. He

suddenly began forgetting his way home. One particular day, he was going in one direction looking for his way, but not remembering. He decided to turn around in the middle of a very busy road. That was bad enough, but what was worse was he turned around in front of a police car. Not knowing the police car was trying to stop him, he let them chase him. Finally, the police stopped him and after talking to him, they realized a problem. They led him home.

He was losing things and finding them in the freezer, under the bed, and in the soap powder. He became less able to do his job which he had been doing for years. He cleaned the furnace with vinegar. Every time the furnace turned on, you would think you were in a pickle factory.

I thought I was the problem. I went to counseling. He refused counseling because he said there was nothing wrong with him. I said we had lots of friends and family. Well, a large majority of family and friends turned their backs on us. I believe losing friends and family was more painful for me than dealing with his disease. I could only turn to my mother and sons. Now, I have to say this in defense of old friends and family. Just because they are not there doesn't mean they were bad people. It just means they were not there, and that is all.

I began going from one doctor to another. No doctor knew what was wrong. Finally, one doctor suggested a test similar to an MRI but MRIs were not available at that time. With the tests available to him at the time, the doctors said, "Well, you don't have this and you don't have that so you have Alzheimer's. To show how little was known about Alzheimer's then – when we were told – the world did not stand still. It did not make an impact on us, in fact, we were hungry and we went out to supper. Who heard of Alzheimer's at that time? Certainly not me, nor my husband and not many other people either. Gradually, TV commercials came on about Alzheimer's. The way I handled it was I would get up and turn off the TV. I would not let Gus see or hear the commercials, and I would just go about my business.

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With time, my husband really began to show signs of his illness. He had to give up driving, which saddened our then 10-year-old son. Our son thought it was exciting riding with Daddy on the sidewalks, grass, and wrong side of the street. After the police came to our house for many of his accidents, my insurance agent told me to turn his license in and they will take away all points. I turned in his license the next day. Now that was a very difficult thing to do, but I had to do it for everyone's safety.

During this time, I became so angry. I was bitter, angry, sad, crying one minute then laughing the next. I threw myself into work. I worked 10-12 hours a day, six days a week. You see both boys were in school. Both boys wanted to help with finances by working, but I would not hear of it.

Every time we saw Gus' doctor, he told us to start thinking about putting him in a home. You have to realize, he had been diagnosed just a few years. I thought, "the nerve of him wanting to take Gus from me and put him in a home. No way, not yet anyway." One day I did go looking at care facilities. What a sad day for me. I did it alone. In fact, I was now doing everything alone. It seemed that no one had the time, the desire to listen or to help, or even the time or desire just to hug me and to tell me that everything would be all right. I felt truly alone. I went from nursing home to nursing home. I was like a mother cat looking for a home for her kittens. I think I felt I was the only one on this earth. I became so angry. I was even angry at G-d.

I never felt sorry for myself. I never said, "woe is me", but frankly I felt so bad then and I still feel bad now for my sons. They missed out so much because they had a sick father, but they have become such wonderful, kind, compassionate, loving, understanding, gentlemen because of it. Remember this, you are probably at your best when the bad is happening. I believe the old saying "WHAT DOESN'T KILL YOU WILL MAKE YOU STRONGER."

This is only a bit of the 15 years that followed. Please take my hand and let me help you. Let me comfort you because I know it can be a long and lonely road.

## Husbands as Caregivers and Survivors

Robert L. Means, MD  
Winston-Salem, N.C.



Spending months and years caring for a sick and dying spouse is a serious challenge to say the least—especially if the caregiving occurs at home. In America, only 25 percent of people die at home although that is where most would prefer to die. Modern medical and surgical advances have prolonged human lifespans and unfortunately, at times, the dying process. Most deaths follow long-term chronic illnesses often associated with dementia.

The burden on the spouse caregiver is immense, lasting day and night, day after day. Chronic fatigue to the point of exhaustion is common, sometimes endangering the health of a caregiver. Certainly the experience has been a grim education. Each situation is unique.

### Caregiving As An Art

It is beautiful to observe an accomplished dedicated caregiver at work. The gentle, efficient movements in grooming, bathing, turning, dressing, and myriad other tasks are reminiscent of the grooming habits of non-human primates—an expression of love. Even though the patient may, at times, become recalcitrant or even belligerent, there is never an expression of exasperation or anger. Kind and gentle, but firm responses are required to get the job done. And it must be done right. For all bedridden patients, an electric hospital bed is a necessity.

Many bedridden patients are unable to move and are subject to bedsores (decubitus ulcers). A visiting nurse specializing in wound care will be helpful in managing these ulcers. A special air mattress with many individual air

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cells is very helpful in preventing pressure points. An alternating air pressure pump repeatedly inflates and deflates these air cells in a rhythmic manner. Such mattresses are necessary, especially in heavy patients who are more difficult to turn frequently.

Caregivers must be able to recognize their own signs of stress. They must realize that they can't do it all. They must not feel guilty when they "give out." It is best to get help when needed from family and many available home care services. Hospice is a wonderful source of help but isn't geared to long-term care. A skilled nursing facility may be the desirable option when the time is right. The first consideration is always the patient's own best interests. Patients will die, but they must do so with minimal discomfort and with love and dignity.

### Be Prepared

I made a major negative decision not to send Mary Jane to an in-patient hospice or to the hospital when she was dying. I wanted her to be with me night and day as long as I could provide everything required in end-of-life care. I had been present in many deaths during my career, and knew that her time was near.

Although nearly moribund, Mary Jane was having some respiratory difficulty. I felt that she would be more comfortable with an oxygen supplement. I called 911 and explained the situation. There was no emergency or need for transport to the hospital. My wife was dying, and perhaps she would be more comfortable with oxygen supplements. All I requested was a canister of oxygen. As my conversation with 911 proceeded, she said, "They are on their way." Within minutes there were bright lights and a fire engine in my front driveway. Multiple personnel were rushing to my front door with a stretcher. I also rushed to intervene and explain the situation. They entered and monitored her vital signs, which, of course, were abnormal. They insisted on immediately taking her to the hospital.

An older fireman seemed to understand and asked if I had a health **Power of Attorney** or

a **DNR** (Do Not Resuscitate) document. I did, but it took some time to find it. Finally they understood and left a canister of oxygen. By then it was probably ineffective. She died peacefully two hours later. The moral of this story is to know where your legal documents are and where to find them!

### **Life After Caregiving**

Once the caregiver has faced the reality of death, the question arises "What am I going to do now? How can I go on without my love?" The mourning begins and never seems to cease. Spasms of despair, tears and self-pity fill days and nights. The dominant emotion is a terrible lonesomeness and a longing to see that sweet smile and loving eyes once again. It isn't possible to focus on much except your grief. Your family and friends try to console you while you try to hold yourself together. The funeral service adds to the reality. Food, flowers, sympathy cards and donations to churches and charities roll in. Personal thank you notes provide some purpose and diversion. Friends invite you to lunch and to go to church - - it helps. Controlling your emotions in public is getting better. And when you are alone at home without a helpmate, you do the chores which you have become accustomed to during the long illness. It feels good to have a sense of accomplishment. You work in the garden and become physically exhausted. The episodes of choking up and tearing become less frequent. Some say it is best to let loose when you feel like it.

The time approaches when the surviving spouse must make some life changing decisions and attempt to answer many questions. Some of the more immediate questions are:

1. Should you stay in your home? Are you able to maintain it and do all that living alone entails? Can you afford to hire help when you need it?
2. Should you downsize?
3. Should you move close to your children?
4. Should you live in a facility with all levels of care and can you afford it?
5. Would you be satisfied with institutional-like food?

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6. Would the entrance fees at some nursing facilities significantly impact your children's inheritances?
7. If you move, would you sorely miss the amenities that you have previously enjoyed, such as privacy and gardens?
8. Should you purchase long-term care insurance while still healthy?

Since most deaths are associated with chronic illnesses, it often may be anticipated. Therefore in every case your death wishes should be discussed with your family and actually documented in advance directives. Only 15-20 percent of patients presently have such directives or living wills. In some cases a signed "Do Not Resuscitate" or "DNR" is quite helpful in avoiding artificial prolongation of life with respirators, tube feeding, etc. Dying should be with dignity and comfort.

### **Long-Term Care Insurance**

When Mary Jane and I married in 1947 one week after my graduation from medical school, she immediately became the banker and major breadwinner of our new family. She did everything possible to allow me to devote myself almost entirely to my professional pursuits during the upcoming five and a half years of internship and residency training in the specialty of General Surgery.

In the late 1950's her mother had her first stroke from what then was called malignant hypertension. Her mother would never be the same again, spending fifteen years as an invalid. Mary Jane would spend alternate weekends going home to relieve her father of caregiving burdens. Mary Jane was an only child and was devastated by her mother's death at the age of 73 in 1965.

Mary Jane continued to control our finances for the rest of her life until her final illness. Remembering her mother's long illness, she had purchased a Long-Term Care policy for herself in the 1970's. Fortunately, she later upgraded this policy to include home care.

When I retired at age 65 she wanted me to obtain a policy also. I thought the premium was too expensive (hers was \$3,450 per

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year). Besides, I thought, when my time comes, it will be quick. Of course it is a gamble, but in my case (now age 83), I previously have given many of my assets to my children and there would be enough left to care for me. In other words, I am insuring myself.

Of course in Mary Jane's case, being cared for at home with my experience in medicine, it was most helpful financially to have the insurance. It paid almost \$4,000/month for caregivers in a 34-month span. If she had lived with her illness as long as her mother, there might have been dire financial consequences. The insurance policy had a weekly limit, which did not cover all expenses, but it did cover about 90 percent.

### **Self Pity**

Several months ago after Mary Jane died, I received a call from one of our long-time friends. She had been very attentive to Mary Jane during her long terminal illness. She knew how I had grieved and said "Bob you should be relieved that she is no longer suffering. She had no quality of life. She is so much better off now." I answered, "Yes I know, but I still miss her." Even in those darkest days when she was completely helpless and unable to do anything except smile when I appeared, I still cherished her presence. Upon awakening each morning, our home was quiet, and I listened for her in vain. Once on a cold foggy morning, a layer of moisture covered the inside window of our bedroom. I wrote her name on it with a fingertip. Later when I returned, her name and the condensation on the windowpane had disappeared. I wept briefly.

"Show some stoicism," I told myself. "Mary Jane was a happy fun-loving person, and would not like to see you so despondent." I reasoned that she would continue to love me and encourage me to carry on our hopes for family and friends. I have struggled to do this and gradually I was able to control my emotions in public. At times in quiet moments, I still indulge my self-pity and give my lachrymal glands a good workout. I believe it is a normal human reaction.

Now that I am living alone, I find it very helpful to stay active. I don't have the energy and stamina that I enjoyed when I was younger and sometimes I must force myself to get up and go. Renewing and maintaining old friendships provide a stimulating fulfillment. Many of my friends have health problems and some can no longer drive. I find pleasure in helping them in any way that I can.

Several weeks ago an old friend invited me to fill in at her bridge club. I agreed, but after hanging up the phone I began to panic, not having played bridge in over twenty years. I called my brother who plays bridge with a friend who teaches lessons on the game. He sent me ten lessons, which enabled me to play and have a very pleasant evening with my old and loyal friends.

### **Faith**

Humans have believed in immortality from far distant historic times. Such thoughts help to sustain me. Although I miss her person, I sense Mary Jane's presence and I am positive that we will reunite eventually at a perfect place in time and space. Religious beliefs and interaction with others of similar faith are comforting to the survivor.

### **Today**

Today, as I am writing, I received a call from an old friend. I had received a sympathy card from Bill after notifying him of Mary Jane's death. But, I didn't receive the usual Christmas card update. I knew of their chronic illnesses, especially his wife's Alzheimer's disease. Louesta and Mary Jane had trained together in medical technology in the mid-40's, and they were two of a kind—happy, outgoing party girls. Bill and Louesta married after the war and he began his career as a physician.

I was offered a position as surgeon for the Norfolk Western and Southern Railway Systems (now Norfolk Southern). It was my job to take care of employee injuries in the Winston-Salem area of this huge railway system. This, along with my surgical practice, kept me busy, but Mary Jane never

complained. She kept the home fire burning and found a life of her own in volunteering. Bill, to our delight, was also a surgeon nearby. As two couples, we bonded and looked forward to annual meetings and would occasionally rendezvous at other times. I had noticed Bill's injuries, received on the beaches of Normandy. Despite this, his wife said he could sew up a wound as neatly as anybody.

With all the above as background to our phone conversation, it was obvious that Bill was still perspicacious. Although on a walker and unable to drive, he was busy in the kitchen and taking care of his beloved wife.

One purpose of his call, I surmised, was to allow his wife to converse with me, perhaps to awaken her mind to happy memories of the past. I listened as he slowly assisted her to the phone. I heard her voice, but words were not intelligible. I spoke of our friendship and pleasant experiences of the past. The tone of her voice seemed happy, but I could not ascertain any comprehension. Their situation mirrored my own in many ways, and no doubt that of millions of older couples around the world -- couples helping one another in waning years. This is normal and the way it should be. There is sadness and this is normal too. I felt empathy for Bill. He knew, as do others in similar situations, that you do what you have to do, not necessarily out of a sense of duty, but because of a deep feeling of love.

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If we have the opportunity to be generous with our hearts, ourselves, we have no idea of the depth and breadth of love's reach.  
- Margaret Cho

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## Preparing for the End of Caregiving

When caregiving ends, you may feel lost and empty. Use the following suggestions to prepare for that time:

- Use respite weekly in order to maintain contact with friends.
- Find a hobby that occupies your time and requires practice to get good at.

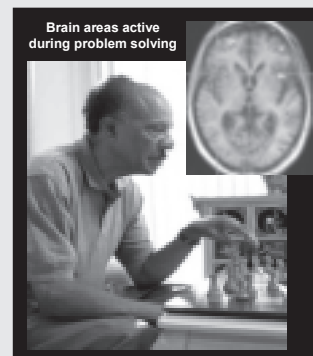
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- Don't wait to place your loved one until you are sick and totally exhausted.
- Tell yourself "I deserve this" when you are having a good time.
- Call friends at least weekly and talk about something other than the disease (listen to NPR if you need inspiration). Tell friends how good it is to hear their voices.
- Try things you never thought you would enjoy—minor league baseball, tractor pull, flea market.
- Go to a restaurant once in a while.
- Get some exercise every day. Many caregivers walk in the early morning before their loved one awakens or after lunch when he/she naps.
- Make sure your physician knows you are a caregiver and schedules regular checks for blood pressure and blood sugar, etc.
- Volunteer at the Alzheimer's Association or other organizations to use your newly acquired skills and strengths.

Used with permission from Geri Richards Hall, ARNP, CNS, FAAN, Banner Alzheimer's Institute, Phoenix, AZ.

### Functional Brain Imaging (fMRI) Studies at the Joseph & Kathleen Bryan Alzheimer's Disease Research Center, Duke University Medical Center

- fMRI is a safe, non-invasive procedure that measures brain functioning during the performance of mental tasks.
- fMRI not only gives us a better understanding of how the brain works, but has the potential to:
  - serve as a method for early detection of dementia.
  - improve treatment monitoring for dementia.
  - guide future drug development.



The Bryan ADRC currently sponsors multiple fMRI studies examining brain changes important to memory, mood and behavior in healthy seniors and those with memory or thinking problems.

#### We need your help.

Participation from all types of seniors and diverse groups allow for study results that are applicable to all peoples negatively affected by dementia.

For more information, please contact Dr. Jeff Browndyke at (919) 668-1586 or toll-free (866) 444-2372

## Have You Heard About?



*Coach Broyles' Playbook for Alzheimer's Caregivers*, Broyles F (2008). Spiral-bound brief book and tip sheet written by Frank Broyles, Athletic Director of the U. of ARK Razorbacks based on his experience caring for his wife. The Alzheimer's Association won the 2008 Caregiver Friendly Awards in part for Coach Broyles' "Playbook." Available in print from the Alzheimer's Assn: (800) 272-3900 and on the web at [www.alzheimersplaybook.com](http://www.alzheimersplaybook.com).

*Everything will be Alright: An Alzheimer's Memoir*, Read G (2007). A former Duke journalist offers personal insights on improving quality of life for persons with Alzheimer's. It begins with an inspirational love story on the Duke campus. [www.iuniverse.com](http://www.iuniverse.com) paperback.

By Us for Us© Guides. *Managing Triggers, Enhancing Communication and Memory Workout* provides examples of cognitive exercises and encourages persons with dementia to develop and maintain regular "workouts" for the brain so as to function better while engaging in enjoyable activities and managing stress. Single copies free from [jnmooney@health-uwaterloo.com](mailto:jnmooney@health-uwaterloo.com) or 519-888-4567, ext 32920.

*An Uncertain Inheritance*, Casey N (2007). Essays by famous writers examine the caregiving relationship from every angle – children caring for parents; parents caring for children; siblings, spouses, and close friends, all looking after one another.

*The Comfort of Home for Alzheimer's Disease: A Guide for Caregivers*, Meyer MM, Mittelman MS, Epstein C and Derr P (2008), Portland, OR: Caretrust Publications LLC [comfortofhome.com](http://comfortofhome.com). Updated practical format, tips and direct care suggestions.

*Family Caregiving in North Carolina: A Guide for Family Caregivers and Prepare to Care* (2008). Free updated, brief and user-friendly 11pp guides. To request free single copies, email [ncaarp@aarp.org](mailto:ncaarp@aarp.org) or call toll-free at 1-866-389-5650.

*Grandma Can't Remember So I Remember for Grandma*, Billington C. (2007). Carin Billington's mother suffered with Alzheimer's for seven years and she shares her own children's viewpoint of understanding and accepting Grandma's changed life.



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*Share the Care*, Warnock S (2008). Provides a road map on how to take a group of ordinary individuals (comprised of friends, relatives, neighbors, coworkers, and acquaintances) and turn them into a “caregiver family” to provide individuals and families with the help they need to meet the daily challenges of caregiving.

*A Family Caregiver Speaks Up “It Doesn’t Have to Be This Hard”*, Mintz SG (2008). This book written by a wife of a man with MS provides lessons from family caregivers across the country, tips for interacting with the healthcare system to better meet the needs of families dealing with chronic illness, and a cogent presentation of how public policy has a profound effect on even the most intimate details of life in caregiving families.

*Wordsworth Dances the Waltz*, Kakugawa F (2007) Honolulu, HI: Watermark Publishing, [www.bookshawaii.net](http://www.bookshawaii.net).. For elementary school children about Alzheimer’s and families. Call toll-free 1-866-900-BOOK.

*Together Again: A Creative Guide to Successful Multigenerational Living*, Niederhaus SG, Graham JL (2007) National Book Network/1-800-462-6420. This book offers positive commentary and solutions based in part on stories told by over 100 people now involved in extended family living relationships. Topics covered include the financial and emotional benefits of living together; proximity and privacy, designing and remodeling your home to accommodate elderly parents. [www.togetheragainbook.com](http://www.togetheragainbook.com).

*The Caregiver Companion: A User-Friendly Guide to Providing At-Home Care*, Morris J, Williams K (2007) Bet Tzedek Legal Services, Los Angeles, CA. [www.bettzedek.org](http://www.bettzedek.org) \$10.00. This book focuses on how to find and pay for home care services, organizing and improving the quality of home care, end-of-life decision-making, and legal and financial issues. Key issues are illustrated by case studies.

*Inside Alzheimer’s*, Pearce N, Forrason Press (2007). How to hear and honor connections with a person who has dementia.

*Dementia Caregivers Share Their Stories – A support group in a book*, Markut LA, Vanderbilt University Press (2005). Dementia caregivers share their stories on coping.

*When a Family Member has Dementia: Steps to Becoming a Resilient Caregiver*, McCurry S, Praeger Press (2006). Steps to ease caregiving one day at a time.

*Alzheimer de la A a la Z: Todo lo que Necesitas Saber Sobre el Alzheimer*, Lokvig Oniro J, © (2006). Alzheimer from A to Z in Spanish.

*To Love What Is*, Shulman AK. Memoir of a well-known writer and wife about caring for husband.

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*Book of Alzheimer's for African-American Churches* (2006). Free print copy from Sanders-Brown Center on Aging, University of Kentucky, 101 Sanders-Brown Building, Lexington, KY 40536. (859) 257-1412, [www.mc.uky.edu/coa](http://www.mc.uky.edu/coa).

*End of Life: Helping with Care and Comfort* (NIA/NIH) (2008). Free downloadable or single copies. [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers).

*Alzheimer's Disease: Helping Yourself Help a Loved One* (2008). Alliance for Aging Research in Washington, DC. Resource Kit provides everything you need to present a workshop or community awareness presentation for Alzheimer's caregivers. Free (while they last) Resource Kit, includes:

1 Leader's Guide with tips and instructions on conducting a brief workshop, plus updated information on the latest treatments and research.

1 Award-winning 2006 dvd with personal stories from a NC three-generation family coping with early Alzheimer's disease (Vignettes previewed at the 2007 Duke Bryan Alzheimer's Conference).

10 Caregiver Resource Brochures with information on caring for yourself while caring for a loved one.

10 NEW Caregiver Workbooks to help families think about important issues and make the most of limited time.

ORDER FREE from [www.agingresearch.org](http://www.agingresearch.org) or call 202-293-2856.



## New Online Help

### Caregivers

[www.agis.com](http://www.agis.com). AssistGuide Information Services—Free Caregiver Kit to help assess your situation and find help.

[www.TheCaregiversGuide.com](http://www.TheCaregiversGuide.com). This free guide provides caregivers with an easy-to-implement and inexpensive way to maximize the well-being of their loved one and reduce the stress association with caregiving.

<http://caregiver.org/caregiver/jsp/fcn>. The National Center on Caregiving at Family Caregiver Alliance has launched the Family Care Navigator, a first-of-its-kind comprehensive online guide intended to help families in all 50 states and the District of Columbia locate government, nonprofit, and private caregiver support programs. Listed also are programs for family caregivers as well as resources for older and disabled adults living at home or in a residential facility.

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<http://aspe.hhs.gov/daltcp/reports/2007>. Does high caregiver stress lead to nursing home entry? by Brenda Spillman and Sharon Long of the Urban Institute. The study found that the more stress a family caregiver experienced, the more physical strain, financial hardship, and behavior challenges, the more likely it was that the care recipient would move to a nursing facility.

[www.wisernow.com](http://www.wisernow.com). New Alzheimer's tips for caregivers. Books and downloadable online materials include Brain Aerobics Weekly and Wiser Now Alzheimer's Tips for Caregivers.

[www.extension.org/family+giving](http://www.extension.org/family+giving). Feature article on Family Caregiving Concerns for Home Safety.

[www.wellspouse.org](http://www.wellspouse.org). Well spouse support groups.

[www.strengthforcaring.com](http://www.strengthforcaring.com). Healthcare resources, caregiving resources, support information, local and national Asian American resources.

[www.wiserwomen.org/portal/index.php](http://www.wiserwomen.org/portal/index.php)? Range of information available to caregivers and care recipients.

[www.agingcare.com](http://www.agingcare.com). This website focuses on the needs of caregivers to the elderly and provides an active forum for connecting caregivers with expert information.

[www.medicareinteractive.org/help](http://www.medicareinteractive.org/help). Medicare Interactive has a special section dedicated to caregivers, including guidance on getting help for a loved one at home, caregiver rights and resources, respite care services, and how to advocate on behalf of a loved one.

[www.cfad.org](http://www.cfad.org). An organization for long-distance caregivers who are caring for an aging parent.

<http://www.familiesoflovedones.com>. Online and print magazine for families of residents in long-term care facilities.

### **Alzheimer's Disease**

[http://alz.org/national/documents/EarlyOnset\\_RL.doc](http://alz.org/national/documents/EarlyOnset_RL.doc). Information resources about early onset Alzheimer's (before age 60) for people with the disease and their families. 2006.

[www.alzforum.org](http://www.alzforum.org). For information on Early Stage Alzheimer's.

[www.aboutalz.org](http://www.aboutalz.org). A quick look at Alzheimer's, a series of four animated 'pocket' films, explains the essence of the disease and its public health implications. *What is Alzheimers?, An Urgent Epidemic, The Race to the Cure and A Message for Patients and their Families*. These films run 2-3 minutes each and are universally accessible – playable on iPods, cell phones, PDAs, laptops and DVD players.

[www.alz.org/townhall/overview.asp](http://www.alz.org/townhall/overview.asp). The Town Hall meeting, a website where people with dementia and families participate in a kind of a town hall meeting online established by the Alzheimer's Association. There is also a message board and chat room.

<http://nlcn.org>. National Eldercare Network. See Alzheimer's and Caregiving and Friend.

[www.storycorps.net](http://www.storycorps.net). Collects stories from persons with memory loss to be archived at the Library of Congress' American Folklife Center (see Storycorps Memory Loss Initiative).

### **Dementia**

[www.dasinternational.org](http://www.dasinternational.org). Run by and for those diagnosed with dementia and provides a chat room open 24 hours a day.

[www.alzheimersforum.org](http://www.alzheimersforum.org). Run by and for those diagnosed with dementia and provides a chat room, many articles and a "predicament of the month" page.

### **Geriatrics**

[www.fearlessaging.net](http://www.fearlessaging.net). This site was developed in an effort to help youth-obsessed Baby Boomers and others overcome their fear of aging.

### **Health Care**

[www.secretary.state.nc.us/ahcdr](http://www.secretary.state.nc.us/ahcdr). N.C. Advance Health Care Directives Website to register your wishes online with the Secretary of State's Office.

<http://www.nationalhealthcaredecisionsday.org>. Find current Advance Directives for every state.

[www.rihlp.org](http://www.rihlp.org). This provides a checklist that will make you get the most of each visit to the doctor.

### **Health Insurance**

[www.socialsecurity.gov/prescriptionhelp/mom.htm](http://www.socialsecurity.gov/prescriptionhelp/mom.htm) Social security campaign to reach family members and family caregivers of Medicare beneficiaries who may be eligible for extra help with prescription drug premiums, deductibles and co-payments.

### **Health Issues**

<http://www.strokeassociation.org/presenter>. Learn about reducing stroke risks, common risk factors and how cardiovascular and stroke risks relate – the American Stroke Association.

<http://www.americanheart.org/presenter>. Diet and nutrition update from the American Heart Association.

<http://www.epi.state.nc.us/epi/fish/safefish.html>. Fish consumption advisories that help you make the healthiest choice in fish to eat.

[www.sis.nlm.gov/outreach/womenshealth\\_overview.html](http://www.sis.nlm.gov/outreach/womenshealth_overview.html). Women's health topics collected by National Library of Medicine.

[www.espanol.ninds.nih.gov](http://www.espanol.ninds.nih.gov). Parkinson and stroke information in Spanish.

## Housing

The National Council on Aging (NCOA) and SNAPforSeniors™ announced the launch of the Senior Housing Locator, an online navigational tool that allows those who use BenefitsCheckUp ([www.BenefitsCheckUp.org](http://www.BenefitsCheckUp.org)) to find senior housing options in their desired area.

BenefitsCheckUp and the Senior Housing Locator are free to users. There is no collection of referral fees from housing providers, meaning that the information is objective and reliable. BenefitsCheckUp users answer a series of questions about their health and income, which are then used to determine whether they are eligible for more than 1,550 public and private benefits programs such as subsidized housing for the elderly, energy assistance, prescription drug savings or health care. [www.NCOA.org](http://www.NCOA.org).

## Legal

[www.nia.nih.gov/alzheimers/publications/legaltips.htm](http://www.nia.nih.gov/alzheimers/publications/legaltips.htm). New legal and financial planning for people with Alzheimer's disease.

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## Travel Safety Tips from the Alzheimer's Association

Having dementia does not mean that it's necessary to stop participating in meaningful activities such as travel; it just requires planning to ensure safety, comfort and enjoyment for everyone.

It's important to weight the costs and benefits of travel for a person with dementia, based on needs, abilities and preferences.

- Changes in environment can trigger wandering. Be sure to enroll in MedicAlert + Alzheimer's Association Safe Return, a 24-hour nationwide emergency response service for individuals with dementia that wander or who have a medical emergency. The enrollment phone number is 1.888.572.8566. Those already enrolled should notify MedicAlert + Safe Return of travel plans.
- Stick with the familiar. Travel to known destinations that involve as few changes in daily routine as possible.
- Evaluate options for the best mode of travel. Based on needs, abilities, safety and preferences, decide what would provide the most comfort and the least anxiety.
- Avoid planning a trip where emergency health services and pharmacies to refill prescriptions are not easily accessible.
- Keep travel simple and manageable: Plan a short trip and avoid multiple stops.
- Avoid elaborate sightseeing trips or complicated tours, which may increase anxiety and confusion.
- Have backup plan in case your trip needs to change unexpectedly. This may mean purchasing traveler's insurance if you have booked flights or hotels.
- If the late afternoon increases agitation, avoid traveling at this time.
- Have a bag of essentials with you at all times that includes medications, your travel itinerary, a comfortable change of clothes, water, snacks and activities.
- Remember to pack necessary medications, up-to-date medical information, a list of emergency contacts and photocopies of important legal documents.
- Allow plenty of time for rest. Don't over-schedule.