# **For Active and Informed Adults**

Fall 2013

From The Heart Of Caregivers ...

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–John, 88 years young Greencroft Goshen resident

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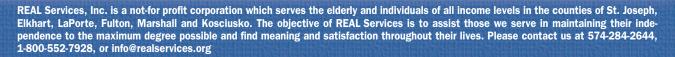
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*On The Cover:* Jane Lorton and her mother Isabel Batson circa 1945



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## **CAREGIVING** – It's complicated.

**Caregiving** – I don't presume to be an expert. But, after working for 28 years in programs and services with our older generations, I have learned a few things. First and foremost – **all of us can expect to feel the impact of this experience called "caregiv-ing"**. It is a fact of life that affects every socio-economic group and all ages. Although most us of do not plan for this role, or discuss the issue with our family or friends, chances are that caregiving will in fact touch our lives.

### I have also learned that:

There is no "one size fits all" solution for caregiving. Families, and the personalities within those families, are all unique and the end result is a distinct caregiving challenge that is different for each and every family. The traditional family roles that were in place before there was a need to provide care continue as each family navigates the responsibilities of caregiving.

- The organized and strong daughter may step forward to organize the care for her mother, and argue with her father over the best course of action.
- In another family, a mother who has always been dependent on her daughter may increase her dependence and have high expectations for her working daughter.
- In yet another family, the mother who has always been independent, and proud of her independence, may not accept help at all. To her daughter's chagrin, this mother prefers to risk her own safety rather than accept help from her daughter.

Each family member brings his/her own perspectives, opinions, and ideas to the caregiving table. These are the very traits that make up the family itself. Geographic separations, extended families, and blended families help to further demonstrate how each household is distinctive. Since there is no playbook, no one-size fits all plan for caregiving, each family is destined to determine what will work for them. While many families proceed in a very private and confidential manner, other families are inclined to discuss their concerns with friends and co-workers.

As noted earlier – I do not presume to be an expert on the topic of caregiving, but I do know experts and I know that **Northern Indiana is rich with resources**. I do not know all the solutions to the caregiving puzzle, but I am fortunate to know others that do have answers and can offer help. The first place to start:

Aging and Disability Resource Center (ADRC) at **REAL Services.** REAL Services was the pilot for the Aging and Disability Resource Center model for the State of Indiana. The concept was initiated by the Centers for Medicare and the Administration on Aging so that families had one central place to turn to for information about Long Term Care. The Aging and Disability Resource Center is available to anyone in Northern Indiana, regardless of age or income. The professionals who work in the ADRC are experts who know all of the community resources, costs of services and the options available to caregivers. Anyone who contacts the ADRC will speak with an "Options Counselor." Each Options Counselor is specially trained, knowledgeable, compassionate, and understanding. Options Counselors provide nonbiased information and arm caregivers with what is needed to make good decisions. Options Counselors are prepared to discuss Medicare, Medicaid, Home Care Providers, Home Modifications and Repair, Senior Housing Options, Elder Law Attorneys, Assisted Living Facilities, Nursing Homes, Support Groups, and more. REAL Services is a private non-profit agency that exists to serve older adults. It is not tied to any medical organization or business. This allows the ADRC to be independent in its recommendations. It is the ONE resource for answers and information about all things



"Aging". To contact the ADRC, call 574-284-2644 or 1-800-552-7928.

In addition to the ADRC, our community can to turn to Alzheimer's and Dementia Services of Northern Indiana – there is not a better trained or a more caring group than the staff and volunteers of Alzheimer's and Dementia Services of Northern Indiana. In their effort to assist family caregivers, Support Groups are coordinated throughout Northern Indiana. In addition, regular training and education is offered to individuals and groups. Families and caregivers become better equipped to provide care after learning more about the disease, treatments and tips. In addition, an Adult Day Service program is offered Monday through Friday where specially trained Nursing, Social Service, and Activity professionals care for individuals with a variety of disabilities. Caregivers from all over Northern Indiana have stated that there is no better resource than Alzheimer's and Dementia Services. To contact Alzheimer's and Dementia Services of Northern Indiana call (574) 232-4121 or 1-888-303-0180.

Our community has services, education, information, and support – options as varied as the needs of each unique caregiver. The best places to learn about these resources are with the experts in the Aging and Disability Resource Center of Northern Indiana – and Alzheimer's and Dementia Services of Northern Indiana.

Rebecca Rassel

Rebecca Zaseck, President/CEO REAL Services

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# **Letter From The Director**

## Caregiver.

It's really just a word, until vou've been one. Now it is an emotionally charged descriptor that elicits an immediate and deliberate response from me - always. I've been a caregiver and just hearing the word can take me back to that experience. It is a word that is imbued with emotion -joy, grief, compassion and a devastating sense of futility.

At that time in my life I was trying desperately to stay on top of all my responsibilities and felt that by dividing my attention to my family and to my mother, no one was getting a very good result. I remember thinking that this wasn't likely to end well. It's especially hard to keep your mind hopeful and optimistic when you know that improvement is unlikely and decline is almost certain. The most difficult part for me was that I wasn't privy to a timeline. In my mind I would have at least had some sense of control if I knew what lav ahead and when to expect it. It seemed especially cruel to experience days of hope, followed quickly thereafter by rapid and unexplained decline. But such is the way for caregivers.

I did my best to stay on top of everything that my mother needed and to anticipate her next need. I was her advocate and her confidant, even as she was losing her ability to communicate and reason. But it was especially challenging to find joy. Most encounters were troubling, grievous and overwhelmingly sad. It took a conscious effort to find joy, but I found it. I began every visit with saying out loud, "what will you teach me today, Mom"?

It helped me to believe that there was a lesson that I had to learn about every encounter and every visit. I needed to believe that there was some kind of good that would eventually come from her illness and from my involvement. I had to believe I would be a better person or better able help to someone else through their experience. There had to be purpose because I didn't want to believe the cruelty of her disease could be "just because".

What I learned about myself was invaluable, but what I learned about her was golden. I could never have learned what I did had we not shared all that precious time when she was so vulnerable. I received the blessings of insight and understanding about who she was and how she had become the person she had become, one who I had often locked horns with. When you love someone there is no limit on compassion or energy.

It was also that experience that taught me to value humility. Those receiving the care, no matter how independent or how proud, have to accept help from anyone willing to give it. There is no room for pride, for arrogance, and no value in "status". At that point, you're hanging onto each thread and grateful to those who will weave the threads into a blanket of love and compassion. Even the most proud are humbled and caregivers know and respect that. I learned not to judge but to go to a place where only compassion resides.

Many times there were weeks of hurtful and unkind comments that came from the depths of her dementia and confusion. But every now and again, there would be a tender and amazingly kind word that let me know how much she valued our being a lifeline for her. Oddly, two years later I only remember the kind words not the hurtful ones. One of the gifts given to caregivers.

Close to the end of my mother's life, I will always believe I was given a glance into her future. It was an odd moment when I was talking to her in the hope that maybe she could hear me, though she herself was unable to communicate. I was telling her that we would all be okay, that there was no need to worry or to be afraid. I reminded her that she would soon go to a wonderful place where she would again see her parents and the brothers she cherished. Suddenly



and unexpectedly, I felt an overwhelming sense of happiness like I had never known before, my heart felt as though it would burst and I was overcome with joy for her. All I could say was, "Oh Mom, it will be so wonderful". I truly believe that in that one brief second, I was given a glimpse of what heaven is. From that moment until her death a few days later, I found a

peace I hadn't known in the year previously as we witnessed her sudden illness and slow decline.

And to me, those are the blessings of being a caregiver. You witness the depth of your capacity to love someone, and if you keep your eyes and your heart open, you receive gifts that sustain you, forever.

In this issue, the amazing Jane Lorton has managed to capture in words and pictures, the heart of a caregiver. You'll see they look just like you and I. You'll also see that theirs is a heart unlike any other. It is tender, compassionate, loving and boundless. I hope you find their amazing stories an inspiration too if you are a caregiver yourself or know someone who is. And as our country continues to age, I hope you remember the stories you've read and continue to support programs that support the caregivers who are out there weaving their blankets of mercy.

pauluson)

/ Joan Cuson, Director Area 2 Agency on Aging/REAL Services, Inc.



Specializing in Short-Term Rehabilitation



## Caregivers.

### What is a caregiver?

The Family Caregiver Alliance defines caregiver as: "an unpaid individual (a spouse, partner, friend, neighbor, family member) involved in assisting another with activities of daily living and/or medical tasks. Formal caregivers are paid care providers providing care in one's home or in a care setting

(daycare, residential, care facility, etc.) In November, 2012, there were 65.7 million caregivers providing care to someone who is ill, disabled or aged. 52 million provide care to adults (aged 18+) with a disability or illness." And according to Gallup research, more than one in six Americans who have a full-time or part-time job report that they assist with care for an elderly or disabled family member, relative, or friend. The economic impact of caregiving in 2009 was estimated to be at \$450 billion per year and will likely continue to be the largest source of long-term care services in the U.S. since the aging population 65+ will more than double between 2000 and 2030, increasing to 71.5 million caregivers! The Evercare National Alliance for Caregiving Study of Caregivers - What They Spend, What they Sacrifice (2007) provides an important indepth look at the financial and other "personal costs" of caregiving; it documented that as many as 17 million people are spending on average more than 10% of their annual income on caregiving expenses. The report also revealed that family caregivers who have an annual median income of \$43,026 spend on average \$5531 each year on caregiving. Further, the study

<sup>44</sup> THERE ARE ONLY FOUR KINDS OF PEOPLE IN THE WORLD: THOSE WHO HAVE BEEN CAREGIVERS, THOSE WHO ARE CURRENTLY CAREGIVERS, THOSE WHO WILL BE CAREGIVERS AND THOSE WHO WILL NEED CAREGIVERS.<sup>99</sup> – Rosalynn Carter reported that at lower income levels, the annual average costs remained about \$5500 – making the financial burden even greater. According to the survey, many family caregivers are involved in both providing hands-on care and paying for needed goods and services. That being said, this issue of REAL Connections is devoted to

the stories of informal caregivers in our communities and the impact caregiving has had on their lives. They are daughters, sons, wives, and mothers; they may work beside you in your office; live in your neighborhood; they may even share your pew in church. Each individual has a unique story to tell and they each hope that by sharing these very personal experiences, other caregivers will be encouraged to continue in their own caregiving responsibilities. In addition, hopefully, other caregivers will be able to glean solutions from these stories in order to lighten their own caregiving burdens.

## We have divided the stories into three (3) sections:

#1. FEELING EMOTIONALLY BURDENED BY PROVIDING CARE FOR ANOTHER PERSON

### #2. FEELING PHYSICALLY BURDENED BY PRO-VIDING CARE FOR ANOTHER PERSON and

#3. FEELING FINANCIALLY BURDENED BY PRO-VIDING CARE FOR ANOTHER PERSON

## Feeling Emotionally Burdened By Providing Care For Another Person

Judy was one of the first caregivers to be interviewed. Her husband was diagnosed with early onset dementia when he was 59 years old. Judy described her husband as her "soul mate" so this was extremely difficult for her, for her husband, as well as the rest of their families. "The emotional toll of providing care for him has been heart breaking. It has been so difficult to watch him lose the threads of the person he used to be, and to feel helpless knowing that I cannot make it better for him, that there is no cure, and that it will only get worse. There are so many emotions that a caregiver goes through daily, depending upon the circumstances of the moment, the stage of the disease, and the length of time you have been traveling on this journey together. Early on, there was shock at the diagnosis, fear of what it all meant for both of us, anger that it was happening, frustration with the futility of the disease and what to expect, pain in my heart for what he must be experiencing, and a sense of total helplessness and devastation. As his disease progressed, I became overwhelmed by the tremendous loss and sense of grieving, but I also found that humor and patience were key to helping us both feel better. I am emotionally rejuvenated by family and friends who are compassionate and caring, *Continued on page 11* 







but I am saddened by those who are not able to deal with the changes in him and would rather 'remember him as he was', and thus bury their heads in the sand. Many of those individuals have either dropped out of our lives or regularly proffer excuses for their absence. As the years and disease have progressed. I continue to be burdened by the emotional loss of everything that we have shared together and the future we had so carefully planned. I am saddened as I watch him slowly decline, and I sometimes feel sorry for myself that I am taking care of my spouse as I would a child or an infant instead of enjoying the strong, independent, accomplished partner with whom I cherished sharing my life. However, there is no resentment toward him as he does not know, cannot speak, nor do most things for himself any more. But he still smiles and gives me 'rays of sunshine' when he has a moment of clarity and responds to my touch, or a kiss, or a smile." Judy indicated that as time has passed and as her husband's condition has deteriorated, she has been drawn to various means for emotional support: "My mother is 86 years old and we are very close. I can call her any time to vent my feelings. If I need to cry, I can cry. My friends are also very positive and we support one another. I could dwell on the negative - you

can choose to wallow in your situation but you don't have to. Alzheimer's Services and their support groups have been of utmost importance during this disease process. It's been important for me to know that someone else understands what I'm going through."

Next, I interviewed Pam who was the primary caregiver for her mother who has since died. "Emotional weightiness has a great impact on caregivers. While I certainly experienced great on-going emotional stirrings including sorrow for what my mom was going through, I also had emotions of love and hope that prevented a 'whirlwind of heavy emotions' from causing an on-going downward spiraling emotional overload. Because of the love and natural connection to my mom, emotions were always at the forefront of everything my family and I did. The pain I felt was real and big; but the peace that God gave was even more real." Even though she was "emotionally burdened", Pam's church, her pastor, her faith gave her inner strength to care for her mother. Pam recommends that caregivers need to carve out personal worship time which was so important to her in reducing the emotional stress of caregiving.

That same advice was echoed by **Martha**, another caregiver who is still providing care for her own mother who is currently living in a long-term care facility. Martha adds "I am always blessed to spend time with my mother but at the same time, it is challenging to spend all the time with her that I would like because of other responsibilities. When I leave her, which could be emotionally burdensome, I just pray and ask God to care for my mother."

**Sharon** is the parent of a special needs son who will soon be twenty years old. In addition,

Sharon is the primary contact for her parents who live in the Indianapolis area. She and her husband feel the emotional stress of caregiving since they are unable to

they are unable to leave their son in the care of 'just' any other person. He functions at the level of an eighteenmonth old child which means he has to be toileted, fed,



dressed, and bathed. And even though he is able to ambulate, he requires one-on-one supervision in order to keep him safe. Sharon and her husband must coordinate their schedules so that one of them is with him at all times. "Being a caregiver is stressful and the family stress is unbelievable" Sharon adds. When Sharon is called away to assist her parents, the emotional stress escalates. For support, they reach out to both sides of their families as well as to good friends and to their faith community. "Part is faith; part comes from family; and part comes from friends."

#### John and his wife Marlow

were living in Chicago when they made the decision to relocate to the South Bend area in order to assist his parents as their health began to decline. John's father, who died in 2010, suffered from dementia. His mother is still living and thriving as are John and his wife. They seemed very happy as they have invested in a new business of professional caregiving, Home Instead. Even though John's mother is currently living in a local healthcare facility, he remains a very "handson" caregiver. And John offered "my father had dementia, which none of us adequately understood at the time, so we were not only feeling guilty but confused. And as the disease progressed, the guilt and

Continued on page 12



## Caregivers.

## Feeling Emotionally Burdened By Providing Care For Another Person

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care-fatigue got much stronger. My family realized too late that you can give all of the love and affection you want, but if your loved one has dementia, you need to be educated in order to provide truly compassionate care."

**Kathleen**, who provides care for her father and is also his legal guardian says: "I find myself heartbroken, watching the decline in my father's condition. I am helpless in helping him. I find few words that would ease this pain. I make every effort to share a warm smile or a chuckle. I am in disbelief at what I am seeing. Even though I am mentally overwhelmed and exhausted, I remind myself to stay peaceful and calm. I know that I over-analyze, I worry about every detail, not only how it will affect my dad but also the other members of my family." For Kathleen, (she has 3 siblings), prioritizing tasks, making decisions, keeping her dad engaged with others is also emotionally draining. She asks herself, at times, "How did I get put in charge? Did I miss anything? Do I have to do all of this?"

## Feeling Physically Burdened By Providing Care For Another Person

According to a report from the Centers for Disease Control and Prevention, caregiving exacts a tremendous toll on caregivers' health and well-being and accounts for significant costs to families and society as well. Family caregiving has been tied to increased levels of depression and anxiety as well as increased use of psychoactive medications, poorer physical health, compromised immune function, and increased mortality. (Kiecolt-Glaser & Glaser, 2001) Estimates suggest that between 40 and 70 per cent of caregivers have clinically significant symptoms of depression. Over time, caregiving may erode one's subjective experience of health. (Wight, 1998) Common complaints among caregivers include fatigue, not getting enough sleep, not eating right, not exercising, and basically not taking care of "yourself". In addition, trying to work and care give, trying to be present to spouse, children, other family members, maintain friendships, and other social connections are major difficulties.

Our interviews with family caregivers reflected the findings in these reports. Most said that their own medical appointments and dental appointments were postponed on a regular basis because of their caregiving responsibilities. Sharon said that anything related to general health, like dentist appointments or check-ups, gets postponed because of her caregiving responsibilities. And keeping connected to friends, going to lunch, other social situations were sometimes delayed or put on hold. In addition, "because our son weighs 130 pounds and he is total care, which includes dressing, feeding, toileting and showering, the physical wear on our bodies in great."

For **Pam**, the physical tasks of caregiving and working a full-time job took its toll on her. Many nights she was unable to sleep. "With both the physical stress and the mental stress...well, it was like a snowball rolling down the side of a snow covered hill — it kept growing. Balance and developing supports for oneself as a caregiver are extremely important. I highly recommend regular times of relief and refreshment for all caregivers. Too often we hear that caregivers themselves get sick due to their duties of caregiving. I hope every caregiver reading this really hears my heart on



the matter: Caring for yourself is caring for your loved one. So I recommend that you do your best to make care giving as much of a team effort as you can."

Because Martha's mother is in a long-term care facility, she reports that the physical toll has been reduced significantly. **Martha** visits her mother in the facility each week but at this time, her mother is not in a position to leave the facility for outings. "When I used to take my mother out, if my husband or son were not with me, it was physically challenging moving her and her wheel chair. I bought a vehicle with her and the wheelchair in mind."

For **Judy**, "It is extremely easy to get so wrapped up in taking care of your loved one that you either



forget to take care of yourself, or you put off allowing yourself time to rejuvenate because you are consumed by their well-being. Extreme stress, constant emotional ups and downs, balancing work and caregiving, worry, eating late and not getting enough sleep DOES catch up with you. I found myself getting light headed, having resonating sounds in my ears and being unable to sleep longer than two hours at a time. And I was just exhausted. I learned that you need to take a little time to stop and smell the roses and do some things for yourself so that your frame of mind can be on task when you must be there for our loved one. and you are fresh enough to give him the love, comfort, support and soulful peace that only you can give him. Being involved in an Alzheimer's and Dementia Caregivers' group has helped me to confirm and reinforce that I need

not feel guilty about taking time for myself in order to be a better care giver and comforter when I am with him."



For **Marlow and J.P.** providing personal care for his father was very difficult. As the physical care needs escalate—help with toileting, bathing, transfers, dressing—the physical burden on the family caregiver can seem overwhelming. "With my dad, whom I considered my best friend, I absolutely did not enjoy being involved with his bathing and toileting. Nor did I thrive on driving across town to 'pick dad up' again after he fell and lay helplessly, like an overturned turtle, desperately trying to get up on his own. It would have helped if I'd known what I was doing. Still, you give care out of love and let the chips fall where they may."

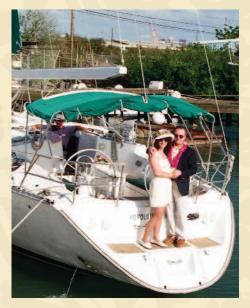
**Kathleen** does not live with her dad but because she is his legal guardian and primary caregiver, she finds less time to pursue her interests in golf and exercise. "There is less time for me, for my husband, for my activities, no time to sleep in on Saturday morning, and my house work gets further and further behind." "I do remind myself to stay peaceful and calm in spite of everything."

## Feeling Financially Burdened By Providing Care For Another Person

According to the State of Indiana Profile, there are 720,000 informal caregivers in our state providing 780 million hours of care and is valued to be \$ 7,500,000!!!

Family caregivers face financial burdens in addition to Physical and Emotional Burdens. On average, the out-of-pocket expenses for a family caregiver are \$2400 a year. (AARP, 2007) And long-term caregiving has significant financial consequences, particularly for women. Many caregivers face the loss of income of the care recipient, loss of their own income if they reduce their work hours or leave the job market, loss of employer-based medical benefits, shrinking of savings to pay caregiving costs, and a threat to their retirement income due to fewer contributions to pensions and other retirement vehicles. (AARP, 2008)

Judy is a perfect example of this scenario; her husband lost his business which meant she became the breadwinner. "Oh my, where to begin? This can be overwhelming and it certainly adds to the already existing stress. Through Alzheimer's and Dementia Services of Northern Indiana. I was able to learn of some of the resources that are available for assistance, and in turn, learned what we do and do not qualify for in terms of that assistance. I also learned that it is important to talk to an elder-care-attorney, if possible, to review your options for the possibility of financially sustaining yourself as time passes and the caregiving progressively becomes more expensive. Nothing is rosy in this picture.



I am thankful to have a job to help pay for his care outside of our home as insurance does not pay for this

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## Caregivers.

#### Continued from page 11

care, but I know that we will ultimately have to begin using our 'retirement' reserves, and I worry what that will mean for my future livelihood. Everyone's situation is totally different, but no matter what the circumstances, this disease causes a tremendous on-going financial burden that weighs heavily on the caregiver."

For **Sharon** and her husband, the financial concern is great. "Our wish is for our son to be able to live in a clean and safe environment. We realize that he will probably live for another 50+ years so we need to have money available to provide for his living arrangements, clothes, food and medical expenses. Given this, we are constantly trying to financially plan for his life."

For **Pam**, "I was fortunate in that I did not lose money nor go into debt while caring for my mom as I did continue to work full-time. I do suggest, however, that someone who has had to reduce their work hours or quit working all together to take care of a loved one, seek financial advice in doing so."

**Martha's** family decided to share responsibilities when their mom's dementia progressed. One sister, a nurse, takes care of all things medical; the oldest sister takes care of finances; the rest of the siblings come together to assure that their mother has visitors and socialization on a regular basis. The entire family comes together for holidays, birthdays, other special events,



because, for their family, even though mom is in a longterm care facility, it is important to carry on their traditions.

"My dad, with the help of my brother, bought a long term care (LTC) policy which, I in my infinite wisdom, thought was expensive and silly (this, at a time when my parents were both still highly functional). A high school teacher with six kids and a wife, how did dad conclude that paying a substantial yearly portion of his income as being a smart choice? As usual, he turned out to be right." This is a quote from John who also states "often the caregiver is the Power of Attorney (POA) so now they have to be stewards over not only of their loved one's finances but also their own family's." Sometimes this can be an overwhelming burden for the caregiver.

Kathleen is the legal guardian

for her father so in addition to being a caregiver, she also has the financial responsibilities. She has three siblings and "as a family we had to come together



at making decisions. This is so important, not only for each of us but also for our dad. Having the support of my siblings has been phenomenal." Kathleen does make a recommendation for anyone who is thinking about guardianship: "When you become guardian, find out what your responsibilities and duties are. You don't want any surprises down the line." For Kathleen, her caregiving duties have, at times, been exhausting. She works fulltime, so when necessary, she has taken vacation hours to accomplish some of her caregiving duties.

## Conclusion

Caregiving....I wrote an article some years ago about my personal caregiving story involving my 30-year old son who went through a lengthy bone-marrow transplant at the University of Iowa. I traveled there once each week throughout the summer of 1994. In 2010 I found myself in another long distance caregiving role, to my mother who lived four hundred miles away.

My mother was one of the hardest working, fearless, and generous individuals I have ever known. When my dad was drafted into World War II, my mother was left with 3 small children to care for and support. I was the youngest at age 5. (Cover photo) Over the years as we've reminisced about those early days, when food was scarce, jobs were few, we would ask how she managed to keep us together all by herself and she'd give us the same answer, "I just did it." And so it was throughout her life. My mother had clarity of purpose and a purpose that impacted the lives of everyone she touched in a positive way. She was always there for anyone in need to do what needed to be done. She worked alongside my dad to support our family until his death in 1978. But his death did not slow her down as she continued working well into her late 80's. When her health began to fail, it was important to me to be there for her because she was always there for me. So in 2010, I started out on another caregiving journey.

Long distance caregiving creates many issues that other caregivers don't always face. Making decisions based on conversations with the care recipient and other family members, locating resources, just knowing when to go, are all considerations not to mention all of the personal issues: Who will take care of my house, my dog? As my mother turned ninety, she was diagnosed with congestive heart failure. She was hospitalized then discharged home on a somewhat regular basis. I'm sure other seniors have experienced the same yo-yoing, into the hospital for IV diuretics, home with assistance until the fluid returns. In June, 2012, my older brother died from complications associated with cancer. It seemed that after his death our mother's downward spiral escalated. Her hospital admissions and discharges increased as did her confusion level. Her wish had always been to spend her last days in her own home, in her own bed, with her family present. So, after the last admission and in-hospital stay, her doctor asked for a family meeting to discuss Hospice. There were five of us listening as the doctor and social worker explained the process. We were fortunate in that there were enough of us to provide the care mother needed in order to fulfill her wishes. We were also keenly aware that not all families have "hospice at home" as an option....Our numbers allowed us this special gift. We took our mother home just before Thanksgiving last year. She died on December 3rd with my youngest brother and me sitting at her bedside....she was 95 years old.

"....it's time for us, as a community to understand the suffering that is shouldered, sometimes silently, by our family members, neighbors, friends, and co-workers. We need to care for the caregiver."

> Long-distance caregiving created quite a challenge for me. While I wanted to share the burden with my siblings who lived closer to our mother, my life was here, my church, my home, my friends. The emotional ups and downs were dramatic. When I was there, I felt guilty because I wasn't here; when I was here, I felt guilty because I wasn't there! And even though I am a seasoned driver, the physical and financial burdens of driving 800 miles monthly took its toll. I only share this with you, the reader, not to gain sympathy, but to emphasize what caregivers everywhere do on a regular basis, without thought to their own personal health and to their pocket books. I'm not an exception - I recently met a woman who lives in California but her parents are here in Indiana. She travels here often to assure that their needs are being met. And remember Sharon, the parent of a special needs son? She traveled recently to the Indianapolis area for several days to assist her parents as they moved out of their family home. Juggling long-distance caregiving with her duties at home must be daunting but Sharon does not complain....it's what she does out of love as a mother and as a daughter. She is a caregiver.

In Jai Pausch's book Dream New Dreams, she talks about her role as her husband Randy's primary caregiver for two years prior to his death from pancreatic cancer in 2008. "My dream is that my story will legitimize what caregivers undergo willingly and bravely as they care for a person they love. Patients need and deserve support, but it's time for us, as a community to understand the suffering that is shouldered, sometimes silently, by our family members, neighbors, friends, and co-workers. We need to offer help; we need to empathize with that person taking on the duty of overseeing the patient's care and well-being. Finally, we need to care for the caregiver." I highly recommend this book to everyone.

Caregivers are all around us. They command our deepest admiration and respect. Christopher Reeve once said "A hero is an ordinary individual who finds the strength to persevere and endure in spite of overwhelming obstacles." I offer my profound gratitude to Judy, Pam, Joan, Martha, Becky, Kathleen, Sharon, John, and Marlow for sharing your stories. In my book, you are all heroes!!

Caregiving articles by Jane Lorton

#### **Post Script**:

For all of you who are caregivers, please check out the Resource Page, Adult Day Services, and the article on Support Groups. And if you are a "long-distance" caregiver, the ADRC can provide information regarding services all across the country. These are all options to assist you in your caregiving journey.



## Solutions/Resources for Family Caregivers

You may know that the world's population is aging — that the number of older people is expanding faster every day. By 2018, 65year-olds will outnumber those under 5 — a historic first. In 2050, developed countries are on track to have half as many people under 15 as they do over 60. In short, the age mix of the world is turning upside down and at unprecedented rates. As we age we will encounter many new situations, and with these new situations, will come questions. REAL Services has a place to turn for answers. Our trained Aging and Disability Resource Center Options Counselors can help navigate through some of the issues facing the aged and disabled and their caregivers.

One of the most stressful times in the lives of the aging and their caregivers can be when someone needs to step in and care for a loved one. The Aging and Disability Resource Center (ADRC) has trained Options Counselors that can help explain a wide variety of options for care. They can speak about Private Pay (out of pocket) options, as well as Medicare, Medicaid Prior Authorization, and Home and Community Based Services Funding.

Sometimes, something as simple as a piece of equipment can mean the difference between staying at home and needing to consider a Nursing Facility. The ADRC has over 1700 program listings and 900 agency listings that could help care for a loved one.

One thing is certain, the world continues to change and as the world changes, so will the face of aging. Finding the answers to all of the different questions can be overwhelming but REAL Services can help. You don't need to know all of the answers; you don't even have to be able to verbalize a question. If you have an eldercare issue of any kind, know you can contact our Aging and Disability Resource Center at 574-284-2644 or 1-800-552-7928. We are here to offer options and solutions to each unique caregiving situation. The professionals who answer the phones are completely trained to address those eldercare issues.

We are here waiting to help. ⊘

## What Is A Support Group? (Another Resource For Caregivers!)

Support groups are meetings held for family members and or friends who are caring for one with a disease diagnosis. There are support groups for Alzheimer's/dementia, Parkinson's, Diabetes, Stroke, Heart, and many others. These meetings focus on providing, not only the support of others in similar situations, but education on the disease process. Group leaders and members provide mutual emotional

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support, exchange coping skills with one another, and problem solve together. Issues discussed during these meetings are kept confidential.

### HOW WILL A SUPPORT GROUP HELP ME?

Through a support group you may:

— gain a better understanding of the disease

learn to deal with a crisis in a constructive way

— be with others having a similar experience

— get advice about a particular problem

— learn about available support services in your community

— obtain support to safeguard your own health and

— get a break from caregiving responsibilities

To find a support group in your area, contact the ADRC at 284-2644 or 1-800-552-7928.

# **Adult Day Services**

According to the Administration on Aging, Adult Day Centers provide another option for family caregivers and are designed to provide care and companionship for seniors who may need assistance or supervision during the day. These programs offer relief to family members who may need to work, handle personal business, or just relax while knowing their relative is safe and well cared for. The goals of the program are to delay or prevent institutionalization, enhance self esteem and to increase or encourage socialization. Many caregivers are unaware of these centers so hopefully, by including this information, more caregivers will pursue this as an option to relieve them, even for a few hours each week or each day.

Most often Adult Day Services are open during normal business hours and may provide a variety of services such as meals, exercise, socialization and recreation. Some may offer to dispense medications, and give showers.

In Indiana, in order to become Medicaid certified, there are Three (3) different levels of Services

### Level 1 Basic Adult Day Services:

a) Monitor and or supervise all activities of daily living (ADL's are defined as dressing, bathing, eating, walking, and toileting) with assistance provided as needed.

b) Comprehensive, therapeutic activities.

c) Assure health assessment and intermittent monitoring of health status.

d) Monitor self-administration of medication.

e) Ability to provide appropriate structure and supervision for those with mild cognitive impairment.

f) Minimum staff ratio: 1 staff to each 8 participants.

### Level 2 Enhanced Adult Day Services:

Basic service (level 1) requirements must be met. Additionally:

a) Provide hands-on-assistance with 2 or more ADL's or hands-on assistance with bathing or other personal care.

b Health assessment with regular monitoring or intervention with health status.

c) Dispense or supervise the dispensing of medication to clients.

d) Psychosocial needs assessed and addressed including counseling as needed for participants and caregivers.

e) Ability to provide therapeutic structure, supervision and intervention for those with mild to moderate cognitive impairments.

f) Minimum staff ratio: 1 staff for each 6 participants.

### Level 3 Intensive Adult Day Services

Basic (level 1) and Enhanced (level 2) service requirements must be met. Additionally:

a) Hands on assistance or supervision with all ADL's and personal care.

b) One or more direct health intervention's required.

c) Rehabilitation and restorative services including physical therapy, speech therapy, and occupational therapies coordinated or available.

d) Ability to provide therapeutic intervention to address dynamic psychosocial needs such as depression or family issues affecting care.

e) Ability to provide therapeutic interventions to person with moderate to severe cognitive impairment.

f) Minimum staff ratio: 1 staff for each 4 participants.

We visited two Adult Day providers in our service area, Milton Adult Day Services in South Bend and Riverview Adult Day Services in Elkhart. We were pleasantly surprised to be met with smiling, happy faces, not only by the participants but the staff as well. Everyone seemed to be busy and engaged in one activity or another. Both of these facilities provide all 3 levels of care and tailor plans of care specifically based on individual need and functioning ability. These plans are changed and or modified on a regular basis as needed.

There are a number of Adult Day Service providers in our 5-county area so we suggest that you contact the ADRC for a complete listing. (574-284-2644 or 1-800-552-7928) Not all centers provide the above services. Many provide activities for recreation and socialization but no assistance for medical needs. It is imperative that caregivers tour the prospective facility and ask questions related to the needs of your care recipient. Prepare questions in advance, noting any special needs or concerns you may have.

Many caregivers we interviewed spoke highly of Adult Day Services, not only for the benefit of their loved one but also, the significance in having a few hours of free time. It was the best solution for them to get a break from their daily caregiving responsibilities. If you are in a stressful, caregiving situation, please make the phone call. You will be glad you did.

Sometimes you will never know the true value of a moment until it becomes a memory.

- Anonymous



# "As Right As Rain"

Effective July 1, 2013, Alzheimer's and Dementia Services of Northern Indiana became a Division of REAL Services, Inc. After much consideration and review, the governing Boards of Directors of both organizations determined that the merger was a winwin for clients, families, the employees, and the community.

Alzheimer's and Dementia Services of Northern Indiana and REAL Services share a common mission – to support the elderly and their caregivers. Our values are aligned in that those we serve come first and foremost.

And, we share a mutual respect and admiration for each other's organization, staff expertise, and programs.

Beyond our shared mission and values, there are many advantages to pursuing this merger:

- \* Efficiencies with a shared financial and benefit administration.
- \* Efficiencies with a combined call center staff
- \* Efficiencies with program delivery
- \* Efficiencies through shared technology
- \* New competencies because of shared knowledge and expertise
- \* Access to new funding sources
- \* Lower meal costs for Milton Adult Day Services
- \* Expanded funding sources for Transportation
- \* Improved services for clients through a one stop philosophy



Pictured above: left to right, Steve Watts, Chairman of the Board of Directors/REAL Services, Inc.; Rebecca Riley Zaseck, President/CEO REAL Services; Bill Jack, Executive Director/Alzbeimer's and Dementia Services of Northern Indiana; and Colette Wolfson, Chairman of the Board of Directors/Alzbeimer's and Dementia Services of Northern Indiana.

As one Board member put it "This is as right as rain".

To make a great effort even better, the merger was supported by the Community Foundation of St. Joseph County. A grant was provided through the Milton Fund to offset the costs associated with this important project. The project was also funded through the Wells Fargo charitable trust.

This formal partnership was initiated when the current Executive Director of Alzheimer's and Dementia Services of Northern Indiana, Bill Jack, decided that he would retire by January of 2014. REAL Services and Alzheimer's and Dementia Services had worked on many important projects in the past, with both organizations working in the spirit of cooperation and coordination to best serve the elderly and their families. The conversation logically turned to a formal partnership that would strengthen both organizations and increase the focus on those served.

Bill Jack has served those with Alzheimer's disease and their families for over 15 years. He has done so with dedication, integrity, financial know-how, and deep compassion. He, his Board of Directors, staff, and volunteers have grown the agency into one that provides more options, more information, more support, in more locations throughout northern Indiana, reaching out to families in Elkhart, Jasper, Kosciusko, Lake, LaPorte. Marshall. Newton, Porter,

Pulaski, St. Joseph, and Starke counties. They have created a place where families can turn to for help in caring for a loved one. This agency, Alzheimer's and Dementia Services of Northern Indiana, is a vision that has been realized.

With that, families will see no changes in the quality or quantity of programs provided by the staff and volunteers who serve them. Even the logo will remain the same. All donations and gifts designated for Alzheimer's and Dementia Services of Northern Indiana will be directed for that purpose.

Effective January 1, 2014, Alzheimer's and Dementia Services of Northern Indiana will have a new Director. Her name is Pam Huffer. She is working with Bill Jack to learn all aspects of his agency, the mission, its values and its clients. The goal is for a seamless transition



for all involved. Pam is qualified for her new responsibilities because of her proven track record in program development, management, budgeting, and serving those with dementia. Her previous roles included Coordinator of the Guardianship Program and the Director of Client Services for the Area 2 Agency on Aging. Pam will take what she has learned from Bill Jack, combine that with her extensive experience, and work to serve the growing population of those who have Alzheimer's disease and dementia. ⊘



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# The New Federal Budget And Resulting Changes

Long before the recent "government shut-down", the Advocacy Committee of the Area 2 Agency on Aging invited Mr. Marc Goldwein, Senior Policy Director, Committee for a Responsible Federal Budget, to speak at a public forum scheduled Thursday, October 3, 2013 at the Kroc Center. Mr. Jim Rahilly, Chairperson Area 2 Agency on Aging Advocacy Committee and Ms. June Lyle, State Director of AARP, Indiana, both commented on the committee's foresight in scheduling such an event in light of recent developments at the federal level!! After a glowing introduction, Mr. Goldwein approached the podium and said: "I used to be an optimist!"

Some of the excerpts from his presentation and from his work on the Committee for a Responsible Federal Budget:

"A number of people have argued that little or no further action is needed to address the nation's growing national debt. The Committee for a Responsible Federal Budget (CRFB) responded to these claims in February with the analysis Our Debt Problems are Far From Solved, which showed that \$2.4 trillion in new savings over ten years was needed to put the debt on a clear downward path as a share of the economy. Now, the improved budget projections from the Congressional Budget Office (CBO) have revived this discussion.

The good news is that the latest projections from the CBO show a significant improvement in debt levels. Our latest CRFB Realistic Baseline now shows the debt rising to 75% of GDP as opposed to 79% by 2023. However, much of this improvement is due to short-term improvements that will change the level but not the trajectory of debt. We estimate putting the debt on a clear downward path as a share of the economy will still require at least \$2.2 trillion of deficit reduction relative to our CRFB Realistic Baseline over the next ten years. If policymakers retain the across-the-board 'sequestration' until it expires in 2021, \$1.6 trillion in further savings will still be necessary to put the debt on a clear downward path.

Progress has been made and it is extremely encouraging to see that deficits are coming down. Yet, despite the progress made in enacting substantial short-term and temporary deficit reduction, policymakers have done little to combat the pressures of population aging, health care cost-growth, and an outdated tax code that will lead to a rising debt trajectory. Whether policymakers replace or retain the sequester, a combination of new spending cuts, entitlement reforms, and tax reforms will be needed to help support longterm economic growth and put the debt on a clear downward path relative to the economy."

- 1. Our debt level is at 12 trillion dollars which is 70% of our GDP (Gross Domestic Product) and has never been this high during peace time.
- 2. It is a myth that our debt problem has been solved.
- 3. Our debt level will continue to go on an upward rise — no country can sustain this level
- 4. Our country has not dealt with our aging population or our rising health care costs. The largest group in American History (Baby Boomers) will be applying for Social Security. The aging population is living longer thus on Social Security longer, on Medicare longer. Revenue has not kept up.
- 5. By 2031-2033 Social Security

will be gone unless there is reform

- 6. By 2024-26 Medicare will be insolvent unless action is taken
- 7. "You can't cut your way out of this, you can't grow your way out of this, entitlement reform won't do it — we need all three."
- 8. The government shutdown is an unacceptable way to govern.
- 9. There is a positive note in regard to the tax code. Both parties are working together toward tax reform.
- 10. We need to work together. As citizens we need to call our representatives, write letters, visit web sites, and send e-mails advocating for change.
- 11. We are faced with difficult problems but they are not insurmountable.

Mr. Goldwein received his B.A. degree in political science and an M.A. degree in economics from Johns Hopkins University where he currently teaches economics. In 2010 he spent nine months as Associate Director of the National Commission on Fiscal Responsibility and Reform (The Fiscal Commission), and in 2011 he spent three months as a senior budget analyst on the Joint Select Committee on Deficit Reduction (The Super Committee). He has also conducted research for the Government Accountability Office, the World Bank, the Historian's Office at the Social Security Administration, and the Institute of Governmental Studies at UC Berkeley. He is frequently quoted in a number of major media outlets including The Washington Post, CNN Money, McClatchy Newspapers, and the Associated Press.



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# The Luncheon Event Of The Year

A record attendance of over 700 people joined us for REAL Services/Area 2 Agency on Aging's Age of Excellence Awards Luncheon held on May 16, 2013 at the Century Center in downtown South Bend. The event was filled with honor and gratitude as 111 people from St. Joseph, Elkhart, Kosciusko, LaPorte and Marshall Counties were celebrated for their selfless giving. Highlighting the luncheon were nine award winners and six-time Grammy Award winner and singer/song writer, Amy Grant! The atmosphere was electrifying as Amy Grant shared about her journey with her mother and father who both were diagnosed with Alzheimer's disease. She also shared about her experiences with Notre Dame Coach Ara Parseghian and the loss of his three grandchildren to Neimann-Pick Type C disease which was so touching and moving. Amy also made the audience laugh and smile while she told stories and sang and played old favorites and new songs from her recently released CD entitled "How Mercy Looks from Here." It was a luncheon that the region will always remember!

Those honored at Age of Excellence are among some 65.7 million caregivers in the United States. The sea of these long-term caregivers contribute more than \$450 billion dollars of care to over 30% of the nation's population. With the number of those over age 65 doubling from 35.1 million to 72 million in just 30 years, the human value and economic impact of unpaid caregivers is phenomenal.

It is for these reasons, and in great appreciation, that REAL Services/Area 2 Agency on Aging host this annual event where ordinary people are recognized for extraordinary acts of kindness to loved ones and their communities. Saint Joseph Regional Medical Center was the Premiere Sponsor and co-host of this year's event. Other major contributors included: Memorial Home Care, American Senior Communities, Help At Home, Inc., Peacock and Company, Inc. and Stanz Foodservices, Inc.

Every person nominated was so very special; and the award winners along with their categories were:

- Education Award Mrs. Fox's Class of North Webster Elementary School
- Volunteer Group of the Year Parrot Heads of Michiana
- Caregiver of the Year Older Adult Vera Burger
- Business of the Year Home Instead Senior Care

# ... Was Awesome!



Pictured above: Steve Watts – Chairman of the Board of REAL Services; J. Larry Neff – President and CEO of Goodwill; and Amy Grant – performer, singer, song writer.

- Professional of the Year Janice Wilkinson
- Caregiver of the Year for a Disabled Person -Bethany Cullum
- Kimble Volunteer of the Year David Burke
- Volunteer of the Year Under Age 60 Tomme Owens
- Hoosier Lifetime Award J. Larry Neff.

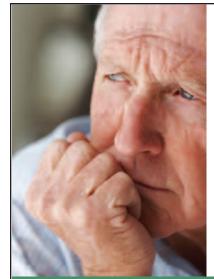
The Hoosier Lifetime Award winner, J. Larry Neff, is currently President and CEO of Goodwill Industries of Michiana, Inc. and has spent his life serving people both locally, nationally and abroad. He's been an active board member for many organizations whose focus is on serving and increasing the quality of life for people with a myriad of needs. Larry has served on the United Way Executive Council, Neighborhood Housing Service Board, Public Sector Welfare Committee, Workforce Investment Board in addition to holding many leadership positions at his church. Under his leadership at Goodwill Industries, a number of programs that now provide training and placement services were instituted and in 2012 these initiatives provided services to over 5,687 clients and 752 job placements in the St. Joseph County community. Larry's achievements have also been recognized by his receipt of the Community Foundation of St. Joseph County Leighton Award for Nonprofit Excellence and the South Bend



Community Hall of Fame compliment his award for the REAL Services Hoosier Lifetime Award. We're grateful for Larry Neff and people like him who make our community great. Mr. Neff has also been nominated for the State of Indiana's 2013 Governor's Service Award.

An honorary lifetime award was given to 92 year old Judge Robert L. Miller, III who has served in both the public and private sector most of his life. Judge Miller is a decorated military serviceman who received the Sagamore of the Wabash Award in 1966 which is the highest honor bestowed by the Governor of the State of Indiana.

Please check our REAL Services website frequently for the announcement of our 2014 Age of Excellence Luncheon date so that you too can share in this wonderful annual community event! Saying "Thank You" never gets old. Nominations are received all year-round and can be sent to Pam Harris, REAL Services, Inc., 1151 S. Michigan Street, South Bend, IN 46601, emailed to pharris@realservices.org or phone (574) 284-7104.





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# Room Makeover Becomes a House Makeover

### "Well, that's nice."

That was the response of Janice Conlon, winner of the Grand Prize in the 2013 REAL Room Makeover, when she was informed that she had won the Big PRIZE in the REAL Services REAL Room Makeover Raffle. The caller thought perhaps she didn't understand the message, so he responded, "Aren't you excited!" Janice responded, "I could scream if you want me to." We couldn't help but smile.

Janice has lived in her South Bend home for 42 years. A modest home in a modest neighborhood, her street is lined with very large trees, giving a real sense of establishment and permanency. Although in her early 70s, Janice only retired in November 2011 after working in the South Bend Post Office for 28 years. She served in the United States Navy as a hospital corpsman and then spent 11 years in the Naval Reserves. Other than military duty, only a six-year stint

with Bank of America in California took her out of Indiana.

Janice has deep roots and connections with Mishawaka High School from which she graduated. She regularly socializes with her friends ("go out with the girls") from high school days. In addition she works out three days a week at the Fitness Center to stay positive and busy. She also enjoys frequenting the Italian Clubs of Mishawaka.

Asked about why she entered the Raffle, Janice was quick to point out how much she appreciated REAL Services. "You do such good work," she said, recounting her personal experience of her mother receiving meals through Meals on Wheels and a professional assessment for nursing facility placement.



Janice has decided on a "house makeover" which will update and spruce and brighten up her whole house. You can see the gleam in her eye when she imagines what that might look like as she talks to the design representative from Peacock and Company.

Beyond the fun of our grand prize winner receiving a house makeover, the REAL Room Makeover Raffle grossed \$86,500. Net proceeds from the raffle will be used to support the Guardianship Program of REAL Services (a program that serves as legal guardian for elderly citizens who have no one else to advocate for them) and the Foster Grandparent Program (a program the places volunteer low-income "Grandparents" in schools and day care centers to mentor children).

REAL Services is grateful to everyone for a very successful event! Congratulations to all the prize winners, although in the eyes of REAL Services, everyone who purchased a ticket was a winner.

## WINNERS OF THE 2013 REAL ROOM MAKEOVER RAFFLE

Grand Prize Drawing August 28 Janice Conlon - South Bend, winner of the Grand Prize, a \$25,000 room makeover by Peacock and Company Ann Marie Thomas - South Bend Babs Maza - South Bend Tim Leman - Edwardsburg Michelle & Gary DeBeck - South Bend Pam Myers - Mishawaka Harry Paege - South Bend Joe - Steve & Bob - South Bend Sandra Zielinski - South Bend Joseph & Holly Hosinski - Granger Ed Druelinger - Granger Monique Weaver - Granger Cindy Frame - South Bend F. P. Nagy - South Bend Mary Esmay - Plymouth Marcy Mangus - South Bend Kym Allsop - Mishawaka John & Jo Broden - South Bend Kathleen Kish - South Bend Ray McQueen - South Bend Frank Kopetski - South Bend

Barbara Dzikowski - South Bend Jacqueline Vanderputten - South Bend James Cummings - Winfield, IL Anita Golba - South Bend Dorothy Kryder - South Bend Linda Lamar - South Bend Joseph Seliga - Plymouth Tammy Knitta - Goshen Michael Ernzen - Granger Kirt & Judy Scherer - South Bend Chelle Dolniak - Mishawaka Vincent Slaby - New Carlisle Steve Pischalko - Granger Shauna Luthringer - Lakeville Tim Leman - Edwardsburg Martin & Katheline Wills - South Bend Andrea Mather - South Bend Jay & Marylee Mattern - Walkerton Janice Seliga - Plymouth Wanda Miedema - Elkhart Debra Jessup - North Liberty John & Lisa Fredlake - Granger James Davis - Mishawaka Cheryl O'Connor - South Bend

Heather & Kevin Gary - Goshen Henry & Nancy Mascotte - South Bend Pat Smith - Niles Anne Cushwa - Brooklyn, NY Bryce Hughes - Russiaville, IN

Early Bird Drawing June 14 Margaret Parent - Osceola Mark Wobbe - Granger Julie Helman - South Bend Rilla Campbell - Granger Cathy Wannerton - Granger Michael Ernzen - Granger Nicole Lehman - South Bend Virginia Fish - Bristol

Summertime Drawing July 26 Birdie McElroy - South Bend Monique Weaver - Granger Michael Ernzen - Granger Mary Klinedinst - North Liberty Karen Koch - South Bend Joyce Stifel - South Bend Ronda & Craig Losee - Granger Jaci Harris - South Bend

The REAL Room Makeover Raffle simply would not be a success without the hard work of our raffle committee and area businesses. We deeply appreciate the support of these wonderful organizations that donated prizes to make the event a success. We are grateful. Thank you.

#### Z-Stone

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# Tips For Living Your Best Life As You Age

Beginning today, we are introducing an article on this topic.....what you can do, what to be aware of as you get older in order to live life to your highest potential. This will be a regular feature in each of our issues so watch this space for more information on how to "LIVE YOUR BEST LIFE AS YOU AGE". We will cover a variety of issues/topics relevant to older adults. If you would like to offer a suggestion on a particular topic, kindly drop us a line, an e-mail, or phone call to express your thoughts. REAL Services contact information can be found at the bottom of the Table of Contents page.

Many of us simply keep on doing the same things we've done all our lives, regardless of the impact it may have on our physical, emotional, or mental wellbeing. And let's face it, as we age, most of us go through changes that may require adjustments in our habits and routines. For example, we may have been exercise enthusiasts all of our lives, i.e. running, jogging, doing aerobics, or other cardio activities but now find that those activities are just too strenuous. It might be time to jog 3 miles instead of 5; or to change the high-impact aerobics to "water" aerobics; or to walk 5 miles instead of jogging. Our bodies change as we age so we need to make adjustments. However, DO NOT STOP exercising; merely change the duration and intensity of those exercises.

Another major concern we face as we age is our memory....we begin to wonder if we're experiencing dementia or something worse when we forget why we went into another room, or when we get to the grocery store and we forgot our list and just can't seem to remember those 20 items? Our first article will address those concerns and answer many of our questions. This is a great article to share with family and friends of all ages. I recently had breakfast with a "young" friend of mine and she said her husband is already worrying about his memory, afraid he's in the beginning stages of dementia. I cautioned her and suggested she do some reading on the subject maybe what he is experiencing is "normal"!!

Barbara Dzikowski, program director for Alzheimer's Services of Northern Indiana is wellversed on this topic and her article focuses on memory. Thank you Barb for being our first guest author in this new series!

# **Memory Loss:** What's Normal and Not Normal as We Age?

by Barbara Dzikowski, program director for Alzheimer's Services of Northern Indiana

### What's Normal?

We've all done it — missed an appointment, forgotten a name, or misplaced our keys. As we age, especially after the age of fifty, we all experience changes in memory from time to time. Common changes include increased difficulty with short-term memory (for example, remembering if you took your medication today or where you put down your reading glasses); a slowdown in the ability to recall information (for example, that "tip of the tongue" experience when a piece of information that you know temporarily slips your mind); and taking longer to learn new things (for example, trying to learn the computer or a new language for the first time as an older adult).

These changes are normal, and they can be annoying. Most of us refer to such times as "senior moments." But these sporadic glitches do not affect our ability to live our normal, day-to-day lives as we have always done.

### What's Not?

When memory changes get progressively worse and do begin to disrupt everyday life, this is a sign of something more serious that needs to be checked out by a physician. There are numerous things that affect memory, including many conditions that can be treated. And so, whether you are age 25 or age 125, it is vital to get a thorough diagnosis when memory problems arise.

Dementia is one of the most misunderstood medical terms in our modern society. "Dementia" is not really a medical diagnosis. Rather, it is an umbrella term to describe a cluster of symptoms, which are the loss of cognitive function (thinking,



reasoning, and remembering) that is so severe that a person is having trouble managing their day-to-day routine. Below are some of the common warning signs of dementia.

### Symptoms of Dementia

Even though we've all experienced most of these at one time or another, if these symptoms are happening frequently enough to disrupt daily life, it is important to consult a physician to determine the cause. Increased incidence of short-term memory loss (for example, frequently missing appointments, repeating the same stories or asking the same questions, not taking medications correctly)

Difficulty doing familiar tasks or using familiar objects (for example, problems with cooking, driving, using appliances)

Difficulty making decisions (for example, getting confused when sorting the daily mail, overwhelmed by a menu and can't make a choice) Communication changes (for example, frequently losing your place in the middle of a conversation, forgetting common words, difficulty naming objects, using the wrong word) Chronically losing or misplacing things (to the point you're spending much of your day hunting for familiar objects)

Getting lost or disoriented easily, sometimes even in familiar places Problems with managing finances and complicated tasks (for example, managing your checkbook and paying bills)

Problems with judgment, connecting the dots from A to B, or saying and doing things that don't make sense (for example, becoming easy prey to telemarketers, impulsive shopping or buying inordinate amounts of the same item, not being able to problem-solve)

Onset of changes in personality (When people are losing their cognitive abilities, they begin to live more by their emotions, rather than by logic. For this reason, you might experience sudden mood shifts throughout the day – sudden confusion, fear, anger, suspicion.)

Loss of interest, or unwillingness to participate, in previously enjoyed activities (for example, avoiding these activities rather than risk making a mistake in public or not being able to handle the situation.)

## Treatable Causes of Dementia

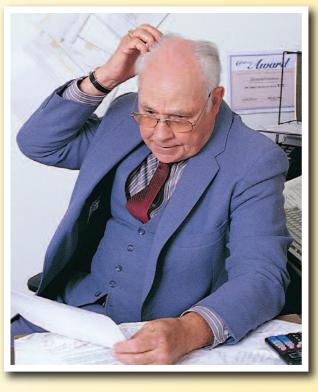
Dementia always has a cause. So, if you or someone you love is

experiencing the symptoms of dementia, it is wise to seek medical attention to determine what condition is causing your symptoms of dementia. The family physician is a good place to start. If he/she cannot determine a cause for your symptoms, the physician should refer you to a neurologist.

It is not difficult to "rule out" treatable causes of dementia or dementia symptoms that are caused by other chronic conditions. Some of the most common treatable causes of dementia are things like medications, depression, chronic stress, alcohol or drug abuse, chronic insomnia or sleep disorders, dehydration, vitamin B12 deficiency or other metabolic imbalance, low thyroid, infections (such as urinary tract infection), and poorly-controlled diabetes. Other types of chronic conditions, such as lung and heart problems, can also lead to poor oxygen levels in the brain, resulting in memory problems during certain periods of the day.

#### **Progressive Causes of Dementia**

"True" or progressive dementia is



caused by conditions like Alzheimer's disease, vascular (or multi-infarct) dementia, frontotemporal dementia, or Lewy-Body disease. Even though there is not yet a cure for any of these progressive conditions, there are some FDAapproved medications that can help manage symptoms. There is also a great deal that families and friends can do to support diagnosed individuals throughout the stages of their dementia and maximize their retained abilities and independence.

That's where agencies like Alzheimer's & Dementia Services of Northern Indiana come into play. For over thirty years, we have offered free programs and services to eleven counties in northern Indiana in the way of disease education, counseling, support, telephone helpline, written materials, website, newsletter, and more. Our primary goal is to support families who are dealing with dementia and teach them strategies, tips, and small changes they can make in their daily routine that can really go a long way to positively support loved ones with dementia. ⊘



Q: I know it's Open Enrollment, and I think I want to make changes to my Medicare Advantage Plan. How can I find out what plans are available for me and how much they'll cost?

**A**: You can always call the State Health Insurance Assistance Program (SHIP) at 1-800-452-4800 for help or to make an appointment to meet with one of our trained SHIP counselors for assistance.

Another great resource is the Medicare website,

www.medicare.gov. This website has a great search tool that allows you to find specific information within the site.

On the Medicare website, you will find the popular Medicare & You handbook. A quick way to find the information you're looking for in this handbook is to search for specific topics. You can find the handbook at this link.

http://www.medicare.gov/Pubs/ pdf/10050.pdf You can even sign up to receive an email with a link to the handbook each time it is updated. One of the most popular features of <u>www.medicare.gov</u> this time of year is the Plan Finder tool.

Whether you currently have a Part D Drug Plan, Medicare Advantage Plan, or Original Medicare, this online tool can help you compare your health care and prescription plan options side-by-side.

To get started, you will need to enter your:

- zip code
- name
- Medicare number
- effective for Part A date
- date of birth

The results will show you a comparison of premiums, deductibles, and additional information for each plan that is available. It will also tell you how that plan is rated.

Once you have chosen a plan, you can enroll in that plan right from the website. Your new plan will begin January 1, 2014.

From <u>www.medicare.gov</u>, you can sign up for Medicare, file an appeal or grievance, find suppliers of Home Medical Equipment, print important forms, and more.

Some of the other resources this website offers include:

- Find doctors & other health professionals
- Find nursing homes
- Find hospitals
- Find home health services
- Find dialysis facilities
- Find health & drug plans
- Find suppliers of medical equipment & supplies

You can visit the SHIP website <u>www.medicare.in.gov</u> as well for Open Enrollment Events in your area, important phone numbers, and links to Medicare related resources.

If you have questions about your Part D Plan, Open Enrollment, or anything else related to Medicare, contact SHIP for help. Call 1-800-452-4800, or visit www.medicare.in.gov. You can also find us on Facebook and Twitter.

SHIP is a free, unbiased counseling program provided by the Indiana State Department of Insurance. To schedule an appointment with SHIP, call 1-800-452-4800, TTY 1-866-846-0139 or visit www.Medicare.IN.gov to find your local site.



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## **REAL and Alzheimer's Services** Volunteer Opportunities!

*all individuals, groups, businesses, and families are encouraged to apply for one-time or ongoing projects . . .* 

# Come be an extension of our agency by volunteering for a REAL Services program

### **MEALS ON WHEELS DRIVER**

Help provide healthy meals to homebound seniors by delivering a hot lunch and prepared dinner to their home. You can deliver once a week or more.

St. Joseph County only. group | individual | ongoing projects

### **GUARDIANSHIP ADVOCATE**

Serve as an advocate for an elderly person for whom REAL Services is the legal guardian. Visit, check on their care, and advocate for their interests and preferences. *St. Joseph, Marshall and Elkhart Counties only.* 

group | individual | ongoing projects

### **SEASONAL PROJECTS**

- yard work rake, mow, trim bushes
- painting interior or exterior
- snow removal shovel and/or salt group | individual | ongoing projects

### **HOUSE CLEANING**

Help with simple house cleaning tasks, or gather a group to do "deep" cleaning and larger organizational projects

group | individual | ongoing projects

### NURSING FACILITY FRIENDLY VISITOR

Meet regularly with local nursing home residents that don't typically have visitors. Sit and talk, or incorporate creative projects.

group | individual | one-time or ongoing projects

### **SMP PROGRAM VOLUNTEER**

Help protect individuals and the future of our government programs by volunteering with the Senior Medicare Patrol program. This program empowers seniors to prevent health care fraud. individual | ongoing projects

### HANDYMAN

Help with simple household repairs. Tasks range from changing light bulbs to fixing a leaky faucet! group | individual | ongoing projects

### **OFFICE VOLUNTEER**

Help with mailings, brochures, and other administrative office tasks. Both small and large projects for various REAL departments.

group | individual | one-time or ongoing projects

### **GROCERY SHOPPER**

Purchase groceries for homebound adults. Get their list, shop for them, and unload the groceries. individual | one-time or ongoing projects

### **ADULT DAY SERVICES VOLUNTEER**

Assist with activities at Milton Adult Day Center. Volunteer once a year, weekly, or monthly.

### **HEALTH EDUCATION PROGRAMS**

Be a leader for workshops which educate individuals on how to live a more healthy life with chronic conditions; teach practical strategies to prevent falls. Programs scheduled in Elkhart, Kosciusko, LaPorte, Marshall, and St. Joseph Counties.



## **REAL and Alzheimer's Services Volunteer Opportunities**

### **SIGN ME UP!**

 $\Box$  I am  $\Box$  My group is interested in the following program(s):

Meals on Wheels			
Guardian Vol. Advocate	Name		
Nursing Facility Friendly Visitor	Name		
SMP Program	Address		
Seasonal Projects	Address		
Housecleaning			<b></b> :
Handyman	City	State	Zip
Office Volunteer			
Grocery Shopper	Daytime Phone		
Adult Day Services			
Health Education Program	E-mail		

**CONTACT US TODAY! Volunteer Department:** 1151 S. Michigan Street, P.O. Box 1835,

South Bend, IN 46634 (574) 284-2644 or (800) 552-7982 — www.realservices.org click on "volunteers"

Due to the sensitive nature of the clients we serve, it is Agency policy that we cannot utilize volunteers with any type of criminal history. Thank you for your understanding.

### Alzheimer's and Dementia Services of Northern Indiana Board of Directors

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– Anonymous

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## **REAL Services, Inc. Office Locations**

### Area Agency on Aging Case Management Offices

Elkhart County 3701 S. Main St. #1005 (120) Elkhart, IN 46517 (574) 875-0606

### LaPorte County

1700 Lincolnway Suite V LaPorte, IN 46350 (219) 324-4199 877-324-4199 (moving in February 2014 to Swanson Activity Center)

### Kosciusko County 720 Winona Av.

Warsaw, IN 46580 (574) 269-1173

### **Marshall County**

510 W. Adams St. Suite #260 Plymouth, IN 46563 (574) 936-3175

### St. Joseph County

1151 S. Michigan St. South Bend, IN 46601 (574) 284-2644 800-552-7928 (IN Only)

### **Caregiver Connection**

317 S. Kenmore St. South Bend, IN 46619 (574) 251-2590

## REAL Services Regional Kitchen for Independent Living

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REAL Services, Inc, is a not-for-profit corporation which serves elderly and individuals of all income levels in the counties of St. Joseph, Elkhart, LaPorte, Marshall, Fulton, and Kosciusko. The objective of REAL Services is to assist those we serve in maintaining their inde-



pendence to the maximum degree possible and finding meaning and satisfaction throughout their lives.

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