Our Mission
Jayhawk Area Agency on Aging, Inc. advocates on aging issues, builds community partnerships and implements programs within Shawnee, Jefferson, and Douglas counties to help seniors live independent and dignified lives.

- Is a 501(c)3 non-profit organization
- Is funded by tax-deductible contributions, federal funds, under state general funds and funds through local governments
- Does not discriminate on the basis of race, color, sex, national origin, age, religion, or disability

KDOA Secretary Shawn Sullivan enjoys hands-on interaction with seniors on his many nursing home visits. Here he visits with seniors at Shepherd’s Center in Cimarron, Kansas.

Kansas Secretary on Aging Shawn Sullivan: Fresh Face, Fresh Ideas

Do not be fooled by Shawn Sullivan’s youthful appearance. Although less than a year into his first term as Kansas Secretary on Aging, he is likely one of the best prepared individuals in recent history to handle the job. Sullivan hit the ground running. He solicited information from those working directly with seniors, formed active committees and has already instituted changes to improve the lives of both aging and disabled Kansans.

At the tender age of 16, Sullivan, whose mother is an RN, obtained his CNA (certified nursing assistant) certification and worked evenings, nights, weekends and summers in an Alzheimer’s unit at a nursing home in Douglas, Kansas. He continued to work in nursing homes throughout his high school and college years. When...
November is National Family Caregivers Month. Former first lady Rosalind Carter once said, “You have either been a caregiver, you are a caregiver, or someone will care for you.”

Reading the statement, I reflect on my early adult years watching my mother care for my great-grandmother and other elder family members, often wondering why the family called upon my mother to provide attendant care, homemaking, meal planner/preparer services, etc. However, as a young person I do not once recall thinking I would become my mother, caring for my elders.

My caregiving began fourteen years ago, caring for my terminally ill husband. Although I use the term “caregiving” I saw myself upholding my marriage vows as a spouse. Little did I know that, following his death, I would become my mother, caring for my elders.

I provided approximately four years of care to my mother with in-home dialysis treatment. I was a long distance caregiver to my step-father making weekend trips to Omaha these past two years, until recently when other family members stepped up to assist. I provided care to my father who, due to glaucoma, was nearly blind yet passed away this past year because of other health problems. But the one who has benefited more from my love and care these past eight years has been “Gran,” my 104-year-old grandmother.

Gran often said, if you want to get something done, you should ask the busiest person!!! She couldn’t have made a better selection!!! As a working caregiver, there are often sacrifices made, and stress can be overwhelming. I felt at times that I was the only person going through such a journey. Then my heart melted from the love and appreciation from my loved ones acknowledging all that was done to help them stay as independent as possible. Did I mention feelings of guilt for feeling so selfish?

One can ask how I handled everything while employed. After all, I was caring for three individuals, one out of state, at one time. No I didn’t wear a Wonder Woman suit, there was no magic potion, looking back it was simple: “Grace.” No it was not always easy. I would have the most beautiful pity party, but I had JAAA’s Caregiver Specialist who had a chair waiting on me five days per week!

Gran transitioned to a nursing facility at the age of 103. But my caregiving did not end.

Yes, I may no longer be the cook, homemaker or provide attendant care, but my visits continue, shopping continues, keeping abreast of her medical needs/treatment and handling her personal business continues.

Fortunately, Gran has no dementia and can direct me in her care. Her body has grown older, but her mind is clear. Gran states she doesn’t know why she is still alive. My simple response to her is that God is not finished with her yet. This petite lady has advised me, taught me, and is my biggest cheerleader by keeping me encouraged. She truly taught me that age is just a number because up until recently, Gran is not finished with her yet. Gran may be tired, but she is long from being finished.

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Gran may be tired, but she is long from being finished.

As her caregiver and a former caregiver to other loved ones, I have been blessed. But fellow caregivers, like Gran has told me and you’ve heard it so many times before, “Take care of yourself.”

A Message from Jocelyn Lyons, JAAA Executive Director

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Marsha Henry Goff, editor

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it came time in college to decide what he was going to do in life, he says simply, "I chose to make a difference."

Sullivan graduated from K-State with a BS in business and a minor in gerontology. He later received a master's in applied gerontology from the University of North Texas, one of the first academic departments of gerontology in the nation. He came to KDOA from Kansas Masonic Home in Wichita, where he served as executive director. Under his leadership, that home was honored by KDOA with a PEAK award for its efforts in culture change embracing person-centered care. He also served as executive director of Lyons Good Samaritan Center and Newton Presbyterian Manor when they won PEAK awards.

He has recently instituted PEAK 2.0, a program that changes PEAK from a "feel good" award to a five-step program that offers financial incentives to encourage nursing homes to become patient centered. Patient centered care provides a more homelike environment which gives patients more control over their daily lives, e.g., allowing them to decide when they go to bed at night, get up in the morning and when they eat.

Sullivan sees the challenges he faces as "great opportunities" to better seniors lives by enabling them to age in their homes where they are happiest. He clearly intends to change statistics that show 5 per cent of Kansans over 65 are in nursing homes, the 6th highest rate — or 6th worst — in the nation. The national average is 3.8 per cent. Curiously, it appears to be the most populous Kansas counties, where services abound to help seniors remain in their own homes, that have the highest rates of seniors in nursing homes.

His best advice to seniors and their prospective caregivers is: "Don’t wait for a crisis. Be prepared for the time when you will need long-term care and know what help is available before you need it."

Sullivan has been working with Lt. Gov. Colyer, KDHE Secretary Moser, SRS Secretary Siedlecki, and Division of Health Care Finance Director Andy Allison to re-shape the state’s Medicaid program. He recently announced two main objectives of KDOA:

1. Improve quality care and services and achieve savings by integrating and coordinating chronic care through a holistic approach, across multiple settings, focused on outcomes.
2. Align financial incentives to focus on outcomes and prevent premature placement in nursing homes.

Updating the Medicaid program is essential to better serve seniors and preserve the system. Because of KDOA Secretary Sullivan’s long, hands-on experience in caring for older Kansans, our state’s seniors can be confident that any changes made will better serve their needs.

[Editor’s Note: You may pick up a copy of Explore Your Options at Jayhawk Area Agency on Aging, 2910 Topeka Boulevard, Topeka, KS, various locations, including senior centers, throughout the communities JAAA serves, or phone 235-1367 in Topeka or 1-800-798-1366 outside Topeka to have a copy mailed to you.]
For the last three years, Jean Stueve, JAAA Fiscal Supervisor, has been braving the frigid waters of Longview Lake in Kansas City, Missouri, while participating in the Polar Bear Plunge. The annual “Celebration of Polar Bears” benefits Special Olympics, a cause dear to Stueve’s heart because her 16-year-old niece, Leah, who has autism, benefits greatly from the social outlet Special Olympics provides. Prior to taking the plunge, Stueve solicits donations from family and friends to support the program.

“Special Olympics doesn’t just benefit the participants, but their families as well,” says Stueve, who plans to take the plunge again on January 28, 2012. She admits that she and other “polar bears” do not stay in the water long. Dressed in colorful costumes, she and other participants dash through the freezing water to high-five wet-suit-clad water rescuers positioned in a line in four-foot deep water.

“You can’t believe how cold the water is!” Stueve exclaims. “It takes your breath away, but, as soon as we are out of the water, support people are there to wrap towels and blankets around us, escort us to heated tents and give us warm beverages.”

She is grateful that Special Olympics has enabled her sister to bond with the parents of other Special Olympians, but it is clearly for love of Leah that Jean Stueve takes the icy plunge.
As I travel Kansas, I hear from folks who have tightened their belts, and they want their Government to do the same. Back in April, the House passed our budget, the Pathway to Prosperity, which does just that. Our plan sought to end budget gimmicks, cut spending by $6.2 trillion, reduce the deficit by more than $4 trillion, simplify our tax code, and establish a plan to modernize Social Security, Medicare and Medicaid. While not perfect, this was a real plan with real solutions to real problems, and Kansans deserve a fact-based conversation about it. Yet, much of the talk around our plan, specifically the changes to Medicare, have been based on misinformation and scare tactics.

Medicare will always be one of the most important social contracts with the American people, but it is a 1965 health care delivery system operating in the 21st Century. We need to preserve Medicare for today’s seniors, but modernize it for the next generation of Americans. To ensure that current seniors’ benefits are unchanged, Congress must begin making these changes soon, and this budget was an attempt to do so.

Under our plan, anyone over the age of 55 will see NO CHANGES whatsoever. However, when folks 55 and under reach retirement age, they will be enrolled in a new kind of health care program similar to that members of Congress enjoy. These future Medicare recipients will choose from a list of guaranteed coverage options and given the ability to pick the plan that works best for them. Depending on income, Medicare would pay a portion of the premium on that plan. The “premium-support payment” would be adjusted so those with lower-income would receive more assistance and wealthier beneficiaries would receive less.

While not easy, fixing this problem is a necessity. If we want our children and grandchildren to have the same opportunities we have enjoyed, we must act quickly to restore solvency to our budgets and modernize the social safety nets.
In 1986, at an age when many couples are thinking of retirement, Tom and Marcella Ryan of Valley Falls converted their barn into a 9-room bed and breakfast. “We were phasing out of farming,” Marcella explains, “and initially thought about building apartments so we’d have rent income. My sister suggested a bed and breakfast instead. At the time, there were only six in the whole state.”

 Appropriately naming their bed and breakfast “The Barn,” the couple doubled its size to 18 rooms in 1989 by building an addition which also included a large indoor heated swimming pool and hot tub. The barn currently boasts 21 rooms and a host of repeat guests who return year after year to enjoy The Barn’s beautiful and restful atmosphere, both inside and out. The 35-acre grounds are graced with a water garden, flowers, hammocks and swings. Indoors, art, plants and comfortable furnishings invite guests to read, play games or visit. Guests are served delicious breakfasts and dinners and are allowed to bring their own food for lunch and snacks.

 The Barn has been a family affair since its inception. Daughter Patricia, now a nurse at Stormont Vail, worked in the bed and breakfast’s office and as head cook for 22 years. Son Tom III, like his parents, does
everything required in the operation of a bed and breakfast, but Tom notes that his son is exceptionally good at computers. You can see Tom III’s work and read more about The Barn at http://www.thebarnbb.com.

Marcella notes that The Barn hosts church groups, scrapbookers, rug hookers, beading groups and quilting guilds who meet to quilt. It is also a popular site for family reunions and recently served as the gathering place for one family celebrating their matriarch’s 100th birthday. The Barn has been the site of 55 weddings and receptions, but consideration for other guests no longer allows those celebrations. During its years in business, The Barn has hosted over a half-million guests.

Tom and Marcella Ryan have no plans to retire. Tom says, “Marcella and I love the business and really enjoy the guests. We get so many repeat guests that we feel like everyone is family. We are still running about 16,000 guests per year and are already taking some reservations for 2015. As we slow down and are unable to carry our work load we just hire more people.”
By Marilyn E. Thomas
JAAA Family Caregiver Specialist

It’s Thanksgiving week and you come home to see Dad who is now a widower and lives alone. Your most recent visits have gone well; Dad looked great, the home has been fairly clean and tidy. Now that it has been a year since Mom’s passing, you are noticing some things going on with Dad and the household. This is a typical scenario with adult children living long distance from an aging parent or loved one.

Contacting the Area Agency on Aging in the area is your first point of reference when seeking options in helping your loved one to remain living independently in their home. Often times older adults just need a little assistance to accomplish this.

Being a caregiver can be challenging and stressful. But it can also be rewarding. Supporting or helping an older adult stay independent requires looking at what is needed. Some ideas to help you get started are to ask questions about meals … does he or she prepare them or can you get meals delivered, such as “Meals on Wheels.” You can ask if the neighbors are involved in providing services. Be sure you include your loved one’s involvement in the decision-making process. Other issues to be addressed are transportation, home upkeep, safety, money and bill paying, as well as personal care and mobility.

Some caregivers provide 24-hour a day care to their loved one and those caregivers need to take care of themselves too. The National Family Caregivers Association offers three tips for family caregivers: 1) Believe in Yourself — try to maintain a positive attitude by recognizing your strengths and limitations; 2) Protect Your Own Health — both physical and emotional health; 3) Reach out for Help — rather than being a sign of weakness, asking for help demonstrates strength and awareness of your own abilities and limitations.

Caregiver support groups can provide relief. Caregiving can also be rewarding in developing a stronger relationship with your loved one and you can find joy and small pleasures in doing things like sharing a meal together, taking time to laugh and getting to know more about the other person, and building memories that last a lifetime.

November is National Caregivers Awareness Month. You can support a caregiver by of-
How to be a patient advocate

By Marsha Henry Goff

A parent quickly learns to be a caregiver because caring for a child’s needs is the natural thing to do. But when the family flips upside down and the parent who cared for the child now needs the child to care for him or her, the reversed roles seem anything but natural to both parent and child.

Giving up control to a child is a difficult thing for a parent to do. Taking control is equally difficult. Fortunately, giving up or taking total control is rarely necessary and everyone is happier when the patient and caregiver can work together as a team.

When I first began accompanying Mom to her doctor’s appointments, I noticed the doctor often addressed his remarks and questions to me. When that occurred, I turned to Mom and posed the question to her or, if I answered, added, “Mom could have answered this, but she didn’t hear your question.”

It is demeaning to an older person to be “talked over” rather than “talked to” so do not allow that to happen. Respect is a two-way street.

A patient advocate must learn to be politely assertive. Do not be intimidated if you lack medical training because your intimate connection and knowledge of your parent can prove invaluable to the doctor in diagnosing problems and determining treatment. If you think something is wrong — either with diagnosis or treatment — it usually is.

Many patients and caregivers are reluctant to seek a second opinion with regard to a medical diagnosis, but a diagnosis labels the patient and sometimes the labels are wrong. Up to 30% of patients are given a different diagnosis when they consult another doctor for a second opinion. My friend Jane’s mother was diagnosed with Alzheimer’s Disease and prescribed the drug Aricept. When it did not seem to be helping, Jane made an appointment with a geriatrician who removed her mother from Aricept and several other of the many medications she was taking. Her mother’s condition improved.

Should you always get a second opinion? Of course not. However, if the treatment does not appear to be working or the patient’s condition is worsening, as was the case with Jane’s mother, a second opinion may be a good idea.

Both patient and caregiver should know what information is in the patient’s written medical records. I was on vacation in California when my sister Vicki phoned to tell me Mom was in the hospital and had weighed in at 70 pounds.

“That can’t possibly be right,” I said, “I’ve only been gone two days.”

Our late mother was a small woman whose normal weight was 90 pounds. I called Mom in her hospital room and she, highly indignant, said, “They weighed me in a sling and I told them my foot was on the bed.”

I insisted they reweigh Mom and the next day when she was weighed, her weight was near normal. However, until I had the inaccurate 70 pound weight removed from her records, several medical personnel who subsequently saw her — a dietitian, a therapist, even her orthopedic surgeon — diagnosed her with “failure to thrive” based solely on her erroneously recorded weight of 70 pounds.

The therapist at a nursing home, where Mom was sent for physical therapy before returning home, told me my mother would be in the nursing home long term. She had not even seen Mom, but was relying solely on the “failure to thrive” diagnosis in Mom’s medical records. Happily, within two weeks, Mom was back at her home where, by her choice, she lived alone although using an electric wheel chair.

Did I always make the right decisions as Mom’s caregiver and patient advocate? No, I did not. But I tried and that is all Mom expected of me. And it is all that any caregiver should expect of him- or herself.

Caregiver

CONTINUED FROM PAGE EIGHT

I learned from my mother . . .

Amazing Aging strives to provide readers with the information they need to live independent and productive lives. We also seek to feature stories of seniors who are active as workers, volunteers or engaged in hobbies. If you know a senior you would like to see featured in a future issue, please contact editor Marsha Henry Goff at mhgink@netscape.net or write to her in care of JAAA, 2910 SW Topeka Boulevard, Topeka, KS 66611.

AMAZING AGING!
Craig Weinaug writes a message to Leo, who is sitting in the wheeled cart from which he sold pencils and other items.

The unlikely friendship that helped produce an Oscar-nominated film

By Marsha Henry Goff

The long-ago friendship that developed between Leo Beuerman, a crippled dwarf, and Catherine Weinaug, a KU professor’s wife, was surprising to everyone except Catherine’s son, then a boy but now Douglas County Administrator Craig Weinaug. He says he was never surprised at anything his mother did. She had a strong, energetic faith and never shied away from recruiting others to help her move mountains.

Leo was born on January 6, 1902. By age 10 he began to lose his hearing and by 28 he was deaf. At maturity, he stood 3 feet 3 inches tall and weighed 60 pounds. He invented devices — including a mini-elevator that helped him up and down the steps at his rural farm house near Lakeview — where he lived with his brother and sister.

With the help of his nephew, Leo adapted an ancient tractor so he could drive to town and back, carrying the little cart from which he conducted his watch repair business and sold pencils and other items on the sidewalks of downtown Lawrence. Occasionally, he would stay in town all night, sleeping in his cart. One night as he was sleeping, he was pulled from his cart and brutally beaten and robbed. He suffered head cuts and other injuries and was hospitalized.

When tender-hearted Catherine read of the attack, she sent flowers to Leo at the hospital, but felt she needed to do more. One day, learning he had been dismissed from the hospital, she followed vague directions given to her by a store clerk to find Leo’s home and visit with him. She was appalled that Leo transported himself about the two-room house on a small wheeled platform and slept leaning against a wooden orange crate. She conversed with him by writing notes on the pad he pressed into her hands.

He was thrilled to have company and asked her, “Will you come again? Will you be my friend?”

“Our friendship is just beginning,” Catherine answered and meant it. She enlisted help from her husband, Charles, and sons, Carl and Craig, as well as members of a Sunday School class of university students she taught. One low income individuals may be eligible for financial assistance in paying Medical Part A & B premiums, co-pays and deductibles as well as help in paying Medicare Part D (prescription drug) expenses.

Untidely, Catherine Beuerman followed the directions to find Leo's home and visit with him. She was appalled that Leo transported himself about the two-room house on a small wheeled platform and slept leaning against a wooden orange crate. She conversed with him by writing notes on the pad he pressed into her hands.

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Sunday, the Weinaugs took Leo to church where he sat between two students who wrote condensed versions of the pastor’s sermon for Leo. Then he went to the Weinaugs’ home for dinner.

He had his first tub bath there. Charles lifted Leo into the tub and left him splashing with glee, while Catherine washed and dried his clothes. “They were almost dry before Leo called Charles to help him out of the tub,” Catherine said. “I was beginning to fear he had drowned!”

Leo emerged from his long soak with a big smile on his face and, according to Catherine “left enough dirt in the tub to plant flowers.”

He ate dinner seated on three encyclopedias. And when he spent the night, sleeping upright while resting his back against an overstuffed chair instead of his orange crate, his earsplitting snores kept the Weinaugs awake and evoked howls from the family’s dog.

Leo became a frequent visitor at the Weinaug home and one day Catherine mentioned to her neighbor, Russ Mosser, who was part-owner of Centron Films in Lawrence, that Leo’s story might make a good movie. She furnished Mosser with Leo’s autobiography, which she had encouraged him to write, and photos of Leo.

Trudy Travis, a gifted writer who recently died at age 90, was assigned to write a script. She followed Leo, watching him struggle with chains to lower and raise his cart onto his tractor and seeing him interact with his customers, most of whom were children.

“Leo Beuerman,” a 14-minute short documentary, was nominated for an Oscar in 1969. The film is still available on DVD and is often used as a motivational tool by businesses.

Leo was totally blind during the last years of his life and friends communicated with him by writing on his back. He lived in a nursing home and helped support himself by making leather key chains and bead necklaces which were sold in local stores.

A bronze plaque, sculpted by artist Jim Patti, sits in the sidewalk at the northeast corner of 8th and Massachusetts where Leo frequently sat in his cart. The wording on the plaque was objected to by some who believed the words represented a negative stereotypical view of handicapped persons. Leo’s friends argued that there was no shame in any form of honest labor and said the words were simply Leo’s way of identifying himself. The plaque features an image of Leo in his cart along with his words reproduced in his own handwriting: Remember me — I’m the little man gone blind. I used to sell pencils on the street corner.

Both Leo and Catherine are gone now, but neither will be forgotten by those who knew them and the story of their unlikely friendship.
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