

# Arkansas Community Living Program

## Consumer Narratives

Consumer A is a 77 year old male who has had a stroke. He is confined to an electric wheelchair and lives with his wife who also uses a wheelchair. He has been diagnosed with hypertension, Parkinsonism, diabetes, arthritis and dementia. Because their income limits them in hiring a caregiver, and their family resides in Illinois, they encounter stressful situations everyday. He needs help bathing, dressing, toileting, eating, transferring, and cannot walk. He also needs help with housework, meal preparation, managing money and medications, shopping, and transportation. The Cash Expenditure Plan (CEP) allowed for 8.5 hours of care/week at \$10.00/hour. The couple was relieved at the aspect of being able to afford some of the proper care needed.

Consumer B is 73 year old female who has Alzheimer's. Her daughters take turns with care giving duties throughout the week. She has been diagnosed with seizures, arthritis, diabetes, emphysema/COPD/asthma, and thyroid disease. One daughter works as a hair stylist and has had to cut back on her hours because of the care she provides. This has put an extra burden on her household. Her mother requires constant supervision and help with bathing. She also needs help with housework, meal preparation, managing money and medication, shopping, and transportation. The CEP allowed for 12 hours of care/week at \$7.00/hour. The daughter is thankful for the extra funds available to make up for the hours missed at the salon.

Consumer C is an 81 year old female married to Consumer D, an 86 year old male. She has been diagnosed with Arthritis. He has had a stroke and been diagnosed with arthritis and Alzheimer's. Their daughter drives 60 miles everyday, roundtrip, to take care of their daily needs. She is unable to work so her income suffers in order for her to take care of her parents. Her mother needs help with bathing, toileting, eating, transferring, walking, and dressing. Her father needs help with bathing and eating. They both need help with meal preparation, housework, managing medications and money, transportation, and shopping. The CEP allowed for 12.25 hours of care/week at \$7.00/hour for each individual. It has provided their very thankful daughter the income she needed in order to help keep her parents out of an institution.

Consumer E is a 79 year old female who has atypical Parkinsonism. She has been diagnosed with hypertension, arthritis, and osteoporosis. Her daughter and grandchildren moved in to help take care of her. Her mother needs help with housework, meal preparation, managing of medication and money, shopping, and transportation. Her mobility is good but occasionally she does need to use her walker. Her daughter helps with everything that is needed and is unsatisfied with the support received from the family. The CEP allowed for 8 hours/week at \$7.00/hour. Her daughter is grateful for the finances because she receives very little financial support otherwise.

Consumer F is a 73 year old male who has diabetes. He has also been diagnosed with hypertension and thyroid disease. He lives with his wife who has difficulty hearing and is physically weak. They have been paying a caregiver to help and were afraid they would have to

stop paying her due to lack of finances. He needs help with transferring, bathing, walking, toileting, and dressing. He also needs help with housework, meal preparation, shopping, and transportation. The CEP allowed 8.5 hours of care/week at \$10.00/hour. They were thrilled to be able to continue the care giving arrangement.

Consumer G is an 81 year old female who has Alzheimer's. She has also been diagnosed with hypertension and osteoporosis. She lives with her daughter and son-in-law who both work full time. They are afraid of leaving her at home during the day because she could do something to harm herself. She is also in need of constant supervision because she has a tendency to wander. However, because of finances they have no choice but to leave her alone during the day. She needs help with bathing, housework, management of finances and medication, shopping, meal preparation, and transportation. The CEP allowed for 6.5 hours of care/week at \$10.00/hour. The family is relieved that they can now hire someone to stay with her during the day.

Consumer H is a 95 year old female who has Alzheimer's. She has also been diagnosed with arthritis and osteoporosis. Both her daughters and son-in-law take turns staying with her throughout the week. One daughter is unable to continue the caring activities due to a decline in health. The other daughter lives 53 miles away and travels back and forth throughout the week. Their mother needs help with bathing, dressing, and eating. She also needs help with housework, management of medication and finances, meal preparations, transportation, shopping, and using the telephone. The CEP allowed for 12 hours of care/week at \$7.00/hour. The family is thankful for the financial support received during this trying time and believes this will help keep their mother from going into a nursing home.

Consumer I is a 70 year old male who has had a stroke. He has also been diagnosed with hypertension, diabetes, thyroid disease, and Alzheimer's. He lives with his wife who must keep a constant watch. She cannot have time to herself for fear that he may wander. Unfortunately they do not have the finances to pay a caregiver. His wife's health is declining and she has feelings of depression and stress. The CEP allowed for 14 hours of care/week at \$7.00/hour. This past weekend was the first time she had been able to leave the house by herself and she never had to worry about her husband's care. She is extremely grateful for the financial means to pay a caregiver.

Consumer J is a 65 year old female who has had a stroke. The left side of her body was left partially paralyzed from the stroke. Her daughter helps take care of her daily needs. She needs help with getting dressed and bathing. She also needs help with housework, transportation, shopping, and preparing meals. The CEP allowed for 12 hours of care/week at \$7.00/hour. She was very happy that she could finally be able to pay her daughter money for the care she was already giving.

Consumer K has experienced bilateral lower extremity amputation and was alone all the time most days (MDS-HC rating at severe impairment). Before enrolling in the NHDG Program, Mr. X could not afford to pay his daughter to help him and she needed an income to meet her own needs. He had fallen several times while transferring from his lift chair to his wheel chair. On one occasion, there was a power outage, and he fell from the lift chair while trying to climb out because it was stuck in the reclining position. He had to stay where he fell on the floor all night.

His daughter and granddaughter were stopping by two days a week, but they both have part time jobs. With the price of gas, they could not check on him as much as they wanted. Mr. X uses the grant to pay his daughter to help her afford the trips to come. He says that now he feels more secure, knowing that his daughter can come in and help him more often. The Care Manager reports a significant change in his emotional status and overall well being.

Consumer L lives alone and is in poor health (MDS-HC rating at severe impairment). Her granddaughter contacted the Care Manager while visiting from Tennessee. She was referred her grandmother's physician. Ms. Y is alone most of the time and her family lives out of town. She is a diabetic and had lost a significant amount of weight since the granddaughter's last visit. Now that she has the NHDG Program (Enrolled in June, 2008), she has an aide to prepare meals and help with her housekeeping. She is back to a more healthy weight and appears to be in a much better frame of mind. Through reduction of isolation and encouragement, Ms. Y's quality of life and immediate prospects have greatly improved.

Consumer M - Doctors told Ms. Z she has six months or less to live. She moved in with her daughter and son-in-law when it became apparent that she could no longer care for herself. Her daughter helped her mother care for Mr. Z two years ago when he was dying of cancer. Soon after he died, Ms. Z became ill. This daughter has watched as her mother has become a shadow of the vibrant woman she was in the not so distant past. Ms. Z (MDS-HC rating of severely impaired) requires twenty-four hour care and her daughter wants to take care of her mother, but was becoming increasingly worn out from the day to day trauma of caring for a critically ill loved one. She calls the Care Manager on many occasions with the need to talk about her role as a caregiver and the stress involved. The Care Manager has made multiple home visits to talk with her; to listen to her thoughts and fears about the prospect of losing her mother. The Care Manager offers practical advice when indicated and facilitates problem solving when something can be done. The NHDG program has made it possible for this daughter and her husband to have some much needed time alone together and has relieved the Participant from feeling like a burden to her daughter and son-in-law. They all have a greater peace of mind knowing that there is someone else to help when they feel the need for a break from each other.

Consumer N is a 69 yr old white widowed male who lives alone in an apartment. He had been turned down twice for ElderChoices but due diagnosis of COPD, CHF, HTN and multiple other diagnosis he was in great need of assistance. He also had several hospitalizations during the past year due to COPD and CHF. He is confined to a motorized wheel chair and is o2 dependent. He has no family support and is unable to pay for in home assistance. He does have a friend who helps him free of charge with shopping and sometimes house work but she is elderly herself and is limited to what she can do. Prior to him starting the Nursing Home Diversion Program his hygiene was very poor because he was afraid to get into the bath tub due to being to unsteady and shaving was sometimes impossible for him due to his hands shaking, his apartment was also cluttered in unclean. Since starting the Nursing Diversion Program it was noted during monthly monitoring visits that his hygiene is much better and is home his much cleaner and less cluttered. His room was even rearrange by is paid assistance to make it easier for him to move around his home. He has been able to live more independently by hiring his own assistant and voices being very pleased overall with the program. Financially, he may be able to maintain himself in home for a longer period of time with the assistance from the NHD grant.

Consumer O is: is an 82 yr old white widowed female who lives alone at home. She was in need of help but did not qualify for ElderChoice. She has a seizure disorder and often will have black out spells due to the seizures which often results in her suffering serious falls causing multiple fractures followed by hospitalizations and rehab stays. She requires the use of a rolling walker to aide in mobility. Upon the assessment visit physical therapy was giving her in home therapy due to weakness and recent falls. She has a niece who helps her free of charge at times with shopping and taking her for doctor appointments. She has paid help that comes in and cleans her home and helps her with personal care but she stated on the assessment visit that she had to have the help the stay at home but she was depleting her savings having to pay for her assistance and felt the Nursing Home Diversion Program would benefit her. Since starting the program, on monthly monitoring visits, she stated she was pleased that she no longer had to spend down her savings to pay for assistance. She stated that if she had to spend all her savings paying for assistance, once her savings was depleted she would have no choice but to go into the nursing home because she cannot live independently at home without help. She stated the Nursing Diversion Program was allowing her to financially remain in her home for a longer period of time.

Consumer P is a 63 yr. old b/m. He lives alone. He has MS and has great difficulty in doing any activities of daily living. He currently does not have an aide as last one that employee packet was sent in on called and said he had changed his mind about working for client. CM talked with client about having agency help but he still wants to hire an individual. Client really needs this help but seems to not want to understand the limitations this grant and aides have.

Consumer Q is a 68 yr. old w/f. She lives with her husband in a rural area. Client has several health problems including severe lung disease. She and her husband had been hiring someone privately to help but stated they had about run out of funds to do this. The NHD grant funds are helping to maintain client in her home.

Consumer R is a 69 yr.old w/m. He lives with his wife who is still working. He had a heart attack and stroke several months ago and this affected his memory and decision making. Client's wife said he cannot be left alone for this reason. She said they had checked into private pay agencies but could not afford this. She said the NHD grant is a great help to them.

Consumer S is an 81 year old male who has colon and renal cancer. He has also been diagnosed with congestive heart failure, hypertension, and arthritis. He lives with his daughter who takes care of his needs. He needs help with bathing, toileting, walking, transferring, and dressing. He also needs help with housework, managing money and medication, meal preparation, and shopping. He was awarded 18 hours of care/week. The CEP allowed for 11.5 hours of care/week at \$6.55/hour.

Consumer T is a 67 year old male who, because of NFD, is confined to a wheelchair. He has also been diagnosed with hypertension, peripheral vascular disease, and arthritis. He must use an indwelling urinary catheter. He lives with a friend who helps take care of him, but also has a full time job. He needs help with bathing, toileting, transferring, and walking. He also needs help with housework, managing medications, meal preparations, shopping, and some transportation.

He was awarded 14 hours of care/week. The CEP allowed for 9.5 hours of care/week at \$9.00/hour.

Consumer U is a 70 year old female who has Acromegaly. She has also been diagnosed with Barrett's, coronary artery disease, hypertension, arthritis, depression, diabetes, and Emphysema/Asthma. She lives by herself and depends upon her neighbor to take care of her daily needs. She needs help with bathing, toileting, walking, and dressing. She also needs help with housework, shopping, and transportation. She was awarded 12 hours of care/week from the assessment. The CEP allowed for 8 hours of care/week at \$10.00/hour.

Consumer V is an 89 year old female who had a stroke and cannot use the left side of her upper body. She has also been diagnosed with congestive heart failure, hypertension, diabetes, and renal failure. Her son lives with her and takes care of her full time. He does not have a job because he has to take care of her. She needs help with bathing, toileting, walking, transferring, and dressing. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 19 hours from the assessment. The CEP allowed 8.5 hours/per of care at \$10.00/hour.

Consumer W is a 72 year old female who has Osteoporosis. She has also been diagnosed with hypertension, arthritis, and macular degeneration. Her son lives with her and takes care of her daily needs. She needs help with bathing, walking, transferring, and dressing. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 12 hours/week from the assessment. The CEP allowed 9 hours/week at \$9.00/hour.

Consumer X is a 74 year old female who has emphysema/COPD/asthma. She has also been diagnosed with arthritis. She lives alone and has her daily needs taken care of by friends and family. She needs help with bathing, dressing, toileting, walking, and transferring. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 13 hours from the assessment. The CEP allowed 10 hours/week at \$8.00/hour. She now has the available funds to hire a more permanent caregiver.

Consumer Y is a 78 year old female who is bedridden. She has been diagnosed with hypertension, arthritis, diabetes, and has had a stroke. She lives with her siblings and they take care of her needs. She needs help with all ADL's and IADL's. She was awarded 40 hours/week from the assessment.

Consumer Z is an 85 year old female who has had congestive heart failure. She has also been diagnosed with peripheral vascular disease, arthritis, gout, and thyroid disease. Her daughter, who has a full time job, takes care of her needs. She needs help with walking, transferring, bathing, dressing, and toileting. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 13 hours from the assessment.

Consumer A is an 89 year old female who has had congestive heart failure. She has also been diagnosed with cataracts and hypertension. She needs help with bathing, walking, and

transferring. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 13 hours from the assessment.

Consumer AB is an 84 year old female who has GERD. She has also been diagnosed with hypertension and arthritis. She lives with a friend who takes care of her daily needs. She needs help with bathing, toileting, walking, and transferring. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 11 hours/week from the assessment.

Consumer AC is a 95 year old female with hypertension and arthritis. She lives alone and her daughter, son-in-law, and granddaughter take turns taking care of what she needs. She needs help with bathing, toileting, walking, and transferring. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 11 hours/week from the assessment.

Consumer AD is an 87 year old female with arthritis and osteoporosis. Her grandson has recently moved in with her in order to help her with daily needs. She needs help bathing, walking, and transferring. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 15 hour/week from the assessment.

Consumer AE is a 75 year old female who was diagnosed with Alzheimer's. She has also been diagnosed with arthritis, osteoporosis, and COPD. She currently lives with her husband who takes care of her, but because of his ailing health his help is limited. When he cannot help, their daughters take turns taking care of whatever she needs. She needs help with bathing, toileting, walking, transferring, and dressing. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She needs constant supervision for her safety. She was awarded 24 hours/week from the assessment.

Consumer AF is an 89 year old female who has Alzheimer's. She lives by herself and is taken care of by her daughter and friends of the family. She is in need of constant supervision. She also needs help with walking, housework, managing medication, meal preparation, shopping, and transportation. She was awarded 14 hours from the assessment. The CEP allowed for 8 hours of care/week at \$10.00/hour.

Consumer AG is an 83 year old female who has Alzheimer's. She is in need of total care requiring help with bathing, toileting, walking, transferring, dressing, and eating. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She lives with her son and daughter in law who take care of her needs. She was awarded 50 hours/week from the assessment. The CEP allowed 9.5 hours/week at \$9.00/hour.

Consumer AH is a 77 year old female who has Alzheimer's. She has also been diagnosed with hypertension and arthritis. She lives with her son who takes care of her daily needs. She needs help with bathing, toileting, walking, transferring, dressing, and eating. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 37 hours from the assessment. The CEP allowed for 9 hours of care/week at \$9.00/hour.

Consumer AI is an 87 year old male who has Parkinsonism. He has also been diagnosed with arthritis, diabetes, and neuropathy. He lives with his wife who takes care of his daily needs. He needs help with bathing, toileting, walking, transferring, and dressing. He also needs help with housework, managing money and medication, meal preparation, shopping, transportation, and using the telephone. He was awarded 27 hours from the assessment. The CEP allowed for 4 hours of care/week at 8.00/hour. He is also saving \$150.00/month to help cover the costs of prescriptions later in the year. Finally, he has put aside money for reimbursement every month on medication he is currently paying.

Consumer AJ is an 85 year old female who has Diabetes. She has also been diagnosed with IBS. She lives with her disabled son who helps her with what he can. She needs help with bathing, toileting, walking, transferring, and dressing. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 14 hours/week from the assessment. The CEP provided \$391.81 to go towards Home Health care.

Consumer AK is an 81 year old female who has Alzheimer's. She has also been diagnosed with diabetes and renal failure. She lives with her friend who takes care of her daily needs. She needs help with dressing, housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 19 hours from the assessment. The CEP allowed for money to be spent on reimbursement for medication and also money to be saved for later in the year when she goes in the donut hole.

Consumer AL is an 84 year old female who has Emphysema/COPD/asthma. She has also been diagnosed with hypertension, arthritis, osteoporosis, neuropathy, and fibromyalgia. She is incontinent with her bladder. Her daughter takes care of the daily needs. She needs help with bathing, walking, transferring, and dressing. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 20 hours from the assessment. The CEP allowed for reimbursement for medication monthly.

Consumer AM is a 78 year old male who has Alzheimer's. He has also been diagnosed with hypertension and irregular pulse. He lives with his wife who has to keep a conscious eye for fear that his decision making is unsafe. She takes care of his daily needs. He needs help with bathing, dressing, and toileting. He also needs help with housework, managing money and medication, meal preparation, and shopping. He was awarded 24 hours from the assessment. The CEP allowed for savings to go towards bathroom renovations as well as 6 hours of care per week at \$9.00/hour to use for respite.

Consumer AN is a 60 year old male who has had a stroke. He has also been diagnosed with hypertension, arthritis, diabetes, and COPD. He lives with his wife who takes care of his daily needs. He needs help with bathing, toileting, walking, transferring, and dressing. He also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. He was awarded 22 hours from the assessment. The CEP allowed for 5 hours of care/week at \$13.50/hour as well as money to be reimbursed for medication costs.

Consumer AO is a 69 year old female who has had a stroke. She has also been diagnosed with congestive heart failure, hypertension, arthritis, and diabetes. She is also incontinent with her bladder. Her daughter has moved in to try and help with her daily needs. She needs help with bathing, toileting, walking, transferring, and dressing. She also needs help with housework, managing money, meal preparation, and shopping. She was awarded 21 hours from the assessment. The CEP allowed for 8 hours of care/week at \$9.00/hour as well as money for reimbursement of her PERS.

Consumer AP is a 66 year old female who has Dementia. She has also been diagnosed with a stroke, hypertension, and COPD. She is taken care of by her two daughters who work full time. They take turn in shifts to help take care of her daily needs. She needs help with bathing, toileting, walking, and transferring. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 17 hours of care from the assessment. The CEP allowed for her to hire a home health agency to provide needed care six hours a week.

Consumer AQ is an 88 year old female who had congestive heart failure. She has also been diagnosed with hypertension, arthritis, osteoporosis, glaucoma, and Emphysema/COPD/asthma. Her daughter works full time and lives 45 minutes away, but helps her mom with her daily needs. She needs help with bathing, walking, transferring and dressing. She also needs help with housework, managing medication, meal preparation, shopping, and transportation. She was awarded 13 hours from the assessment. The CEP allowed for 3 hours of care/week at \$11.00/hour as well as reimbursement for medication.

Consumer AR is a 97 year old female who has Alzheimer's. She has also been diagnosed with hypertension and is incontinent with her bladder. Her daughter and granddaughter take turns taking care of her daily needs. She needs help with dressing, bathing, toileting, walking, and transferring. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 23 hours from the assessment. The CEP allowed for 9 hours/week at \$9.00/hour. She can now afford to pay her daughter to help and her daughter does not have to worry about being as financially strained.

Consumer AS is a 74 year old male who has had a stroke. He has also been diagnosed with Alzheimer's, hypertension, arthritis, cancer, and diabetes. His wife and daughters takes care of his daily needs. He needs help with bathing, toileting, and dressing. He also needs help with housework, managing money and finances, meal preparation, shopping, and transportation. He was awarded 17 hours from the assessment. The CEP allowed for 9 hours/week at \$9.40/hour.

Consumer AT is a 63 year old female who has had congestive heart failure. She has also been diagnosed with arthritis and cirrhosis. She lives by herself and her daily needs are taken care of by her neighbors. She needs help with bathing, toileting, walking, transferring, and dressing. She also needs help with housework, meal preparation, shopping, and transportation. She was awarded 16 hours from the assessment. The CEP allows 7.5 hours/week at \$10.00/hour. She is thankful that she can have someone to help on a consistent basis.

Consumer AU is a 90 year old female who has Alzheimer's. She has also been diagnosed with hypertension, arthritis, thyroid disease, and macular degeneration. She lives with her son and daughter-in-law who take care of her daily needs. She needs help with bathing, transferring, dressing, and toileting. She also needs help with housework, managing money and medication, meal preparation, shopping, and transportation. She was awarded 16 hours from the assessment. The CEP allows 8.5 hours/week at \$10.00/hour.

Consumer AV is a 77 year old female who has emphysema/COPD/asthma. She has also been diagnosed with arthritis and macular degeneration. She lives with her husband who takes care of her daily needs. She needs help with bathing, walking, and transferring. She also needs help with meal preparation, housework, managing money and medication, shopping, and transportation. She was awarded 16 hours from the assessment. The CEP allows for \$416.80 to be paid to a home health agency. This allows her to receive 6 hours/week of care.

## **The Smiths: Thankful Recipients of the Nursing Home Diversion Modernization Cooperative Agreement**

By: Erica Sweeney



A former baseball player and singer in a gospel group, James Smith developed Alzheimer's after having a stroke in 1992.

But, the process was slow, says his wife and primary caregiver, Rose. James, who drove a truck for a drug company for 39 years, started forgetting to make deliveries. He also began losing interest in activities that the pair had done together, like fishing, going to ball games and traveling. James now has two types of Alzheimer's and dementia. His Alzheimer's has reached the third stage, Rose says – she calls it a “slow process of the inevitable.”

Rose works tirelessly to care for James. It is a 24-hour-a-day, seven-day-a-week job. And, the Nursing Home Diversion Modernization Cooperative Agreement program has been a huge help.

“It has been a great program,” she says. “I would be totally insane without it.”

Forgetting things and not recognizing people have come with James's condition. He has difficulty with both long-term and short-term memory. “Very seldom does he know me as his wife,” Rose says.

Also, James “walks all the time.” He is rarely quiet and still, constantly walking around the house and sometimes leaving the house without Rose. James even gets up and tries to go to work on some days. There is an alarm system that will alert her if he leaves, and neighbors will bring James home or call Rose if they see him leave the house. Only during church services does James “sit in one spot,” she says.

“He's so friendly. He thinks he knows everybody. He'd get in the car with anybody,” Rose says of her husband.

A sweet man with graying hair, James, who is 71, sat quietly during our interview. He enjoyed talking about singing with a gospel group for 25 years, being a pastor for 20 years and being a catcher for a baseball team when he was younger. James likes to go to church to listen to the preacher, but seemed sad when he said that he hasn't been able to sing at church in a while.

“I don't understand Alzheimer's,” Rose says. “He can walk and fuss. To watch him slowly deteriorate is painful. It's not even the same person that you knew.”

Rose, who worries about her husband's wandering, originally wanted to put him in a nursing home for his safety, but she felt that he could be better cared for at home.

“I've been to nursing homes,” Rose says. “It's so cold there. It looks so lonesome. It's hard [to send him there] especially when he has been around a loving family.”

The Smiths, who live in Conway, Ark., were referred to Carelink, an area agency on aging that serves central Arkansas, by James's doctor. A representative from Carelink called them to discuss the nursing home

diversion program and signed them up in late March. “We’ve always taken care of ourselves,” Rose says, so programs like this were new to her.

Because of the funds that the Smiths receive, Rose gets some much-needed relief in caring for James. They receive home-delivered meals. And, the funds also allow for other caregivers, provided through Carelink, to take care of James for up to 12 hours a week. A caregiver comes usually for four hours on Friday afternoons and eight hours on Saturday. Sometimes the caregiver comes for all 12 hours at once, so that Rose can “relax mind and body.” Just having someone sit with James is a welcomed relief.

“Getting away for an hour is paradise,” she explains. “But I could use more. That 12 hours is like heaven.”

The program has proved to be invaluable to Rose and James. Rose greatly appreciates the help that the program provides and that the program considers both “the sick and the caregiver.”

“I call it my program,” she says. “It’s not for the patient but for the caregiver. Without it, we wouldn’t have anything – just me.”

Rose, who is 61, was diagnosed with breast cancer in 2000 and had a mastectomy. Because of the medical bills, the Smiths were in danger of losing their house, but Rose’s daughter bought it for them. Rose is now cancer free, but has to be re-checked every six months. The stress of caring for James takes its toll, and, stress is “bad for a cancer patient,” she says.

“It messes with my mind,” Rose explains, noting that she has little time to herself – “even going to the bathroom is a struggle.”

Rose and James have been married for 25 years and have six children, all from previous marriages, and 11 grandchildren between them. James’s children never visit or help out, Rose says, but her daughter helps sometimes. So, that leaves only Rose to care for James.

Because it was getting harder and harder for Rose to keep James at home, the nursing home diversion program has helped her take a break from caring for him 24/7. She gets little sleep because she has to sleep lightly so that she can awake easily if James leaves the house or needs something. She also wakes him up a couple of times during the night to take him to the bathroom, so that he doesn’t go in bed.

“I want to keep him home as long as I can,” she says. “I am the only one that he has to do it.”

And, James is very glad to be at home. “I like living at home,” he says. “It’s a good thing.”

James seems very appreciative of his wife and compliments the care that she gives him. “She gives me a lot,” he says.

Before the program, she had little time to herself and had to bring James with her everywhere. “It was like he was tied to me 24/7,” she says. Because of the program she gets time to rest and do things like shop with girlfriends, take a long, hot bath or get her hair done. She also can go to her own doctors’ appointments.

Rose feels that programs like the nursing home diversion grant are extremely beneficial to not only her family, but to society in general.

“I appreciate the grant because I feel that in some ways America has disregarded their older people. This helps them retain their dignity of staying at home. I appreciate them for thinking about the elderly because most feel thrown away. It shows that people care.”

There is a lot of love between James and Rose. In fact, he told her that he loved her the first time that they met. Rose says that they have had no serious arguments or problems, and never went to bed angry in their marriage. The gratitude that she feels for being able to keep him out of a nursing home and for the help that she gets in caring for him is inexpressible. “Without him, I’d be all alone,” she says. It is evident that Rose would do anything for James.