Caring for a Family Member with Alzheimer's Disease

It is a most insidious affliction, slowly, but inexorably squeezing the spirit and life from its victims. Walter Moseley, an author better known for his character Easy Rollins in a popular detective series, described a victim in his book The Last Days of Ptolemy Grey. "When you deal with a person who's experiencing dementia, you can see where they're struggling with knowledge. You can see what they forget completely, what they forget but they know what they once knew [sic]. You can tell how they're trying to remember."

The non-afflicted often make jokes - whistling through their private graveyards - about the disease and its debilitating effects to hide its horror while silently praying that neither they nor their loved ones will experience a similarly slow, lonely descent into darkness.

Alzheimer's is the only cause of death in the United States that cannot be prevented, slowed, or cured. A 2017 Washington Post article noted that the U.S. has spent billions of dollars on Alzheimer's research without producing a single drug that alters its course. Due to the lack of successful treatment, Alzheimer's continues to ravage the nation's elderly:

- Forty-four of every 100 Americans over the age of 75 have the disease, and an estimated 5.4 million individuals of all ages have Alzheimer's dementia, reports the 2017 Alzheimer's Disease Facts and Figures.
- An estimated 500,000 new cases of Alzheimer's will diagnosed this year, growing to more than 7 million sufferers by 2030, according to The BrightFocus organization.
- One in ten males and one in five females between the ages of 45 to 65 will develop Alzheimer's, according to a 2015 study by researchers at the Univ Bordeaux Segalen and Boston University's Schools of Medicine and Public Health.

History of Alzheimer's Disease

No one is prepared for Alzheimer's, not its victims, not their family. A diagnosis turns the world upside down. We neither know what causes it or how to cure it. It primarily affects the aged, but we do not understand why.

The clinical description of Alzheimer's - a progressive neurodegenerative disease which begins with the insidious deterioration of higher cognition and progresses to severe dementia - fails to convey the devastating impact upon the affected or their caregivers.

The disease was first noted in a lecture by Dr. Alois Alzheimer at a medical meeting of German psychiatrists in the Fall of 1906. Despite its description - "a peculiar severe disease process of the cerebral cortex" - the attending physicians showed little interest in the subject. Until 1977, physicians used the diagnoses exclusively to individuals between the ages of 45 and 65.

For much of the 20th century, mental illnesses have been shrouded in secrecy and shame. People with mental illness are often considered dangerous, unpredictable, incompetent, and responsible for their disease. As a consequence, sufferers were usually kept in isolation by families, committed to public asylums, or imprisoned. A 2014 report noted that people in the early stages of Alzheimer's disease often deny or hide their problems and refuse to seek care due to the stigma of mental illness.

In 1980, Chicago businessman Jerome H. Sloan founded the Alzheimer's Association to promote knowledge about the disease that killed his first wife. The Association has led efforts to change how physicians identify the illness and calculate the number of afflicted people. The hoped-for results include the identification of the biomarkers - detectable measures of biological changes in the brain - that indicate the presence of Alzheimer's to facilitate early diagnosis and treatment before permanent disability occurs.

Symptoms and Prognosis

Alzheimer's initially affects the parts of the brain dealing with memory, followed by language, reasoning, and social behavior. As the brain changes, a person with the disease gradually loses his or her ability to live independently. Symptoms appear an average of 2.8 years before diagnosis with a median survival of 8.3 years after, according to research by Johns Hopkins Bloomberg School of Public Health.

Research by the Mayo Clinic indicates that the first sign of Alzheimer's - forgetfulness or mild confusion - is often overlooked since everyone has occasional memory losses. As the disease progresses, those affected may experience depression, apathy, and mood swings, often withdrawing from others. Distrust in people around them, irritability, and aggression are not uncommon. Many have delusions, lose their inhibitions, or wander.

Stages of Alzheimer's Disease

While most people with Alzheimer's disease live 4 to 8 years after diagnosis, some live as long as 20 years. The illness progresses through seven major clinical stages - the "Global Deterioration Scale" - each more debilitating than the previous stage:

- Stage 1 (Preclinical Alzheimers or no impairment). Individuals in this stage show no outward impairment and are entirely independent; they may not know they have the disease. Most continue to work and perform routine activities such as driving a car, shopping, and engaging in social activities.
- Stage 2 (Very mild impairment or normal forgetfulness). Symptoms remain slight or undetectable, such as occasional forgetfulness. The signs are often confused with the normal progression of aging. There are no apparent problems with work or social activities. Family and friends may not be aware of the disease's effects.

Stages 1 and 2 typically span 2 to 4 years.

- Stage 3 (Mild impairment or decline). The impairment will be evident such as getting lost when traveling a familiar route, being unable to remember what was just read, or misplacing or losing a valuable object. Work quality declines and the individual has difficulty learning new skills. While many sufferers continue to work, employers may be required to simplify job responsibilities. The person with Alzheimer's may experience mild to moderate anxiety so caregivers may advise counseling.
- Stage 4 (Mild Alzheimer's or moderate decline). The symptoms are evident, the first point that Alzheimer's can be confirmed. Signs of decline include decreasing awareness of current or recent events, lost memories of personal history, and trouble handling finances and bills. Lifestyle changes no driving, help with paying bills and writing checks, shopping for groceries may be necessary.
- Stage 5 (moderate dementia or moderately severe decline). Independent living is no longer possible for people at this stage. While remembering their own and close family members' names, they have little recall of significant events, weather conditions, or their home address. They have confusion with time and place. While personal hygiene and eating are not yet a problem, they need help choosing the right clothes for the weather, cooking, or taking care of their finances.

Stages 3, 4, and 5 can last from 2 to 10 years.

- Stage 6 (Moderately severe Alzheimer's). Symptoms include being unable to choose clothes or dress, and a decline in hygiene with help needed for bathing, teeth cleaning, and toilet activities. They may confuse family members with other people and experience personality changes. Periods of fear of being alone, frustration, shame, and paranoia are typical as is stuttering and sleeping during the day to wander at night. Constant personal care is necessary at this stage.
- Stage 7 (Severe Alzheimer's). This stage can last from 1 to 4 years during which people with Alzheimer's will gradually lose their ability to speak, sit up independently, or hold their heads up. Body movements become more rigid and painful. Some develop infantile reflexes like sucking. There is no ability to respond to their surroundings, many becoming immobile necessitating 24/7 care. The most frequent cause of death is pneumonia.

Three of four people with Alzheimer's disease will spend 1 to 4 years in a nursing home during the disease's last two stages where two-thirds will die. The majority of nursing home deaths are the result of Alzheimer's dementia,

Care Requirements and Costs

Caring for a person living with Alzheimer's requires managing symptoms that caretakers of people with other diseases do not face. Instances of extreme anxiety, inappropriate behaviors (obscenity, removing clothes), and aggression, even violence, may occur. As the person passes through each stage of the illness, the needs of more and intimate care increases, ratcheting up the pressure on caregivers.

According to the Alzheimer's Association 2017 Report, a caretaker is expected to

- help with household chores, shopping, preparing meals, providing transportation, arranging for doctor's appointments, managing finances, and legal affairs, and answering the telephone.
- help the person take medications correctly, either via reminders or direct administration of drugs.
- assist with bathing, dressing, grooming, and feeding and helping the person walk, transfer from bed to chair, use the toilet and manage incontinence.
- manage aggressive behavior, wandering, depressive mood, agitation, anxiety, repetitive activity and nighttime disturbances.
- find and use support services such as support groups and adult day service programs.
- make arrangements for paid in-home, nursing home or assisted living care.
- hiring and supervising others who provide care.

In addition to the above, caretakers may be required to manage other patient health conditions ("co-morbidities" such as arthritis, diabetes or cancer) while providing emotional support and a sense of security to the victim and other family members.

Family Caregivers

What is heartbreak? ... When you are helping your loved one with dementia perform a task of everyday living like dressing or toileting [sic] and they look at you with a mixture of confusion, sadness, and fear and ask. "What do I do now?

Family members suffer alongside their loved ones and have been called "the second victims of Alzheimer's" and "the invisible patients." The Alzheimer's Association estimates that 15 million Americans - most often family members - provide unpaid care to those with the illness. Three-quarters (74.2%) of caretakers of people with Alzheimer's disease will spend more than four years providing care versus 53.4% of caregivers helping the elderly without Alzheimer's dementia. Alzheimer's caregivers share certain characteristics including being:

- Older spouses. More than 95% of victims with Alzheimer's disease are over the age of 65, according to the Alzheimer's Association. Unsurprisingly, one-third of caregivers are 65 or older and likely to be married to the patient.
- Children and children-in-law. More than one-half of caregivers are taking care of a parent. One-quarter of caregivers care for an aging parent and children under the age of 18 the "sandwich generation" of caregivers.
- Women. Two-thirds are women, either wives or daughters. Twice as many women as men spend more than 40 hours per week giving care or have cared for someone with dementia more than five years. Two and one-half times as many women live with the person with Alzheimer full-time.

Alzheimer's Impact on Caregivers

Spouses and family members provide most of the necessary care to Alzheimer's patients during the early and middle stages of the disease, many feeling as they have no other choice but to take the role. Dr. Henry Broadly, Professor of Aging and Mental Health at the University of New

South Wales, notes in the Dialogues of Clinical Neuroscience journal that family caregivers "are critical to the quality of life of the care recipients, but pay a high cost in the quality of their own lives. The adverse effects for a caregiver include

Diminished Physical Health

Various studies indicate that family caregivers have an increased risk of cardiovascular problems, lower immunity, poor sleep patterns, slower wound healing, and a higher incidence of a chronic condition such as anemia, diabetes, and ulcers.

Caregivers of Alzheimer's patients tend to see their physicians more often, abuse prescription medicines, drink alcohol more often in higher amounts and smoke tobacco. These habits - combined with a general lack of exercise - leads to poor health and higher morbidity.

Loss of Emotional Well-Being

Researchers have confirmed a high correlation between incidences of depression, anxiety, and stress with caregivers of dementia patients. Maria Shriver, the founder of The Women's Alzheimer Movement, warns family caregivers: "No matter who you are, what you've accomplished, what your financial situation is - when you're dealing with a patient with Alzheimer's, you yourself feel helpless ... As the disease unfolds, you don't know what to expect."

Leeza Gibbons, TV talk show host whose mother was diagnosed with Alzheimer's in 1999, added, "Caring for an Alzheimer's patient is a situation that can utterly consume the lives and well-being of the people giving care, just as the disorder consumes its victims." The combination of worry and the feelings of loss as a loved one vanishes under the onslaught of dementia is especially damaging to family caregivers.

Feelings of Social Isolation

Almost 70% of family members providing care to a person with Alzheimer's are women. In addition to the care provided to the patient, many are expected to continue fulfilling responsibilities of motherhood and marriage at the same time. As a consequence, they often experience feelings of sadness, anger, exhaustion, and then guilt for being "selfish."

Unfortunately, those around caregivers tend to focus on the Alzheimer's patient, overlooking the strain on their caregivers. Remotely-located family members may reduce their visits and offers to assist, returning to their normal activities before the diagnosis. As a consequence, caregivers often feel "trapped" and resent the absent family members.

Caregivers may sacrifice leisure and hobbies, reduce time spent with friends and other family members, and quit working to meet their self-imposed obligations to the person with Alzheimer's. Some researchers believe that "the longer a caregiver remains in his or her role, the more likely negative outcomes are to occur" - the "wear and tear" theory.

Growing Financial Costs

The costs of caring for a person with Alzheimer's are significant, especially for the 41% of the families earning \$50,000 or less reported in the 2017 Alzheimer's Disease Facts and Figures. As a consequence, most sufferers must rely on the public social programs of Social Security, Medicare, or Medicaid to cover the bulk of the costs of care and living expense with families and other third parties covering any shortfalls.

According to a CBS News report, the lifetime cost of care for an Alzheimer's patient is \$329,360 in 2017 dollars. Families bear 70% of the expenses through out-of-pocket expenses and unpaid care. Forbes magazine reported that annual Medicare costs per patient with Alzheimer's in 2017 were \$23,487, more than three times the cost per patient without the disease (\$7,223).

The victim's savings, family members, or others covered additional annual out-of-pocket costs of \$10,315. These costs do not include the lost wages of caregivers who must cut their hours or quit jobs to provide needed care.

Families already coping with stagnant wages, rising college costs, escalating healthcare costs, and looming retirement will have increased burdens if Congress restructures the nation's social safety net to reduce budget deficits and the National debt.

Positive Feelings and Outcomes

While much attention is focused on the adversities that Alzheimer's caregivers experience, Dr. Sarah Sanders' research indicates that 80% of caregivers also have periods of joy interspersed with the stressful periods. The positive feelings include enjoying togetherness, sharing activities, feeling a reciprocal bond, spiritual and personal growth, and more profound religious faith.

Tim Brennan, a victim of early onset Alzheimer's, captures the hopes of all caregivers in his words: "With wings, as of eagles, I've flown, like a dove I'm with you always, my offspring, my love One day, you'll see rainbows and sunshine again You'll sense my presence riding upon the wind As aloft, with great ease, extends forth your kite Even so, came God's spirit And my soul took it's flight."

7 Tips to Ease the Burden of Caregiving

An estimated 30% of the population cares for an aging relative. Heather Levin of MoneyCrashers offers excellent advice for all caregivers. However, caring for someone with Alzheimer's is often more difficult and heart-wrenching due to the extended, relentless progression of the disease.

Depression is twice as common among caregivers for dementia patients as caregivers for others. Spouses of the victims are especially vulnerable, being two and a half times more likely to develop depression than non-spousal caregivers. Social workers and Alzheimer's counselors suggest that the burden can be lighter by implementing these steps:

1. Have the "Conversation" with elderly parents.

S. Jay Olshansky, writing in Frontiers of Medicine, wonders if the rise in heart disease, cancer, stroke, Alzheimer's, Parkinson's, and other age-related fatal and disabling conditions are part of a Faustian bargain for longer lives. As I wrote in an earlier Moneycrashers article about 6 must-have conversations between elderly parents and children, the consequences of aging are inevitable, and no one escapes its effects.

Most seniors understand the need for an honest discussion about their futures and willingly participate in making their wishes known. Severe illnesses and death follow no timetable so addressing these issues before they become problems will lessen any tension or misunderstandings.

The elderly most fear a loss of their mental facilities and the accompanying independence, according to most polls. A conversation with an elderly parent should include the possibility of Alzheimer's in their future and what steps they might wish for their care when they are unable to make decisions for themselves.

Be aware that your loved one may talk of euthanasia or suicide following a diagnosis of Alzheimer's. A study reported in 2018 found that patients diagnosed with the likelihood of dementia - an inevitable outcome of Alzheimer's - have an increased suicide risk. Esther Heerema, a social worker with 20 years of experience working with Alzheimer's patients, provides 8 steps on how to respond to suicidal thoughts from a person dealing with dementia.

Few countries in the world accept an advance directive for suicide. In those states in America where assisted suicide is legal, a patient must be capable of making decisions for themselves ("competent"), have a terminable disease, and prognosis of death within six months or less. It is highly unlikely that a person in the final stage of Alzheimer's would meet the requirements.

2. Understand the Options for Care

The progress and appearance of specific symptoms of Alzheimer's are uncertain, making fixed plans ineffective. Multiple factors - family relationships, the general health of the patient, proximity of caregivers to the patient, and finances - influence treatment options. The most common care options are:

- Home care. In the initial stages of Alzheimer's, most people continue to live at home their own or with family with monitoring by family members and friends. New technology video monitoring, GPS locating devices, wearable IDs with location technology, electronic door locks are available to create a safer environment and distance monitoring. As symptoms of the disease advance, family members may recruit outside medical and non-medical help to assist with care. The type of assistance needed is acting as a companion, helping with personal care, and assistance with household chores (cleaning, shopping, cooking) in addition to skilled care for medical problems.
- Adult Day Centers. Many day centers are designed to create a safe environment and have personnel with specific training to work with Alzheimer's patients. Patients may

attend daily, several times a week, or occasionally to participate in crafts, music, and exercise (weekend and night sessions may not be available. Centers provide meals, and some centers provide to and from transportation from the patient's home and day centers. Perhaps the greatest benefit is to caregivers, allowing them a respite from constant care and free time. Caregivers should be aware that their loved ones may resist going to a center, but many quickly adjust and enjoy the social atmosphere.

- Residential care. Living at home may not always be an option for a person with Alzheimer's, necessitating residential care. Early-stage patients able to live alone safely might use retirement housing with limited supervision but options of social activities, transportation, and household help. Assisted living is similar to retirement housing but includes meals and more supervision. Memory care units are facilities specially designed for Alzheimer's and other dementia patients. They provide round-the-clock care with specialty-trained staff. Continued care retirement communities (CCRCs) provide various levels of care within the same location, allowing patients to move from one stage of Alzheimer's to another without the stress of unfamiliar staff and surroundings. According to reports, quality of care at residential facilities varies significantly; family members should exercise due diligence when selecting the most appropriate setting. The website AgingCare suggests some questions to ask when choosing a facility for a patient with dementia.
- End-of-life care. Hospice facilities are designed to care for people who are terminally ill and in the last six months of life. Their purpose is to alleviate the pain of the patient and give them dignity in the final stages. They also are trained to counsel caregivers and family dealing with the end-of-life. Mary McCoy's article "What is Hospice Care" provides useful information about facilities and knowing when the time is right.

3. Involve Family Members

Dealing with a parent suffering Alzheimer's disease is emotionally devastating, especially when the parent-child roles reverse and the child must make decisions for a parent incapable of caring for themselves. It is especially difficult if family members cannot agree on the proper way to proceed or who will make the final decisions.

Family relationships are complicated, often estranged. Dealing with a spouse or a parent with Alzheimer's brings out the best and worst among siblings. Most often, a child who lives near the patient becomes the primary caregiver, taking on the lion's share of the daily responsibilities, hopefully with occasional help or financial assistance from siblings. In other cases, siblings use the excuse of distance or other priorities as an excuse to avoid their participation in care activities or decisions.

Involving other family members in decisions about care and finances reduces stress for all involved, especially for caregivers who may be the only source of physical help due to their proximity to the patient. If the persons with Alzheimer's is capable, they should participate in decisions as much as possible.

Primary caregivers should be aware that a decision to move a parent or spouse from home to a care facility is hugely emotional, especially if the parent resists the move. Being able to rely on

other family members to support the decision when it comes is critical. Bonnie Lawrence of the Family Caregiver Alliance in a PBS NewsHour story offers tips for siblings who suddenly find themselves caring for parents.

4. Identify financial resources

The annual and lifetime costs of care for a person with Alzheimer's are significant. While government assistance is available, patients are expected to use personal resources before being eligible for financial help. Providing the right option during each stage of the disease by moving through the multiple options - traveling the continuum of care - is the appropriate strategy to minimize overall costs.

Patients are expected to remain the primary source of funds for care as long as they are financially able. Nevertheless, consideration for a surviving spouse is essential when developing a financial plan to pay for Alzheimer's care. Potential funding might be available through

- Social Security. People living with early-onset Alzheimer's may qualify for Disability and Supplemental Income benefits before retirement age. The Social Security Disability Resource Center details the process for filing for disability for persons with Alzheimer's disease. Family caregivers who are remote to the patient will find the Social Security Representative Payee Program useful.
- **Medicare**. Medicare is a health insurance program generally for people over age 65 but is not intended for long-term care. Nevertheless, there are some benefits for Alzheimer's patients, including limited coverage stays in a nursing home or a limited amount of home care. Also, Medicare will provide an extensive benefit for end-of-life care.
- Long-term care insurance. While the purchase of long-term care insurance is controversial, your stricken family member may have a long-term care insurance policy in effect. Policies usually pay different amounts for different services (\$50 daily for home care; \$100 a day of nursing home care) with policy limits of the number of years benefits will be available or a total maximum cost.
- Retirement plans. Pensions, IRAs, and other deferred savings accounts may be available in the event of early-onset Alzheimer's depending on the plan's guidelines. As a consequence, funds can be withdrawn without the 10% early withdrawal penalty. Qualified retirement plans and IRAs can be transferring into annuities without triggering a tax consequence. As detailed in the book Annuities for Dummies by Kerry Pechter, the options for different payout schemes, guarantees, and recipients have increased over the year. For example, all or a portion of the retirement funds could be converted into a single-premium immediate annuity (SPIA) that will provide an income stream as long as either spouse is living with a guaranteed "period certain" minimum number of years.
- Insurance policy cash values. Owners of life insurance policies have several options to convert the policy before death, including selling the policy for a lump sum in return for the right of the buyer to collect death benefits, viatical settlements, accelerated death benefits, policy loans, and converting the policy in exchange for care. While all of these options may not be available to everyone, the Paying for Senior Care website of the American ElderCare Research Organization provides explanations of each.

- Reverse mortgages and HELOCs. Spouses with a spouse suffering from Alzheimer's, over the age 62, and significant equity in a home should consider a reverse mortgage to free up cash with a guarantee that the surviving spouse will be able to remain in the house until their death or move without having to make payments on the mortgage. Families who do not meet the requirements for a reverse mortgage can utilize a home equity line of credit (HELOC) for free cash from the equity balance. The lender establishes a line of credit that can be used as needed until the balance of the loan. However, a HELOC unlike a reverse mortgage, interest must be paid on the amount outstanding, and any unpaid balance of credit is due at the end of the term.
- Veterans Administration. The Los Angeles Times reported a study that found that veterans of the Iraq and Afghanistan wars with mild traumatic brain injury (15%-20% of those who served) were more than twice as likely to develop Alzheimer's and dementia as those with an injury. Fortunately, the VA provides a variety of support options for veterans with Alzheimer's or dementia including its special Aid & Attendance program.
- Medicaid. America's public health insurance program for low-income and the elderly has become the primary funding sources for the care of patients with Alzheimer's. According to the Henry J. Kaiser Family Foundation, about one-quarter of adults with dementia living in the community has Medicaid overage each year. Medicaid programs are run by each state with different qualifications for coverage. Those who qualify for Social Security's Supplemental Security Income are automatically eligible for Medicaid in most stares. Most states provide an income spend-down options for seniors with too much income or assets (excluding a home, vehicle, and other personal assets.

In addition to the above programs, the National Council on Aging provides a checklist to find other sources of benefits for older adults.

5. Implement advance directives

Assigning the right to a responsible third-party, usually a trusted family member, to make financial and medical decisions for an incapacitated person should be done as soon as possible following a diagnosis of Alzheimer's. Attorney Brad Sauer, in an article for alzheimers.net, warns that the assignment must be made when the assignor is competent to make decisions, a particular risk for those experiencing Alzheimer's in the middle or late stages.

The rights are only exercisable when the assignee is incapable of making decisions for themselves. Documents to be considered are a

- Living Will. A living will is a set of written directions that documents medical treatments that a person might wish to have or avoid in the future if they are disabled. Dr. Barak Gaster has developed a sample form of an advance directive specifically for Alzheimer's patients.
- **Powers of Attorney**. These documents designate a person who will make medical or financial decisions for the assignee if the assignor is incapable of making decisions. The assignment might be for a specific period or indefinite (appropriate for those with Alzheimer's).

• **Living Trusts**. People with significant assets might establish trusts to manage their property during incapacity and after death.

Before creating or signing any legal documents, seek competent legal advice. Former attorney Mark Theoharis identifies 5 Legal Facts You Need to Know About Incapacity Planning. Failure to execute these documents when the family member is competent may require that family members pursue legal control by a court-ordered guardianship (conservatorship), often a lengthy and costly process.

6. Take caregiving classes.

Dementia, an inevitable symptom of Alzheimer's that appears in different stages, creates unique caregiver challenges. Most of the Alzheimer's Association's local chapters provide free workshops and training programs for family caregivers.

The subjects of the classes typically include understanding the symptoms and care needs, expected relationship changes, ways to maximize safety, and preparing for emergencies. Training is designed specifically for family caregivers with many subjects available online through e-learning workshops.

7. Join a support group

According to the Family Caregiver Alliance, 40%-70% of family caregivers experience clinical depression, loneliness, and isolation. The lack of social interaction and stimulation often leads to weight gain and high blood pressure. Caregiver burnout is not unusual, nor the feelings of guilt that accompany fatigue and resentment over the situation.

There are a variety of online support groups - 50+ on Facebook alone - as well as local groups in all regions of the country. Do not expect or require perfection in your role as a caregiver; Mark, a caregiver quoted on the Caregivers Stress website recommends, "Measure yourself by the teaspoon, not the scoop shovel, and you might find more of yourself that you didn't even know you had lost..."

Final Word

Alzheimer's is just one of the brain changes that affect older people and result in physical, mental, and emotional change. Some are more debilitating than others, but all of them require adjustments by the sufferer and his/her loved ones. Everyone knows someone who is or has experienced symptoms of brain abnormality in varying degrees, perhaps themselves or someone in their immediate family.

Aging not only brings mental diseases, but cancers, heart problems, and other health problems. While some people take a caregiving role, no one - patient or caregiver - has to bear the burden by themselves. Caregivers need to remember to take care of themselves and ask for help when they need it or feel overwhelmed.

Something that might seem trivial to the offeror - offering to sit with a patent for an afternoon, going grocery shopping for the caregiver, making a phone call to let caregiver and patient know you are thinking of them - can make a huge difference in lives and attitudes. Remember the words of Aileen H., another caregiver writing on the CaregiverStress site, "We all need help one time or another."