

briefs



Caregiver

The author has requested that he remain anonymous.

To celebrate our 56th wedding anniversary, my wife and I attended a dinner theater production of *They're Playing Our Song*. After Act 1 and being served dessert during the intermission, Sara asked me, "Are we going home now?" She had no idea there would be an Act 2; indeed, she did not remember there had been an Act 1. Later, when we returned home and settled ourselves in the living room, she inquired if I had done the dinner dishes yet.

That's the way it is when one has Alzheimer's disease. It is six years now since Sara was diagnosed (as conclusively as is possible) with this memory depriving disease, but years earlier that the first symptoms appeared. Sara began to avoid responsibilities in social functions and her interest in handcrafts waned. Although she had no accidents or near accidents, Sara decided not to drive her car when she began to feel a vague incompetence. And there were other problems, Sara unexpectedly fell a few times and eventually was diagnosed with Parkinson's, another brain cell degenerative disease.

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Alzheimer's and Dementia

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by Cheryl Asmus, Coordinator, Family and Youth Institute

As baby boomers age, there will be a dramatic increase in the size of Colorado's older population in the 21st century. With this increase in the older population, we will witness increases in dementia resulting from strokes, Parkinson's and Alzheimer's. Diseases that cause dementia affect both the individual and the family in devastating ways. An estimated 10 percent of people over 65 and almost half of those over 85 currently suffer from Alzheimer's disease. Families provide on-demand care for their loved ones with dementia as most of dementia sufferers require 24-hour care and can never be left alone. Families often respond to the needs of the elderly in their family, but the burden of this care giving cannot be underestimated. In addition, one-third to one-half of caregivers are employed outside the home and 12 percent eventually quit their jobs to become full-time caregivers. This issue of the *FYI Briefs* is devoted to the topic of care-giving for people with Alzheimer's and other dementia. The month of November 2003 was both National Caregivers Month and the third anniversary of the National

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Families: The Mainstay in Caring for the Elderly

by Clifton E. Barber, Professor and Head, Department of Human Development and Family Studies,
Colorado State University

The personal story shared by an anonymous caregiver in this issue of the Family and Youth Institute *Briefs* poignantly illustrates the challenges of caregiving. The fact that the person who contributed this story elected to remain anonymous is revealing, as caring for a loved one is often played out in quiet isolation. These quiet acts of sacrifice, rendered by unpaid caregivers, are inspiring. While those who render selfless care can never be fully acknowledged, the anonymous writer reminds us to pay tribute when we can.

Despite the fact that caregiving often goes unnoticed at the personal level, the societal magnitude of caregiving is difficult to miss. In the news, almost daily, are stories and articles on formal care and programs, help from social service agencies, nursing homes, and/or government programs. Research repeatedly finds that informal care by families is the mainstay to caring for the elderly. Currently, more than 22.4 million informal caregivers – mostly spouses, adult children and other relatives – provide unpaid help to older people who are frail and dependent. Although there have been substantial changes in family life, American families demonstrate remarkable resilience in taking care of their loved ones. They provide such assistance as shopping, transportation, household chores, bathing, dressing, preparing meals, and administering medications. Collectively, informal caregivers contribute in the neighborhood of \$257 billion annually to the nation's health care system – an amount that significantly reduces costs to Medicare, Medicaid and private payers.

Caring for Caregivers: The National Family Caregiver Support Program

One cannot help but be concerned with the well-being of the author of the featured case example in this issue of *FYI Briefs*. How long can he manage to provide such loving care? Despite the contribution they make to society and to the loved ones for whom they care, family caregivers – most of whom are female – grapple with substantial stresses and burdens. Most studies report that caring for

a frail and dependent elderly loved one can negatively affect one's emotional and physical health, current and future earnings, and the ability to address personal needs. As the baby boom generation ages, there will be a significant increase in the number of older people needing long-term care and community-based services that provide personal assistance, respite care, home modifications, etc. But what about those who render care: who will care for the caregivers? The National Family Caregiver Support Program is one useful resource for support of family caregivers (see box).

Employed Caregivers

Rarely do caregivers – especially adult child caregivers – shoulder only the caregiving role. Frequently, caring for an elderly loved one is a juggling act, including the difficult task of balancing family and work commitments. One-half of all informal caregivers are also employed. According to projections by the National Alliance for Caregiving, by 2007, roughly one in 10 employed workers will also care for an elderly loved one. As partners in the concept of "Communities of Care," employers can help caregivers by providing consultation and referral, education and support, flexible hours, and help with accessing resources and services.

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Eldercare Locator

The U.S. Administration on Aging has established Eldercare Locator, a nationwide service designed to help older adults and their families find support services. The goal is to provide caregivers with information and resources that will help older adults live independently and safely in their homes as long as possible. Services that can be accessed through the Eldercare Locator are adult day care, information and referral, case management, elder abuse prevention programs, financial assistance, nutrition services, home health services, legal assistance, personal care, respite care, senior housing options, senior center programs, telephone reassurance, transportation, and volunteer services. The toll-free telephone number is: 1-800-677-1116. Web access is <http://www.eldercare.gov>.

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Caring for a Loved One Suffering from Dementia

As indicated in the personal story in this issue, caring for a spouse suffering from dementia requires special understanding of the unique caregiving requirements when Alzheimer's disease (AD) is involved. The occurrence of AD is not a normal development in the aging process. It is characterized by a gradual loss of memory, decline in the ability to perform routine tasks, disorientation, difficulty in learning, loss of language skills, impaired judgment and ability to plan, and personality changes. Over time, these changes become so severe that they interfere with an individual's daily functioning, resulting eventually in death. The disease can last from three to 30 years after the onset of symptoms, with 10 to 12 years being typical.

Alzheimer's disease affects as many as four million Americans. Most people diagnosed with AD are older than 65. However, it is possible for the disease to occur in people in their 40's and 50's. Recent research shows links between some genes and AD, but in about 90 percent of cases, there is no clear genetic link. New and promising approaches for working with people who have Alzheimer's and their caregivers have emerged. For example, through the Alzheimer's Disease Demonstration grant program now funded by the Administration on Aging (AoA), new dementia-specific approaches to early identification, treatment and community-based care have been developed. Another project, known as REACH (Resources for Enhancing Alzheimer's Caregiver Health), was a national initiative established in 1995 by the National Institutes of Health. Collectively, these projects have been successful in working with low-income, ethnic minority and rural families.

For more information about Alzheimer's Disease, services and resources, see the websites listed in the adjacent box or contact the National Alzheimer's Association (24-hour Toll-Free Nationwide Hotline: 1-800-272-3900; Web Site: <http://www.alz.org>).

Minority Aging - Hispanic Caregiving

This article would be incomplete if we did not at least acknowledge the issue of minority aging and caregiving. Historically, most caregiving research focused on White caregivers. Fortunately, this is changing. The past decade has witnessed a welcome and remarkable spate of inquiry

Barriers Often Encountered by Hispanic Caregivers

- inability to negotiate the system
- uninformed of available services
- a mistrust of the federal government, through which many services are funded
- a culturally-held notion of family independence
- inadequate outreach and the method for how information is given

The National Family Caregiver Support Program

The enactment of the Older Americans Act Amendments of 2000 established the National Caregiver Support Program. This program calls for all states, working in partnership with area agencies on aging and local community service providers, to have five basic services for family caregivers:

1. Information about available services.
2. Assistance to caregivers in gaining access to services.
3. Individual counseling, organization of support groups, and caregiver training to assist caregivers in making decisions and solving problems relating to their caregiving roles.
4. Respite care to enable caregivers to be temporarily relieved from their caregiving responsibilities.
5. Supplemental services, on a limited basis, to complement the care provided by caregivers.

Additional information available on the web at:

<http://www.aoa.gov/prof/aoapro/caregiver/caregiver.asp>

regarding minority caregivers.

Minority elders comprise an increasingly larger proportion of those age 65 and over (65+). According to 1995 data, 15 percent of all older Americans (age 65+) are members of minorities (8 percent Black; 2 percent Asian or Pacific Islander; and less than 1 percent American Indian or Native Alaskan). People of Hispanic origin represent 4.5 percent of the older population. This will change significantly by the year 2050, when Hispanics are expected to constitute 17.5 percent of the elderly population.

The Hispanic population in the United States is living longer and growing older. The older Hispanic population is one of the fastest growing groups in the nation. Between 1990 and 2050, the number of Hispanic elderly (age 65+) is projected to grow from 1,162,000 to 13,770,000 (see Day, 1996).

"La familia" (the family), not an individual, is the vehicle for providing caregiving among Hispanics. One challenge in serving this population of caregivers is the culture of migration – the notion that this is a revolving door population due to transparent borders that exist between the U.S. and Latin American countries, resulting in transnational families. Support systems for caregivers must not only work with the family members residing in the U.S., but pay attention to family living outside the border. Survey results from the recent AARP survey of the "sandwich generation" (i.e. those individuals who care both for dependent children and elderly parents) roles and functions of caregiving show that family caregiving in Hispanic families is multigenerational. Eleven percent live in three-generation households, and six percent have extended family arrangements. Thirty-four percent of Hispanics care for their elderly compared with ten percent of non-Hispanics whites.

Parental expectations regarding the receipt of care from adult children are influenced by norms of reciprocity.

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That is, elderly Hispanic parents expect to receive assistance and support from their adult children in later life. Hence, it is not surprising that many studies report that Hispanic families are extremely supportive and protective of their elders. Nor is it surprising that Hispanic caregivers experience high levels of stress because they feel guilty that they do not give enough.

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Online Resources: Guides for Alzheimer's Caregivers

There are several basic but very good online caregiving guides available. Among the best, is an AoA resource entitled, "Because We Care." This guide can be accessed at:

http://www.aoa.gov/prof/aoaprof/caregiver/carefam/taking_care_of_others/wecare/wecare.asp. Another guide, specifically for Alzheimer's Caregivers, can be accessed at:
<http://www.alz.org/Caregivers/overview.asp>.

Caring for Loved Ones continued from page 1

Caregiver Support Program – Caring for the Caregivers program through the Administration on Aging.

Our featured article is a personal account by a man loving, living with, and caring for his wife of 56 years as she slips away from him and into Alzheimer's. His intelligent and poignant story opened my eyes to many of the intricacies of this very personal loss for both the woman with the disease and her husband. It is beautiful and informative at the same time. Clif Barber, Ph.D., department chair of Colorado State University's Department of Human Development and Family Studies describes the importance of family caregivers to the individual and society as they often provide a service that saves the American health care system billions of dollars every year. He also stresses the importance to acknowledge the issues that surround minority caregivers and provides some resources for caregivers. Paul Bell, Ph.D., director of the Center on Aging at Colorado State University, teams up with Yvonne Myers, Health Systems Coordinator for Columbine Health Systems in Fort Collins, to discuss some of the relevant factors when choosing a long-term

care facility for a person with Alzheimer's or other dementia. Kenneth Tremblay, Ph.D., Cooperative Extension housing specialist at Colorado State University, provides a bulleted list for home modifications that make housing safer and caregiving more manageable for the elderly family member with dementia. We conclude with Elizabeth Garner, coordinator of County Information Services for Colorado State University Cooperative Extension, providing us with projected increases in the older population, the elderly disabled and those with Alzheimer's disease. She also includes statistics on the current and future living arrangements for this population.

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problems. They can provide some relief from symptoms, but cures are still beyond medical science. Slowly, over time, Sara's gait became more unsteady and her memory more clouded. Coinciding with this, it became harder for her to perform tasks. As her competence fell, my responsibilities grew. More importantly by far for both of us is that as Sara's memory fails, her personality fades. One's personality is literally the product of brain activity.

We sit together in our living room. I want to share with Sara the rough draft of a memoir about my elementary school days that I have been writing. She listens quietly but, unlike years ago, she doesn't respond in any vital way. There is no criticism, no playful teasing and no suggestions. It is the same if I want to share my speculations or feelings about an article or book I have read. I sorely miss that interaction that once was such an engaging and stimulating part of our life together. My feeling is that only part of Sara is present now. I am losing her by degrees.

I recall a dream I had in mid-June of 1995, relatively early in the onset of Sara's Alzheimer's. I quote here the notes from my journal: "I felt I was getting ready for a very serious undertaking. It gradually seemed to focus on crossing the Pacific. It would be a journey I could not possibly complete. I would be swimming, and I would die on the way. I had a sort of surfboard-boat upon which Sara would be riding. I would push it from behind. I found myself in the water. Sara was on top of the board; I didn't see her but I knew it was she. The water felt comfortable. I kicked with my legs, and we moved swiftly thru the water. I was surprised how quickly we moved. Yet I still knew that eventually I would tire and that I could not possibly complete the journey."

That dream well describes the experience I have had up to the present time. As heart-rending as the ultimate fate brought by these diseases is, up to now I believe we have both managed well. We accept the situation that we are in, and in spite of it seek opportunities to live, grow and enjoy life. There is a lot one can do! Never underestimate the resilience of life. In the last six years, we have driven out to

Options for Long-Term Care

by Paul A. Bell, Director, Colorado State University Center on Aging, and Yvonne Myers, Health Systems Coordinator, Columbine Health Systems

The progression of Alzheimer's takes anywhere from three to 30 years, with 8 to 12 years being typical. As the disease—or any dementia—progresses, the individual becomes more and more dependent on others for care. Initially, the caregiver reminds the loved one of things to do, names of individuals, words not recalled, and helps the person keep track of personal finances. Eventually, the person with dementia needs help bathing and dressing, using the toilet, and eating.

Although 85 percent of all caregiving occurs at home by family members, most of the time Alzheimer's eventually leads to institutional care because the family members cannot provide constant 24-hour care. A short-term stay of a few days to a few weeks in a specialized facility for dementia care—known as respite care—may help the caregiver take a needed vacation or otherwise recover from caregiver stress. More common is a long-term placement, where the needs of the person with dementia are so demanding that they may actually be better met in a permanent institutional setting. Often, the functional level of the person with Alzheimer's improves somewhat with nursing home placement because that environment and the professional caregivers are better able to support the skills that still remain.

In selecting a facility, it is important to match the level of functioning of the individual with dementia to the level of care provided in the facility. Higher-functioning individuals may benefit from an alternative-living facility or assisted-living residence that has trained staff and appropriate activities. Here the person is able to perform many functions with guidance from the staff. Lower-functioning individuals who depend on staff to bathe, dress, use the toilet, and eat may benefit from a skilled nursing facility that has more staff per resident. Today, facilities that have multiple dementia units represent a continuum of care intensities as the disease progresses and the need for more personal care increases.

The most common mistake families make is to decide placement based on building appearance and price. Study after study shows that quality of care is most closely related to staff quality, staff training and programming—the management of daily activities of the residents. Having a small unit of no more than 20 or so beds is usually less confusing for the person with dementia than a larger unit of 30 or 60 beds, so having three or four units of 15 to 20 beds each, where the level of care intensifies as the disease progresses, is desirable. Finding the right level of care is extremely important. By Colorado regulation, a facility is not allowed to take a person with needs the facility cannot handle, so expect a staff member to do an assessment of the person's level of functioning prior to and after admission.

If wandering is a problem, a secure or locked unit is advisable. The family must have legal authority in the form

of a medical power of attorney or a court-issued guardianship to place a loved one on a locked unit. By law, a person who does not need a locked unit cannot be placed in one. Wandering can be minimized by decorating the resident's room with familiar furnishings from home and with diverting activities, such as baking bread, reminiscence games or watching pets.

Good facilities—whether locked or not—provide adequate space for walking indoors and out. Ideally, outdoor spaces should have a path that leads away from the building and returns to it in a loop. The perimeter of outdoor spaces should have a fence that is tall enough to block the view into neighboring areas. If the dementia resident can see into neighboring areas, he/she will want to explore those areas and potentially become lost. Therefore, a facility should take advantage of the “out-of-sight, out-of-mind” principle and not entice the resident to want to escape. The same strategy should be used for doors that separate the dementia unit from the rest of the facilities. These doors can be disguised by a scene painted on them.

Mirrors should not be in the halls of a dementia unit or in the individual rooms. People with advanced dementia do not remember what they look like and their image in a mirror makes them think a stranger is in the room. Falling out of bed—especially a strange bed—can be a problem that may be alleviated by a double bed or a waterbed.

Incontinence – loss of bowel and bladder control – is inevitable at some stage of dementia, but initially incontinence is due to inability to find the toilet in a strange place. A trash can or flower pot may inadvertently take on this role. A good facility will make the toilet easy to find, perhaps by having it behind a pulled curtain instead of a door, and having a picture of a toilet on the door frame to help orient the resident. Staff can regularly ask the resident if he/she needs to use the bathroom.

Keeping the person with dementia engaged in meaningful activities is extremely important. Sometimes these activities include aspects of personal care, such as folding clothes as they go into the dresser, having soothing music (perhaps from the period of the individual's adolescent years) during bathing and eating times, or getting exercise while using a walker or wheelchair. Group activities such as having the residents sit in a circle and engage in reminiscence exercises or rolling a beach ball to each other can bring cognitive delight as well as provide beneficial physical activity.

These and other strategies are systematically taught by the Alzheimer's Association Rocky Mountain Chapter through their Alzheimer's Learning Institute (ALI). Experts conduct ALI training sessions throughout Colorado. For details contact them at 1-888-535-3241 or 303-813-1669.

Baby Boomers Begin to Require Long-Term Care

by Elizabeth Garner, Coordinator, County Information Services, Cooperative Extension, Colorado State University

The aging of America has long been of interest to researchers primarily due to the incredible impacts the baby boom generation (those born between 1946 and 1964) have made on American society. "Boomers" were studied as they impacted K-12 education, entered the workforce and now as they begin to leave it.

In 2000, 40 percent (over 150,000) of the population 65 and older (65+) in Colorado reported some type of disability. Holding percentages constant, this could result in more than 400,000 people over 65 requiring some type of assistance in 2030. By 2030, it is estimated that there will be 1.09 million people over 65 in Colorado, representing 15.5 percent of the population, over two and one half times the amount in 2000. As the baby boomers move into the 65 and older age group, there is growing concern of how Colorado can respond to the needs of the elderly and their caregivers.

The population over 65 in Colorado grew by almost 90,000 between 1990 and 2000 to number 416,000 in 2000 and represented 9.7 percent of the total population in the state. Of the population over 65, the age group over 85 grew at the fastest rate between 1990 and 2000 - by 47 percent to reach over 48,000¹. The older population will continue to grow significantly in the future and will expand greatly between the years 2010 and 2030 when the baby-boom generation reaches 65. Understanding the size, location and demographic characteristics of this age group will help prepare Colorado for this transition.

The 416,000 Coloradans over 65 are not distributed equally throughout the state. Currently most of the population 65 and older is concentrated in the Eastern Plains while the baby boomers have concentrated in mountain counties. Using the variable "percentage of the population" does mask the absolute size of these age cohorts. The metro counties of Denver, Jefferson, El Paso and Arapahoe each have more than 40,000 people over the age of 65. Almost 50 percent of all Coloradans over 65 live in these four counties. Similarly, these same counties plus Adams, each have over 100,000 baby boomers and 56 percent of all baby boomers live in these five counties².

Living Arrangements

Most older Coloradans (95 percent) still live in households while the other 5 percent live in "group quarters" - primarily nursing homes. Of those in households, 67 percent of them live with family members. For those who do not live with family, 96 percent of them live alone while the other 4 percent live with non-relatives. There are over 128,000 Coloradans over 65

who do not live with family, two-thirds are women and 97 percent live alone. Seventy-eight percent of the householders over 65 own their home. The percent of those over 65 living in nursing homes declined between 1990 and 2000 from 5 percent to 4 percent³.

Disability and Alzheimer's Disease

In 2000, 40 percent of Colorado's older population (159,000) reported having at least one disability. Coloradans over 65 reported sensory (15 percent), physical (27 percent), mental (9 percent), self-care (8 percent) or going outside the home struggles (18 percent)⁴. One in 10 adults 65 and over and one of two adults over 85 have Alzheimer's disease⁵. Using these proportions, it is estimated that in Colorado, in 2000, there were more than 41,000 individuals over 65 and more than 24,000 individuals over 85 impacted by this disease. If Colorado's population over 65 grows to 1.09 million as it is expected by 2030, over 109,000 individuals could be diagnosed with Alzheimer's disease.

Status of Nursing Care and Assisted Care Facilities

Experts estimate the number of Coloradans over 65 will increase by over 260% between 2000 and 2030, reaching 1.09 million. The sheer numbers of elderly will put a strain on home- and community-based services, nursing facilities, and long-term-care facilities. In Colorado in 2001, there were 16,855 nursing facility residents or 4 percent of the population age 65 and over (65+), which is a decrease from 5 percent in 1990. On average, there are 44 nursing facility beds per 1,000 people 65+, and the occupancy rate for these beds is 84 percent⁶. If this population increases to what is projected, in 2030 the demand for nursing care beds may rise to 43,600, requiring an increase of approximately 27,000 more beds.

Nursing care facilities monthly fees range from \$3,000 to \$9,000 per month⁷. In Colorado in 2001, the state average was \$140 per day and the US average was \$150⁸. Assisted living costs are about one half that of nursing facilities.

The length of stay at nursing care facilities depends on the condition and needs of the resident. The average stay for new entrants in the National Nursing Home Survey was 257 days where the median was 22. Since nursing home residents have either long- or short-term stays, the average length of stay data is skewed.

The demographics of nursing home residents have changed over the last two decades. The proportion of nursing home residents in the older age groups is increasing, with those age 85 and older growing from 35 percent in 1977, to 47 percent in 1995. The proportion

Baby Boomers ... Long Term Care *continued from page 6*

of nonwhite nursing home residents increased from 8 percent in 1977 to 12 percent in 1995. When new entrants were followed to their discharge, the proportion of residents discharged after three and six months changed only slightly over the past two decades, representing about two-thirds of the new entrants. However, the percentage of residents staying three months or less has increased from 12.4 percent in 1977 to 17.3 percent in 1995.

The increased percentage of short-stay residents, along with the increased availability of home care and other long-term care options that can prevent or delay nursing home placement, has resulted in a population of older and more functionally impaired nursing home residents⁹. For assisted living, the average resident age is 85, and 80 percent of the residents are female and 97 percent are unmarried or not living with their spouse. Compared to those in nursing facilities, those in assisted living have fewer ADL (Activities of Daily Living) impairments. Twenty-five percent had a low need, 50 percent had a medium need and 25 percent had a high need for assistance. The average length of stay reported by the Assisted Living Federation of America, ALFA, is 2.2 years with a median of 2.0 years¹⁰.

In 2003 the oldest baby boomer is 57. Within the next decade (2013) the number of people 65+ are estimated to increase by 35% and within two decades (2023) by over 100%. The aging of the baby boomers will again impact many institutions in America as “boomers” did when they entered grade school, college and the workforce. Colorado must prepare itself to be ready for the types of services and products that its aging population will require.

^{1,3,4} Census 2000

² Demography Section, Colorado Department of Local Affairs

⁵ Alzheimer's Association

^{6,8} AARP, “Across The States 2002”

⁷ Agency on Aging, (http://www.aoa.gov/eldfam/Housing/Housing_Services/HH_Assisted_Living.asp)

⁹ Deja-Vu All Over Again, ~ Or Is It? - Nursing Home Use in the 1990's, <http://www.lib.muohio.edu/dlib/pdfretrieve.php?folder=scripps/&oclc=46516927>

¹⁰ Department of Health and Human Services, <http://aspe.os.dhhs.gov/daltcp/reports/litrev.pdf>

Becoming a Caregiver *continued from page 4*

California five times, visiting friends where we had lived for so many years. We have made two trips to eastern Kansas, and one to New York and New England. Nearer home, we often go up to Estes Park and Rocky Mountain National Park. We used to walk around town or on the trails. When walking any distance was no longer possible, we got a wheelchair and Sara makes the circuit around Sprague or Bear Lake on wheels. It's good exercise for me, too! We attend the theater a lot. When plays became too difficult to

follow, we increased our attendance at musical concerts: classical, swing and Dixieland. Unlike drama, the pleasure of music is in the moment of its playing; one doesn't need to remember in order to enjoy it. The same is largely true with the visual arts, so we visit the Loveland museum or some of the exhibits in Denver. Again, the museums provide wheelchairs. At home, we dial in classical music radio and have music on tape and CDs as well. Nearly every week we attend our religious meeting, and afterwards visit with one of our daughters. Occasionally, we go to some entertainment together with family.

As for the daily routine of living, I do the cooking, housekeeping, laundry, see to Sara's medications, help her bathe and dress, and take care of incontinence emergencies that sometimes occur. I do not consider such chores a burden. It is in our nature to be active, and I have taken as my guide that I ought to do the work that I find at hand. There has always been plenty of it! I consider it fine therapy for releasing tensions. In addition, I find time to work a little in the garden, to write, and to attend literature classes now and then.

That said, there is no denying that Sara and I face a trying and undesirable future. Sara walks most unsteadily; often she needs help in order to stand or to get out of bed. On her 87th birthday, she dropped down as she stepped off the front porch - not hard, just appeared that her knees bent and she sat down on the stoop. Last week, she toppled off the vanity chair as she was untying her shoes. She did not understand how that had happened to her.

The truth is, Sara is virtually without memory now; only I and our daughters remain clear to her. She struggles to hang on. Often she asks me where it was we met; was it in Elgin? She has the right to an answer but clearly there is little content to that word for her. Knowledge of her granddaughters is muddled. She can't remember who her doctors are, any event that transpired over three minutes ago, or any plan we have made for the day.

I am struggling to support Sara in this ocean of forgetfulness. I know I must keep her afloat, but I also know that in the end I shall fail. She realizes her dependence upon me and appreciates my help. Every time I get up in the night with her, help her stand, bring her a pain pill, help clear her confusions, she thanks me. We are engulfed in our love for each other. But it is a love full of melancholy, so different from the love we knew 56 years ago. Then we were inspired by beginnings; now we are obsessed with endings. Once in a while, such gloomy realizations depress me. Perhaps, as my dream revealed, I shall tire and fail. “But not yet,” I tell myself. “Courage. There is still work to do.”

Home Modifications for People with Alzheimer's Disease

by Kenneth R. Tremblay, Jr., Professor, Department of Design and Merchandising, and Cooperative Extension Housing Specialist, Colorado State University

Families typically care for people with Alzheimer's disease for an average of four years. There exist a variety of home modifications that can increase safety and comfort.

- Add safety devices such as a motion detector, door alarm and fall protection alarm.
- Install a distinguishing feature on the house front such as a colorful or unusual mailbox or paint the home in a bright color.
- Remove doormats or throw rugs, or secure them to the floor.
- Secure locks on doors to control wandering behavior.
- Add childproof locks on cupboards and medicine cabinets to reduce risk of poisoning.
- Lower hot water temperature to reduce risk of burning.
- Remove unnecessary furniture that reduces open space; a simple, spacious furniture arrangement is best.
- Make sure all furniture in the home is sturdy.
- Eliminate extension cords and keep electrical cords out of the flow of traffic.

- Create signs with symbols designating areas of home.
- Keep sentimental items out to help with memory.
- Maintain proper lighting indoors and outdoors and add nightlights for nighttime movement
- Place the television in a location where it is easily accessible and where it will not reflect a glare.
- Use contrasting colors in the home to give important objects more visibility and emphasis.
- Have a fenced-in, lockable, open yard to prevent wandering behavior.
- Use low-cost devices such as door knobs with levers that operate easily with a push, grab-bars in the shower and by the toilet and tub, a hand-held showerhead with a flexible head, and adjustable rods in closets.
- Confine living quarters to one floor to avoid stairs.
- Install an intercom system for emergencies.
- Tint windows, or install awnings or window coverings, to reduce glare and better control light.

It may be a good idea to have an interior designer, architect, or occupational therapist come into the home and help determine which modifications work best. A good resource is *The complete guide to Alzheimer's-proofing your home* (www.agelessdesign.com).