

EARLY ONSET DEMENTIA  
A NATIONAL CHALLENGE, A FUTURE CRISIS



## **ACKNOWLEDGEMENTS**

This report was prepared by Katie Maslow, Associate Director for Quality Care Advocacy, Alzheimer's Association, Washington, DC. The Alzheimer's Association acknowledges Kenneth M. Langa, MD, PhD, Division of General Medicine and VA Center for Practice Management and Outcomes Research, Mohammed U. Kabeto, MS, Division of General Medicine, and David R. Weir, Ph.D., Institute for Social Research, University of Michigan, Ann Arbor, MI, for their valuable work in preparing the HRS data used for the Alzheimer's Association report.

# Early Onset Dementia: A National Challenge, a Future Crisis

---

## REPORT SUMMARY

A new assessment of data by the Alzheimer's Association focuses light on a younger generation of individuals who suffer from Alzheimer's and other forms of dementia in contrast to the widely held view that these diseases only afflict older Americans.

Newly analyzed data from the Health and Retirement Survey (HRS) indicates that there may be as many as a half a million Americans under age 65 who have dementia or a cognitive impairment at a level of severity consistent with dementia. Combining this with data from other studies, the Alzheimer's Association calculates that there are between 220,000 and 640,000 people with early onset Alzheimer's or related dementia in the U.S. today.

This report incorporates the new analysis of data from the Health and Retirement Survey (HRS) with a survey conducted by the Alzheimer's Association and in-depth, personal interviews, all of which paint a picture of the early onset of Alzheimer's and dementia among a hidden generation of Americans under age 65.

The conclusions drawn from these new data, shed much needed light on the vulnerability and unique circumstances faced by this generation of Americans, most of whom are baby boomers, who will change the face of disease and health care in coming decades. The survey research includes extensive personal testimony from people with Alzheimer's, and together with the other reports offers policy makers new insights that may help them address health and long term care needs over the next decade.

## KEY FINDINGS

- § Getting a diagnosis for early-onset Alzheimer's and dementia presents serious problems for individuals under the age of 65. Health care providers generally don't look for the disease in younger patients and it can therefore be months or years before the right diagnosis is made and proper treatment can begin.
- § Many people with early onset Alzheimer's and other dementia are still working when their symptoms emerge. Due to the nature of the condition, changes in their job performance or behavior may not be understood or addressed. The workplace can become a difficult environment.
- § Those who leave their jobs before diagnosis may be denied employer assistance that would otherwise be provided to individuals with disabilities.
- § Many who have early onset Alzheimer's and other dementias do not apply for government disability payments under Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI) or other disability programs, either because they are not aware of available benefit programs or they are unaware that a person with dementia has a qualifying disability.
- § Many individuals with early onset Alzheimer's and other dementias have low incomes and are in need of assistance, but have a difficult time getting it.
- § Many with early onset Alzheimer's and other dementias are in poor health, have higher rates of serious medical conditions, are much more likely to be hospitalized, and have higher out-of-pocket expenditures for prescription drugs.

- § Almost one-third of people with early onset dementia have no health insurance. People with dementia have trouble buying private health insurance. If they are not covered by Medicare or an employee plan and do not qualify for Medicaid, they may not be able to afford health care and other essential living expenses.
- § People with early onset Alzheimer’s and other dementias who require long-term care services, face high out-of-pocket expenses that, depending upon their age and financial circumstances, may not be covered by Medicaid, Administration on Aging programs or other programs that pay for long-term care services for some people age 65 and over with dementia.
- § Existing medical care, home care or community service programs may not be appropriate for early onset individuals.
- § Family members and other care partners often lack the information and support they need to provide care to their loved ones.

## CONCLUSION

The study concludes that not nearly enough is known about the unique characteristics of early onset diseases or the problems faced by those who have them. There also remains an inadequate amount of data available on the actual number of early onset individuals and their condition.

The Alzheimer’s Association recommends a number of steps be taken in order to meet the needs of the early-onset generation of individuals with dementia.

## RECOMMENDATIONS

---

1. **A government-private** sector sponsored national study to determine a more precise number of people with early-onset dementia, the causes of their dementia and the unique problems with which they are confronted.
2. **Research** devoted specifically to the prevention, the progression and delay of early-onset disease.
3. **A national** education program, with specific and separate components aimed at the general public; health care professionals, particularly those in a position to diagnose the disease; family and volunteer caregivers; employers, and human resources personnel.
4. **Analysis** of work environments for employees who have early onset Alzheimer’s and other dementias with emphasis on workplace accommodations that may enhance their lives and their productivity.
5. **Dissemination** of information regarding Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Medicare, Medicaid and other programs that aid people with disabilities.
6. **Elimination** of the 2-year waiting period for Medicare coverage of those under age 65 who’ve qualified for SSDI.
7. **Affordable** health insurance for individuals with early onset Alzheimer’s and other dementias who do not have access to or are not eligible for existing insurance programs.
8. **Expansion** of Medicaid income limits to accommodate those with early onset.
9. **Expansion** of Administration on Aging (AoA) funded services to accommodate under-age 60 individuals with early onset Alzheimer’s and other dementias.
10. **More** participation of those with early onset in program planning and public education designed to meet the needs of those affected.

## EARLY ONSET DEMENTIA: A NATIONAL CHALLENGE, A FUTURE CRISIS

Alzheimer's disease and other dementias are devastating conditions that create huge emotional, financial, and physical challenges for the person and his or her family. These conditions usually affect older people. When they occur in people under age 65, the conditions cause additional and unique problems because they are so unexpected and because most of the potentially helpful programs and services are designed for and targeted to older people.

The term *early onset dementia* refers to dementia that first occurs in a person under age 65. The dementia may be caused by Alzheimer's disease or other diseases and conditions.<sup>1</sup> People who have early onset dementia may be in any stage of dementia – early, middle, or late.

New data from the Health and Retirement Study (HRS), a large, nationally representative survey, indicate that in 2000, 480,000 Americans age 55-64 had cognitive impairment at a level severe enough to be considered disabling.<sup>2</sup> The HRS data do not specify the causes of disabling cognitive impairment, and it is not clear how many of these people had Alzheimer's disease or other dementias.<sup>3</sup>

Two other studies suggest a tentative range of 220,000 to 640,000 for the number of Americans with early onset Alzheimer's disease and other dementias.<sup>4,5</sup> Additional research is needed to develop a more precise figure, but the proposed range provides a plausible first estimate and indicates that the number of Americans with dementia that first occurs before age

65 is much higher than is generally acknowledged. They are people like:<sup>6</sup>

**Deborah Mauro:** Deborah was a physical education teacher in the Auburn, Maine, school system, a marathon runner, bicyclist, and downhill skier. She was diagnosed with Alzheimer's disease in 1999, at age 49. Her husband, John, took care of her at home until 2005. She now lives in a residential care facility in Maine. She can no longer walk and does not recognize her husband or their adult children, Krista and John.

**Gerald Michalak:** Jerry was an elementary school teacher in the Williamsville Central School System and an educational consultant to school districts across New York state for 31 years. In 1998, he began to experience memory problems. His primary care physician first diagnosed the problem as stress. Further loss of cognitive abilities led to his retirement in 2000, and he was finally diagnosed with Alzheimer's disease in 2005, at age 62. Currently, he lives at home with his wife Janet in Getzville, New York.

**Woody Hoffman:** Woody was a senior finance officer in the Berkeley, California, Public Works Department. He was diagnosed with Alzheimer's disease in 2002, at age 59, and had to retire in 2003, because of the disease. His diagnosis came only four months after he married Cathy Dodd. Woody was an avid weightlifter, runner, and bicyclist. He continued these activities until late 2005, when another bicyclist ran into him during his daily bicycle ride on the Golden Gate Bridge. Woody suffered severe spinal cord and

traumatic brain injuries. He continues to exercise both mind and body as part of his rehabilitation in a skilled nursing facility in California.

**Dick Ryan:** Dick was a city planner in Boulder and Vail, Colorado. In his mid-40s, he left his job and met and married Darlene. He never worked again but stayed home to care for their son. He had been a quiet, gentle man who loved golf, but in his mid-50s, he began to have sudden rages and odd behaviors. Dick was diagnosed with frontotemporal dementia in 2003, at age 63. The family moved to Texas a few years ago, and Dick now lives in a secured assisted living facility there.

**Tracy Mobley:** Tracy was a nurse technician in a hospital intensive care unit in southwest Missouri. She was diagnosed with Alzheimer's disease in 2002, at age 38. From the onset of symptoms, Tracy kept a diary and wrote a book, *Young Hope*, which chronicles the journey she and her family took to get a diagnosis at such a young age. Currently, Tracy lives at home with her husband, Allen, and their 11-year old son, Austin, who provide much care and support.

Little is known about the problems confronted by Americans with early onset dementia. This Alzheimer's Association report uses information from the HRS, a 2004 Alzheimer's Association survey,<sup>7</sup> and a few other studies to begin to piece together a picture of these problems. The picture is not complete, but the report provides a startling first view of the large, unmet needs of Americans with early onset dementia and their families.

The report emphasizes the perspectives of people with early onset dementia. Quotes from their responses to the Alzheimer's Association survey are shown in italics to convey their perceptions and concerns about

the problems they face. For people who were not able to complete their own survey, the report uses quotes from family members and other care partners to convey a personal perspective about problems that result from early onset dementia.

## PROBLEMS CONFRONTED BY PEOPLE WITH EARLY ONSET DEMENTIA AND THEIR FAMILIES

### 1. Difficulty getting an accurate diagnosis

Because dementia is usually considered a condition of older people, it is not expected in younger people. When a person under age 65 goes to a doctor with symptoms of dementia, the doctor may not even think of dementia as a possibility. Some doctors may not know how to diagnose early onset dementia or feel confident diagnosing it. As a result, getting an accurate diagnosis can be a long, difficult, and frustrating process.

One third of the responses to the Alzheimer's Association survey indicate that it took more than a year from the time the person first sought medical attention for his or her symptoms to the time when a diagnosis of dementia was made. Some people had to wait four to six years, and some received one or more wrong diagnoses before finally being diagnosed with dementia.

Ø *"No one understood my symptoms. I had many MRIs. I was always confused, but no one understood" (person was diagnosed with Alzheimer's disease at age 50, five years after first seeking medical attention for her symptoms).*

Ø *After going to three different neurologists and two internists, I went to (a university medical center) and got help. All the doctors thought I was too young to have brain disease” (person was diagnosed with frontotemporal dementia at age 56, 18 months after first seeking medical attention for his symptoms).*

## 2. Loss of employment and job-related income

Most older people with dementia are retired, but many people with early onset dementia are still working when their symptoms emerge. Alzheimer’s disease and some other diseases and conditions that cause dementia have a slow, gradual onset. Over time, the person loses the ability to perform his or her usual job tasks, but the reason for this change may be not be understood by the person, the employer, or co-workers. Thus, the person may lose self-esteem and the feeling of being a productive person and a valued employee and co-worker.<sup>8</sup>

Some people with early onset dementia are fired or leave their jobs voluntarily before getting a diagnosis. In these situations, work disability may never be formally recognized, and employer responses that are usually triggered by work disability, such as work accommodations and referrals for disability benefits, do not occur.

Ø *“By the time I was given a diagnosis, I had had several years of failing at my job, been forced to retire, become penniless. Had I had a diagnosis, (my employer) would have been legally bound to give me a lesser job. What a waste!” (person was diagnosed with vascular dementia at age 52).*

Losing one’s job has a huge financial impact. The HRS data show that average annual income was much lower for people age 55-64 with disabling cognitive impairment than for people of the same age with normal cognitive status (\$17,840 vs. \$42,852 per year). More than 60% of those with disabling cognitive impairment had annual income below \$11,000.

## 3. Difficulty obtaining Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and other disability payments

SSDI and SSI are federal government programs intended to provide a floor of income for people who cannot work because of a disability but are not old enough to receive regular Social Security retirement payments. Both programs use the same disability requirement: the person must be unable to work because of a medical condition that is expected to last at least a year or result in death *and* is severe enough that the person cannot do any kind of work..

Ø *“We were not aware that the problem was Alzheimer’s disease when the person had to quit work two years before diagnosis. Therefore, we didn’t apply for disability insurance” (care partner of a person diagnosed with Alzheimer’s disease at age 64).*

Most U.S. jobs provide Social Security coverage. People who meet the disability requirement and have worked long enough in jobs with Social Security coverage are eligible for SSDI. Those who have not worked long enough in covered jobs are eligible for SSI if they have very low income and assets (up to \$603 income per month and \$2,000 assets in 2006). Some jobs have other disability programs. To apply for disability payments, however, the person or family must be aware of these programs *and* aware that the person has a disability.

The HRS data show that 29% of people age 55-64 with disabling cognitive impairment were receiving SSDI disability payments. Another 18% were receiving SSI disability payments.

Some people with early onset Alzheimer's and other dementias apply for SSDI or SSI disability payments but are denied because the Social Security Administration decides they do not meet the disability requirement and can still work.

Ø *"Social Security denied x 2, say can work and learn new skills in spite of diagnosis" (person was diagnosed with Alzheimer's disease at age 40).*

Despite the importance of SSDI and SSI disability payments for people with early onset dementia, no organization is currently tracking how many of these people apply and are denied or the reasons for the denials.

#### **4. Lack of health insurance and high out-of-pocket expenditures for medical care**

Unlike almost all older people, people under age 65 generally do not have Medicare. People with early onset Alzheimer's and other dementias who receive SSDI get Medicare after a 2-year waiting period, and people who receive SSI get Medicaid in most states. Thus, SSDI and SSI are important not only for disability payments but also for health insurance.

The HRS data show that 26% of people age 55-64 with disabling cognitive impairment had Medicare; 29% had Medicaid; 35% had employer-provided health insurance, either through an early retirement or disability program or a spouse's job; and some people had health insurance from two of these sources. The

data show that 29% of people age 55-64 with disabling cognitive impairment had no health insurance.

Lack of health insurance is clearly a major problem for people with early onset Alzheimer's and other dementias. In addition to diagnostic and other medical care related to their dementia, many of these people also need medical care for other serious acute and chronic conditions.

The HRS data show that many people age 55-64 with disabling cognitive impairment had serious co-existing medical conditions, including hypertension (64%), heart disease (34%), and diabetes (28%) – conditions increasingly associated with dementia – as well as arthritis (47%), lung disease (11%), and cancer (8%). Nearly half (48%) were reported to be in poor health. People age 55-64 with disabling cognitive impairment were four times more likely than those of the same age with normal cognitive status to have been hospitalized in the previous two years. Their out-of-pocket costs for medications were four times higher, and they were two times more likely to have received medical home health care.

Some people with early onset dementia try to buy private health insurance and are denied because of their dementia. Those who succeed in buying the insurance are likely to face high premiums, deductibles, and co-payments, and high out-of-pocket expenditures for medical care that is not covered by the insurance.

Ø *"Once our health insurance company became aware of the increased costs for diagnosis, doctor visits, and prescriptions, they increased our premiums 60%. We are stuck paying \$1,007 a month, for a family of 4, which covers the doctor and 3 prescriptions" (care partner of a person diagnosed with Alzheimer's disease at age 51).*



There is a clear gap between the income and assets a person or family would need to pay for private health insurance and basic living expenses, on the one hand, and the income and assets a person can have and still be eligible for Medicaid. As a result, some people with early onset dementia and their families are forced to choose between paying for health insurance and needed medical care vs. paying for basic living expenses, not only for the person with dementia, but also for other family members, including minor children.

### **5. High out-of-pocket expenditures for long-term care**

Families usually provide care at home for as long as possible for people of any age with dementia. In the late stage of dementia, most people require nursing home care. Some use assisted living and other paid long-term care services, such as adult day care, respite care, and in-home personal care, at various times in their illness.

In 2005, the average annual cost of nursing home care was \$64,240;<sup>9</sup> the average annual cost of assisted living was \$34,860,<sup>10</sup> and average costs were much higher in some parts of the country. Home and community-based services are less expensive, but total costs can add up if the services are used consistently over long periods of time, as they often should be to benefit the person and provide relief and assistance for the family.

Medicaid pays for long-term care services for people under age 65 with dementia if they meet the SSI disability requirement, have low enough income and assets to be eligible for Medicaid, and meet any additional state eligibility criteria for the specific services they need.

The Administration on Aging (AoA) pays for long-term care services, such as adult day care, transportation, meals-on-wheels, and services to support family caregivers, but only for people age 60 and over. People with early onset dementia who are under age 60 and their family caregivers are not eligible.

### **6. Lack of appropriate medical care, residential care, and community services**

People with early onset dementia who responded to the Alzheimer's Association survey emphasized strongly that all medical, residential care and community service providers should, first and foremost, treat them as viable people with feelings, thoughts, and capabilities.

Ø *“Please don't pull the plug too early. I am still quite capable of many things and continue to strive to maintain self reliance” (person was diagnosed with Alzheimer's disease at age 62).*

Most services for people with dementia are designed for and targeted to older people. People with early onset dementia who responded to the survey said they do not fit in and feel uncomfortable with these services. They said they need, and generally are not able to find, support groups and adult day programs specifically designed for and targeted to younger people. They also said they need transportation, volunteer opportunities, supported employment, social activities, and help for their families, especially young children and teenagers.

Family members and other care partners noted the same service needs for the person with dementia. They stressed that when a person with dementia feels out of place in a support group or adult day care program for older people, the person often refuses to go to the program. Care partners also stressed that existing information and programs do not meet their needs.

Ø *“I always feel ALONE in dealing with someone diagnosed sooo early in life” (care partner of a person diagnosed with Lewy body dementia at age 57).*

Some people with early onset dementia and their care partners complained that medical, residential care, and community service providers do not know how to treat or provide care for people with early onset dementia. Training to address this problem is not generally available. Moreover, much of the information that would be needed as a basis for such training does not exist. Likewise, information that government agencies and private organizations need to plan for appropriate services for people with early onset dementia does not exist.

These six problems are clearly interrelated. Problems in getting an accurate diagnosis contribute to lack of understanding about the reason for changes in a person’s job performance and subsequent failure to apply for disability benefits. Lack of health insurance and low income limit access to potentially helpful services that could reduce the emotional, financial, and physical challenges of dementia for the person with the condition and his or her family.

### **STEPS TO REDUCE THE PROBLEMS CONFRONTED BY PEOPLE WITH EARLY ONSET DEMENTIA AND THEIR FAMILIES**

Many steps could be taken to reduce the problems confronted by people with early onset dementia and their families. A first step is greater general awareness of early onset dementia.

Research to develop more precise information about the number of people with early onset dementia and the diseases and conditions that cause their dementia is

essential. This information is needed to support greater general awareness about early onset dementia, training for medical, residential care and community service providers, and planning for appropriate services for people with the conditions and their families and other care partners.

Research on approaches to prevent and delay onset and progression of diseases and conditions that cause early onset dementia is also essential. Government and private organizations that pay for biomedical research should solicit and fund research on early onset dementia, and advocacy for research dollars should include early onset dementia explicitly.

Other steps that could be taken to address the six problems described in the report are:

- § **Increase** awareness of early onset dementia and the importance of accurate diagnosis among doctors and other health care professionals.
- § **Provide** training for doctors about how to diagnose early onset dementia and about the availability of specialized diagnostic centers.
- § **Increase** awareness of early onset dementia among employers and human resources personnel, including the importance of referrals for disability benefits.
- § **Provide** information about possible work accommodations for people with early onset dementia and how the legal requirements for work accommodation apply to dementia.
- § **Develop** and disseminate accurate, easily accessible information about SSDI, SSI, and other sources of disability payments; encourage prompt applications; and provide help with applications, if needed.

To see additional information on this topic, log onto [www.alz.org](http://www.alz.org)

§ **Analyze** the reasons for SSDI and SSI denials, especially denials based on a person's alleged ability to work, and advocate for any needed changes in the disability requirement.

§ **Eliminate** the 2-year waiting period for Medicare.

§ **Advocate** at the federal and state level for explicit consideration of people with early onset dementia in any initiatives to expand affordable health insurance, including initiatives for buy-in to Medicare, Medicaid, and the Federal Employee Health Benefits Program.

§ **Advocate** at the state level for extension of Medicaid to people with early onset dementia with income above current limits and for a package of services that meets their needs;

§ **Advocate** at the federal level for extension of AoA-funded services to people under age 60 with early onset dementia and their family caregivers.

Also important are steps to engage people with dementia, as individuals or in groups, such as the Alzheimer's Association's Advisory Group of People with Dementia and the Dementia Advocacy and Support Network International (DASNI), along with families and others -- researchers, health care and community service providers, employers, human services personnel, government and private organizations -- in learning more about the characteristics and service needs of people with early onset dementia and planning to meet those needs.

## A CALL TO ACTION

A growing number of men and women with early onset dementia are speaking out about their experiences and service needs. Families are also speaking out, along

with the person with dementia or in his or her place, if necessary.<sup>6</sup>

**John Mauro** is a devoted caregiver and strong advocate for his wife Deborah, who is no longer able to speak out for herself, and for all people with early onset dementia. He meets with state and local legislators, raises concerns about early onset dementia at every opportunity, and works with the Maine Alzheimer's Association Chapter to increase awareness of and services for people with dementia and their families.

**Gerald Michalak** is an active member of the Western New York Alzheimer's Association Chapter, committed to learning more about Alzheimer's disease and helping others with the disease, including authoring an article about telling friends and family about an Alzheimer's diagnosis for the chapter newsletter. He has volunteered to participate in the Alzheimer's Disease Neuroimaging Initiative sponsored by the National Institutes of Health in the hope of finding a cure for this disease. On March 7, 2006, Jerry traveled to Albany to participate in the Alzheimer's Association New York state lobby day, where he met with his state senator and his assemblyman. He and his wife Janet, who retired from teaching in 2004 to spend more time with Jerry, have two grown sons, Nathan and Justin.

**Woody Hoffman** was an active member of the Northern California and Nevada Alzheimer's Association Chapter before his injury in late 2005. He captained a Memory Walk team; spearheaded many programs for early onset dementia; testified in Sacramento on Alzheimer's legislation; and was honored as an "Outstanding Advocate for Alzheimer's." He continues to inspire and defy the odds as he regains physical and cognitive function following his injury. Cathy Dodd is a highly regarded Chapter volunteer and committee member. Since Woody's injury, she has scaled back her job responsibilities in the University of California, Berkeley's

MBA programs to be at Woody's side and advocate for rehabilitation for him and other people with dementia.

**Darlene Ryan** is an active member of the national board of the Association for Frontotemporal Dementias. She is a strong advocate for her husband, Dick, and other people with frontotemporal and other dementias. She continues to run her pharmaceutical manufacturing business, raise their son, and visit and bring Dick home for family dinners on weekends whenever possible.

**Tracy Mobley** has written a second book with the help of her 11-year old son; it is an interactive storybook for children to explain Alzheimer's disease and dementia and suggest ways that children can help. Tracy continues to volunteer as an advocate with the Southwest Missouri Alzheimer's Association Chapter and the Dementia Advocacy and Support Network International (DASNI). She has also led a national project to create a Dementia Memory Quilt which will be displayed in the Alzheimer's Association national office in Chicago.

---

The Alzheimer's Association congratulates these individuals and the many others who are working to increase awareness of and concern about early onset dementia and those affected by it. We encourage others to join us in ongoing efforts to resolve problems and improve available services for people with early onset dementia and their families.

---

## NOTES AND REFERENCES

1. Dementia is a syndrome of decline in memory and other cognitive abilities, such as language and judgment, that is severe enough to interfere significantly with work, usual social activities, and relationships with others. Dementia can be caused by Alzheimer's disease, cerebrovascular conditions (e.g., multi-infarct disease and stroke), frontotemporal conditions, Lewy body disease, Parkinson's disease, Huntington's disease, and other diseases and conditions.
2. The Health and Retirement Study (HRS) is a longitudinal survey of a nationally representative sample of people age 50 and older in the U.S., including people living in the community and nursing homes. The University of Michigan's Institute for Social Research and Survey Research Center has conducted the survey every two years since 1992, under a cooperative agreement with the National Institute on Aging. In 2000, the HRS interviewed about 19,000 people, including 6,513 people age 55-64. With weighting, the 6,513 people age 55-64 represent 23,859,596 Americans age 55-64. In 2000, the HRS sample in the age group 50-54 was not nationally representative; for that reason, HRS data on that age group are not included in the Alzheimer's Association report. More information about the HRS is available online at <http://hrsonline.isr.umich.edu>.
3. The HRS uses several methods to measure cognitive status. For each method, an approach was developed for the Alzheimer's Association report to classify cognitive status as normal, borderline cognitive impairment, or disabling cognitive impairment. The HRS does not provide information about the causes of cognitive impairment. The term *disabling cognitive impairment* is used throughout the report to refer to a level of cognitive impairment severe enough to cause functional limitation, as required for a diagnosis of dementia. Additional information about how cognitive status is measured in the HRS and how cognitive impairment was classified for this report is available in the report.
4. Data from the Rochester (MN) Epidemiology Project show that from 1990 to 1994, 4.6% of new cases of dementia occurred in people age 40-64 (Knopman DS, Petersen RC, Cha RH, et al. Incidence and causes of nondegenerative nonvascular dementia: A population-based study. *Archives of Neurology*. 2006;63:218-221.) Extrapolating to the U.S. population and assuming the same average survival for people with early and late onset dementia and that 4.5 million people age 65 and older have dementia, this proportion supports an estimate that about 220,000 Americans have early onset dementia.
5. A telephone survey of a nationally representative sample of U.S. households found that in 2003, 1.2 million people age 18 and older in 640,000 households said they provided unpaid care for a person age 50-64 with Alzheimer's disease, dementia, or mental confusion (National Alliance for Caregiving. *Caregiving in the U.S.* [Bethesda, MD: 2004], and Alzheimer's Association and National Alliance for Caregiving. *Families Care: Alzheimer's Caregiving in the United States, 2004*. [Washington DC: 2004].) These figures support an estimate that 640,000 Americans age 50-64 had early onset dementia.
6. The named individuals in this report are not HRS respondents.
7. The Alzheimer's Association survey was conducted in 2004. A 2-page questionnaire was mailed to 200 people with early onset dementia and then posted on the Association's website. Responses were received for 94 people

with early onset dementia, including some survey forms completed by the person with dementia and other forms completed by a family member, other care partner, or the person with dementia and care partner together.

8. Harris PB, and Keady J. Living with early onset dementia. *Alzheimer's Care Quarterly*. 2004;5(2):111-122.
9. MetLife Mature Market Institute, *The MetLife Market Survey of Nursing Home & Home Care Costs*. Sept. 2005.
10. MetLife Mature Market Institute, *The MetLife Market Survey of Assisted Living Costs*. Oct. 2005.