INDEX

Executive Summary ......................................................... Pages 2-3

The Rise of Alzheimer’s Disease ........................................ Pages 4-12

Rising to Meet the Challenge Ahead ................................. Pages 13-14
EXECUTIVE SUMMARY

Genworth Financial’s Long Term Care Protection business recently marked its thirtieth year, making it the longest tenured provider of long term care insurance in America. As the leading protector of families with long term care needs, Genworth has acquired a unique historical perspective on the costs associated with diseases requiring such care. Genworth’s underwriting companies have insured more individuals, paid more claims and demonstrated greater financial stability than any other provider of long term care insurance operating today.

Among the many lessons learned over the past three decades, perhaps none is more profound than the fact that the number of claims for the care of individuals suffering from Alzheimer’s disease and other forms of dementia has grown to nearly forty cents of every dollar paid out to caregivers. This single statistic points to trend lines that should be cause for concern for individuals and families planning for their future, as well as for governments at every level charged with caring for populations that will be unable to pay for the care they will need.

Genworth has found that the proportion of claims and percentage of claim dollars related to cognitive care has increased dramatically. We have also found that the form of care provided is adapting in order to offer greater flexibility to families and caregivers.

For example, between 1993 and 2003, Genworth has seen an increase in the frequency of cognitive claims of 35 percent. The number of cognitive claims increased ten-fold in that time, reaching an all time high of approximately 6,000 claims in 2003.

The incidence of cognitive claims has affected the percentage of dollars paid out for such care as well. The annual dollar amount paid out has experienced a 12-fold increase in that decade, reaching approximately $120 million of cognitive care claims in 2003.

Genworth has noted that the allocation of cognitive care claims is moving from nursing homes to home health care and assisted living facilities. In 1993, the overwhelming choice for cognitive care was a nursing home. Almost all cognitive care claims – 98.5 percent – went to nursing homes. The remainder of claims went to home health care, at one percent, and just one half of one percent went to assisted living facilities.

By 2003, the proportion of cognitive care claims going towards nursing home care fell to 70 percent. Home health care claims increased to nine percent, and assisted living facilities grew to 21 percent of cognitive care claims. This data demonstrates a change as to where Alzheimer’s disease patients receive care, and Genworth has helped facilitate this trend by offering flexible long term care options (Figure 1).

Setting of Long Term Care 1993

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1%  1%
98%
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Setting of Long Term Care 2003

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21%  9%
70%
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Source: Genworth Financial, Inc., October 1, 2004 Figure 1

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In examining the past 30 years of claims data and looking at demographic trends in the coming decades, Genworth recognizes that although long term care insurance will help mitigate the costs to help address Alzheimer’s disease, the situation requires a concerted campaign to study, prevent and treat the disease, as well as to educate Americans.

It is also a wake-up call for every American – including caregivers, health professionals, advocates, policymakers and those of us in business that we need a more cooperative and collaborative framework for treating and tackling these tragic ailments. It’s not enough to insure for the expense of long term care, expand the funding of government health care programs or even focus on containing the rising cost of health care. We need to do all of that and more. We need to raise awareness and understanding among all Americans so that we can not only continue our focus on providing care and treatment today, but also put new energy into discovering cures and methods of prevention tomorrow.

This is the first of what we hope to be many initiatives for sharing Genworth’s experience as the leading provider of long term care insurance. From the inception of our core business in 1974 to today, we know that long term care insurance has helped thousands of families care for those who suffer from Alzheimer’s disease by providing an invaluable link between private sources of support and government programs. Long term care insurance enables families to provide consistent care without the patient having to lose all of their assets.
While there is clear evidence that the number of cases continues to escalate, the scientific community is studying how long patients can survive with the disease, and how to treat and delay the symptoms. Typically diagnosed over age 65, patients with Alzheimer’s disease live an average of eight to ten years but may live as many as 20 years after the initial onset of symptoms. Approximately 100,000 victims are lost to the disease each year and there are 360,000 new cases of Alzheimer’s disease annually.

Today Alzheimer’s disease is referred to as the “Disease of the Century” because of its escalating prevalence.

**Demographics**

There is a strong correlation between countries with high elderly populations and the incidence of Alzheimer’s disease. In every nation where life expectancy has increased, so has the incidence of Alzheimer’s disease. Although younger people can get Alzheimer’s disease, it is much less common.

Alzheimer’s disease is of particular concern to the United States because of our large aging population, especially the 77 million baby boomers who will begin to be eligible for retirement in the next several years. The strain of caring for aging boomers will create tremendous demographic and financial pressures on our country.

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4 Decision Resources (April, 2000).

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Annual direct and indirect treatment costs are estimated at $100 billion, according to estimates used by the Alzheimer’s Association and the National Institute on Aging.12

The Congressional Budget Office (CBO) calculated that total expenditures for long term care services for the elderly in 2004 – excluding the cost of donated care – will total approximately $135 billion. Much of the long term care is required by those seniors suffering from Alzheimer’s disease.

Cost of the Crisis
The challenge of providing adequate care for the millions of Alzheimer’s disease patients is acutely felt by families, caregiver communities and within all levels of government. Alzheimer’s disease represents a significant financial burden, as patients with advanced stages of the disease require constant care and monitoring.

Financial Impact on Families
The financial impact of caring for an Alzheimer’s disease patient can be enormous, and more and more families are confronting these costs. Today, Alzheimer’s disease affects one out of every three families in the U.S.13

9 Alzheimer’s Health Assistance Foundation, “Alzheimer’s Disease Research.”

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Alzheimer’s disease to advanced stages often requires full-time, professional care. For those families that must place the Alzheimer’s disease patient in an assisted living or nursing facility, the costs are often staggering. The annual cost for nursing home care in the U.S. ranges from $35,900 to $166,700, with the average at $57,700. For comparison, the average cost for college undergraduate education is $22,520 per year.

The largest part of the direct costs of caring for Alzheimer’s disease patients comes from nursing home care. Almost all families pay this out of pocket. The care of an Alzheimer’s disease patient, viewed as custodial care, is not covered by Medicare or most health insurance plans. Given that medical insurance coverage for any kind of long term care – cognitive or non-cognitive – is restricted, many patients and caregivers face severe financial burdens when the need for long term coverage arises.

Most Americans are not wealthy enough to fully fund their long term care needs through private savings and must rely on public programs provided at taxpayer expense by state and federal government such as Medicaid and Medicare. In 1965, Congress passed the Social Security Act, which established these programs. Medicare addresses the specific medical care needs of the elderly, as well as the needs of persons with disabilities and kidney disease. Medicaid serves those who are destitute and financially unable to afford proper medical care (Figure 4).

15 U.S. Department of Health and Human Services

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In addition, according to a study by Georgetown University’s Long Term Care Financing Project, state Medicaid programs and vulnerability to changing state budgets vary, so the security net provided by Medicaid is inconsistent. Coverage can be heavily dependent upon in which state the patient resides.

Financial Impact on Government:
Reliance on Medicaid and Medicare programs is burdensome for both families and the government. Medicare was established in response to the specific medical care needs of the elderly, while Medicaid was created as a response to the inadequacy of medical care for those receiving public assistance.

Medicaid requires those needing long term care services to spend down their assets, which may include their savings and other assets before government programs will cover expenses such as nursing home care. According to the Department of Health and Human Services, this accounts for more than half of nursing home residents, who have technically become “poor enough” to qualify for Medicaid coverage.

For the government, the number of Alzheimer’s disease cases and related care costs that are covered by Medicare and Medicaid are escalating at a rapid pace. Direct medical costs associated with Alzheimer’s disease are expected to surpass $250 billion each year.24

The Medicare rate per 1,000 enrollees for skilled nursing facilities has grown five-fold from 1982 to 2001. The rate of persons served by home health agencies increased more than two-and-a-half times from 1982-1997, but has since declined.25

By 2010, Medicare costs for beneficiaries with Alzheimer’s disease are expected to increase 54.5 percent, from $31.9 billion in 2000 to $49.3 billion. Medicaid expenditures on residential dementia care will increase 80 percent, from $18.2 billion to $33 billion in 2010, according to a report commissioned by the Alzheimer’s Association.26

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Federal Funding for Alzheimer Research Fiscal Years 1990-2004
(in millions of dollars)

Because Medicaid coverage is maintained by individual states, those states which will have a greater proportion of seniors in the coming decade will have a greater financial burden. For example, all but two states, Pennsylvania and Rhode Island, and the District of Columbia will experience an increase in number/percentage of seniors with Alzheimer’s disease between 2000 and 202527.

The government’s financial role extends beyond helping families and caregivers assist Alzheimer’s disease patients. In terms of Alzheimer’s disease research, the federal government spent approximately $660 million in fiscal year 200328. This represents a marked increase from 1980, when the National Institute on Aging allotted $20 million to research the disease29 (Figure 5). Within that time, many important medical advances have been made in the understanding, diagnosis and treatment of Alzheimer’s disease. Increasing government resources to research Alzheimer’s disease is an important investment towards mitigating the medical and financial effects that are projected for this disease in the coming decades.

Genworth Long Term Care Protection
As the past thirty years have demonstrated, the role of private long term care insurance providers has been an important option for families and caregivers of Alzheimer’s disease patients. Private long term care insurance can fill the gap between an individual’s ability to pay for care and what the government can provide through Medicaid and Medicare.

Long term care is different from health care, and it is not typically covered by health insurance plans, HMO plans, Medicare or Medicare supplemental policies. While health insurance is designed to cover care from a doctor or in a hospital, long term care includes personal care, such as help with bathing, eating or dressing.

As the private insurer who has provided more long term insurance coverage than any other in the U.S., Genworth is in a unique position to note trends in the proportion of cognitive care, and the form that care is taking because Genworth is the leading provider of long term care insurance in the U.S.

The number, frequency, and claim dollar amounts have all increased exponentially for cognitive care claims. For Genworth, nearly 40% of all claims paid on long term care policies are dementia related.

27 Alzheimer’s Association Fact Sheet, “Alzheimer’s Disease Growth: U.S. Will see average 44 percent increase in Alzheimer’s disease by 2025.” June 7, 2004
29 Alzheimer’s Association Fact Sheet, April 5, 2004.
Between 1993 and 2003, Genworth has seen a 35 percent increase in the frequency of cognitive claims. In that same time, the number of cognitive claims increased ten-fold, reaching an all time high of approximately 6,000 claims in 2003.

Along with the frequency and number of cognitive claims, the annual dollar amount paid has experienced a 12-fold increase. Approximately $120 million was dedicated to cognitive care claims in 2003.

At the same time, Genworth has noted a dramatic shift in the setting in which cognitive care is occurring. In 1993, the overwhelming choice for cognitive care was a nursing home. In fact, 98.5 percent of cognitive care claims dollars went towards nursing home claims. Just one percent went towards home health care, and one half of one percent went towards assisted living facilities.

In sharp contrast, by 2003 the proportion of cognitive care claims going towards nursing home care plummeted to 70 percent. Home health care claims increased to nine percent, and assisted living facilities grew to 21 percent of cognitive care claims. Patients and their families are opting for more flexible and varied choices to address Alzheimer’s disease and dementia related problems. This data underscores the role of long term care insurance in providing options to families and caregivers as to how best to treat the Alzheimer’s disease patient.

The number of individuals acquiring long term care insurance is limited, yet growing. More than nine million Americans have purchased long term care insurance policies, and coverage continues to expand each year. Despite this growth, a nationwide analysis reveals a concentration of long term care insurance plans by states. As of 2002, half of all individual policies were sold in just ten states: California, Florida, Illinois, Iowa, Minnesota, New York, Ohio, Pennsylvania and Washington.

Looking Ahead
Demographic trends in the U.S. indicate that the size of the older population (65 and older) will double over the next 25 years, reaching 70 million by 2030. At this rate, the U.S. could see a 70 percent increase in Alzheimer’s disease cases, affecting 7.7 million Americans. The 85 and older group is currently the fastest growing segment of the population, and is the group that carries the greatest likelihood of developing Alzheimer’s disease.

The extended outlook is even more sobering. By 2050, 13.2 million older Americans are expected to have Alzheimer’s disease if the current numbers hold and no preventive treatments or cure becomes available.

Despite several promising advances in the scientific study of the disease, if there are no breakthrough treatments or findings on preventative measures, the disease threatens to bankrupt the healthcare system. Alzheimer’s disease and other forms of dementia requiring long term care will overburden Medicare and Medicaid.

Long Term Care — Impact of Not Having Coverage
As the past several years have revealed, many individuals who do not have long term care insurance and require home care or facility placement face an overwhelming financial burden. Nearly one-third of all long term care bills are paid by individuals and families out of pocket. As a result, 70 percent of single people and 50 percent of married couples who require long term care become destitute.

AHIP LTC Insurance Market Surveys, “Ranking of Long Term Care Insurance Sales by State.”


According to a study by America’s Health Insurance Plans, long term care insurance sales have been growing at a rate of approximately ten percent annually from 1988 to 2002.\(^{35}\)

Genworth believes that long term care insurance helps Americans plan for long term care, instead of taking the financial risk of losing their life savings in order to become eligible for government programs.

In addition to long term care insurance, a multi-pronged strategy that includes more resources for research and education is required to adequately address the impending impact of the rise of Alzheimer’s disease.

**Expected benefits of increased funding, research and education.**

Investing in research on the causes, diagnosis and treatment of Alzheimer’s disease could help improve the quality of life for patients and possibly aid in preventing or delaying the onset of the disease. From a medical perspective, the earlier those patients can be diagnosed, the better the possibilities are for treatment that is more effective. Earlier detection, advances in medicine and thoughtful ways to think about how to finance care for patients can blunt some of the devastating effects of the disease.

**Research**

In the past thirty years, there have been tremendous advances in diagnosing and treating Alzheimer’s disease. As early as November 1983, when President Ronald Reagan designated November as National Alzheimer’s Disease month, the extent of the disease that would eventually claim him was not widely known. Our country lacked even a basic infrastructure for developing Alzheimer’s disease research.

Despite many unknowns about the disease, ranging from diagnosis to treatment, there are opportunities for significant progress within the scientific community. According to the Fischer Center for Alzheimer’s Research Foundation. Scientific research on Alzheimer’s disease falls into five general areas of research:

1. Identifying possible causes – including risk factors, the clarification of the underlying biological processes associated with the disease and genetics. In fact, there is some evidence to suggest that some of the risk factors of heart disease and stroke – high blood pressure, high cholesterol, low levels of folate – might predispose people to Alzheimer’s disease;

2. Improving early diagnosis of Alzheimer’s disease – including the recognition of cognitive and biological “markers” for the disease and increasing the use of brain-imaging techniques to detect brain changes prior to symptoms;

3. Developing new treatments – including drugs that target the underlying biological changes in the brain and non-pharmacological approaches to managing the behavioral symptoms of the disease;

4. Prevention – including the role of education, diet and environment in the development of Alzheimer’s disease. At the same time, studies showing that physical, mental and social activities could be protective factors against Alzheimer’s disease; and

5. Caregiving – including acknowledging what types of educational programs are most effective and what types of support are most useful.\(^{36}\)

The research community is focused on the search for an “Alzheimer’s disease vaccine”.\(^{37}\) The U.S. Food and Drug Administration (FDA) has approved five drugs to treat Alzheimer’s disease symptoms that affect memory and thinking skills and there are dozens of experimental Alzheimer’s disease drugs at various stages of development worldwide.\(^{38}\)


Preliminary research points to immunotherapy, a treatment that stimulates the body’s immune system, as a potential approach to preventing Alzheimer’s disease.

Although a cure may seem out-of-reach today, scientists claim that with sufficient investment in research, preventing Alzheimer’s disease may become an achievable goal within the next 10 years.

**Education**

There are opportunities for improving the outlook for Alzheimer’s disease care by targeting consumers and physicians with key facts about the disease. By raising awareness among primary care and general practitioners as to the cognitive tests they might conduct on patients, there is a greater possibility that the disease might be identified earlier.

Physicians, even those who do not specialize in geriatrics, must become more aware of warning signs and be knowledgeable about the newest treatments available to stave off the effects of Alzheimer’s disease. Because there is such a defined trajectory of the number of likely Alzheimer’s disease cases as the population ages, concerted efforts should be made to make any interaction between a senior and a medical practitioner as informative as possible.

On an individual patient level, there is a relatively low awareness of Alzheimer’s disease, particularly in regard to the importance of being tested. Seniors should be prepared for doctor’s visits including bringing a list of symptoms such as memory problems and their frequency, a list of past and current medical problems and a current list of medications, herbal remedies and dietary supplements.

In addition, the Alzheimer’s Association has developed the following list of Ten Warning Signs to

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**What are the primary areas of Alzheimer’s research?**


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# Ten Warning Signs of Alzheimer’s Disease

1. **Memory loss.** One of the most common early signs of dementia is forgetting recently learned information. While it’s normal to forget appointments, names or telephone numbers, those with dementia will forget such things more often and not remember them later.

2. **Difficulty performing familiar tasks.** People with dementia often find it hard to complete everyday tasks that are so familiar we usually do not think about how to do them. A person with Alzheimer’s may not know the steps for preparing a meal, using a household appliance or participating in a lifelong hobby.

3. **Problems with language.** Everyone has trouble finding the right word sometimes, but a person with Alzheimer’s often forgets simple words or substitutes unusual words, making his or her speech or writing hard to understand. If a person with Alzheimer’s is unable to find his or her toothbrush, for example, the individual may ask for “that thing for my mouth.”

4. **Disorientation to time and place.** It’s normal to forget the day of the week or where you’re going. But people with Alzheimer’s disease can become lost on their own street. They may forget where they are and how they got there, and may not know how to get back home.

5. **Poor or decreased judgment.** No one has perfect judgment all of the time. Those with Alzheimer’s may dress without regard to the weather, wearing several shirts on a warm day or very little clothing in cold weather. Those with dementia often show poor judgment about money, giving away large sums to telemarketers or paying for home repairs or products they don’t need.

6. **Problems with abstract thinking.** Balancing a checkbook is a task that can be challenging for some. But a person with Alzheimer’s may forget what the numbers represent and what needs to be done with them.

7. **Misplacing things.** Anyone can temporarily misplace a wallet or key. A person with Alzheimer’s disease may put things in unusual places, like an iron in the freezer or a wristwatch in the sugar bowl.

8. **Changes in mood or behavior.** Everyone can become sad or moody from time to time. Someone with Alzheimer’s disease can show rapid mood swings — from calm to tears to anger — for no apparent reason.

9. **Changes in personality.** Personalities ordinarily change somewhat with age. But a person with Alzheimer’s can change dramatically, becoming extremely confused, suspicious, fearful or dependent on a family member.

10. **Loss of initiative.** It’s normal to tire of household, business activities or social obligations at times. The person with Alzheimer’s disease may become very passive, sitting in front of the television for hours, sleeping more than usual or not wanting to do usual activities.
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Services to host a National Summit on Alzheimer’s Disease to examine the current Alzheimer’s disease research agenda at NIH, priorities for current and future federally supported Alzheimer’s disease initiatives, information and education programs for health care professionals and the public, and challenges and opportunities for the research community and the public.

In addition, the Act would codify three existing Alzheimer’s disease research programs into law at the National Institute on Aging (NIA): 1) the Alzheimer’s Disease Prevention Initiative, 2) Cooperative Clinical Research, and 3) Caregiving Research.

The Act would strengthen the federal government’s commitment to Alzheimer’s disease research, provide much-needed financial support to caregivers and educate the public about advances in research. By doubling the funding for Alzheimer’s disease research at the National Institute of Health, researchers will have the resources to make significant breakthroughs.

The legislation would help families who care for Alzheimer’s disease patients by increasing the availability of respite services such as respite care, home health care, counseling and training. The bill proposes doubling funds for two existing initiatives, the National Caregiver Support Program – from $125 million to $250 million – and the Alzheimer’s Demonstration Grant Program – from $12 million to $25 million. The bill would also help family caregivers pay for the costs of caring for a loved one by providing a $5,000 tax credit, which would be an immediate help to the millions of families who cope with this devastating disease.

Although we have focused primarily on the financial aspect of long term care for Alzheimer’s disease, Genworth fully recognizes that increased funding of government health care programs, medical research and education are significant priorities in addressing the impending epidemic. With access to data trends on incidence of disease and types of care required over the past 30 years, we have a better sense as to where individuals, private insurers, non-governmental organizations and the government must focus on to prepare the country to deal with this devastating disease.