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To: Ruby Shamir/OPD/EOP@EOP

cc:

Subject: Re: LT

Sweet Ruby,

Happy New Year to you as well!

Here's the long term care information you've been asking me for.

Let me know if you have any questions.

Devorah



Ltcpap.j04 this is from last year

we are introducing basically the same policy this year -- modification in bold

**15. Long-Term Care Initiative.** An initiative that has already been well received and has already begun to receive bipartisan support is the long-term care proposal. Last year, you proposed a major, seven-part initiative that would: (1) provide a **\$2,000** tax credit for people with long-term care needs or their families to offset the costs of care; (2) create a new Family Caregivers Program that offers respite services, information, and other assistance; (3) offer private long-term care insurance to Federal employees; (4) improve nursing home quality; (5) expand Medicaid options for community-based services; (6) encourage assisted living facilities for Medicaid beneficiaries; and (7) conduct a \$10 million education campaign on long-term care for Medicare beneficiaries. (Cost: about \$6 billion over 5 years)

## BACKGROUND: PRESIDENT CLINTON'S LONG-TERM CARE INITIATIVE

January 4, 1999

*Americans of all ages, particularly the elderly and their families, fear developing a need for intense, ongoing long-term care. Unlike acute care, long-term care is rarely paid for by private insurance and Medicare, and is more likely to require out-of-pocket expenditures. It also takes a huge financial and emotional toll on family and friends who provide most of this care. Because of its complexity, however, no single policy can "solve" this problem. Thus, the President is proposing a multi-faceted initiative to provide immediate assistance with long-term care & help prepare for what will surely be one of the great challenges as the baby boom generation ages.*

### GROWING NEED FOR LONG-TERM CARE

- \* **Who needs long-term care.** People with chronic illness or disability not only need doctor, hospital and other acute care services -- they also need a wide range of services to manage their health conditions and perform basic activities of daily living. For example, people with strokes may be bed-bound due to paralysis and need help with eating, moving and changing their feeding tubes. Diabetics or people with congestive heart failure may require frequent injections, medication and doctor visits. People with Alzheimer's disease often need constant monitoring and changes to their physical environment to allow them to live at home safely. Long-term care encompasses these and other services. It is probably the most complicated area of health care, since it varies based on a person's specific condition and limitations as well as access to care from institutions, health providers, families and friends.

About 5 million Americans of all ages have significant limitations (cannot perform 3 or more activities of daily living without assistance) because of illness or disability and thus require long-term care. Nearly 2 million of these people live in nursing homes; the remainder live in the community and benefit from irreplaceable and uncompensated caregiving from countless relatives and friends. In addition, millions more Americans have chronic illnesses or disabilities that are less limiting but still require long-term care.

More than two-thirds of people with long-term care needs are elderly -- nearly half of all people age 85 and older need assistance with everyday activities. Older women are more likely to need long-term care than men; three-fourths of nursing home residents are women.

- \* **The aging of America will create a greater need for long-term care.** The sheer increase in number of elderly in the next century means more chronic illnesses. The number of people age 65 years or older will double by 2030 (from 34.3 to 69.4 million), so that one in five Americans will be elderly. The number of people 85 years or older will grow even faster (from 4.0 to 8.4 million). By 2050, the number of older, disabled people could double.
- \* **Not just a challenge for the elderly.** About 2 million people with substantial long-term care needs are younger than age 65. The rate of disability has been rising among children. In part, this reflects a little-noticed effect of the success in helping premature, sick, or disabled newborns. Their increased survival through infancy has led to a need for long-term care as they grow up. Also, many adults have long-term care needs due to lifelong health conditions

(e.g., cerebral palsy) or conditions developed as adults (e.g., multiple sclerosis).

## **LONG-TERM CARE SYSTEM**

- \* **Medicare was not designed to cover long-term care.** Long-term care costs account for nearly half (44 percent) of all uncovered, out-of-pocket health expenditures for Medicare beneficiaries. When it was created in 1965, Medicare was modeled after a typical private insurance policy and thus did not include long-term care coverage.

Unfortunately, nearly 60 percent of all Medicare beneficiaries -- and two-thirds of people under age 65 -- do not realize that Medicare does not pay for long-term nursing home care. This means that the majority of Americans are unprepared for the financial and emotional challenges of paying for and/or providing long-term care.

- \* **Medicaid is already the major payer of long-term care, but historically has focused on nursing homes.** Medicaid is the largest payer of long-term care in the nation. It covers two-thirds of nursing home residents -- many of whom become eligible for this income-related program because long-term care costs impoverish them. Nursing home costs average almost \$50,000 per year. About 80 percent of Medicaid long-term care costs are for nursing homes.

The remaining 20 percent of costs are for home and community-based long-term care services. The share of Medicaid long-term care spending going toward home and community-based services has more than doubled in the last 10 years. Ten years from now, Medicaid spending on these services is projected to equal spending on nursing homes. The President has encouraged the shift away from Medicaid's "institutional bias" by approving over 300 waivers for local home and community-based care programs and proposing to repeal the need for such waivers. Notwithstanding these advances, not all Medicaid beneficiaries with long-term care needs have community-based options, and many people with long-term care needs don't qualify for Medicaid at all.

- \* **Private insurance is relatively new, untested, and covers very few people.** Only about 4 million Americans -- 1.5 percent of all Americans -- have private long-term care insurance. In part, this reflects the newness of the coverage, the inconsistency of benefits across policies, variable regulation, and low demand. Given their cost, even if every baby boomer who could afford private insurance purchased it, less than one-third of long-term care costs would be paid for by private insurance in 2030.

- \* **Families and friends provide most long-term care.** Informal caregiving is a part of family life for many Americans. About 70 percent of caregivers report it being a positive experience. Only about one-third of the 5 million people with substantial long-term care needs lives in a nursing home -- virtually all of the 3 million community-based people with similar needs rely on one or more relatives or friends for help. The millions of caregivers that provide nearly full-time assistance for these people with severe needs are part of a larger group of Americans that help people with less intense long-term care needs.

However, the costs of such caregiving -- in time, money, and physical and emotional strain --

can be large. Two-thirds of working caregivers report experiencing conflicts that cause them to rearrange their work schedules, work fewer hours, or take an unpaid leave of absence from work. Most of the primary caregivers for the elderly are elderly themselves. Their average age is 60 years old, and half are older than 65. About one third describe their own health as "fair to poor." This presents problems since informal caregiving often requires physical work like heavy lifting, frequent bedding changes, dressing and bathing. These stresses tend to be more severe for families of people with Alzheimer's disease. Such caregivers tend to experience greater time demands, family conflict, strain, mental and physical problems, and financial hardship.

## **LONG-TERM CARE INITIATIVE**

The challenges of providing and financing long-term care are clearly large and multi-dimensional. No single policy can provide the answer. As such, the President is proposing a four-part, \$6.2 billion (over five years) initiative takes important steps to address complex long-term care needs (described in detail in subsequent pages):

- \* **Direct financial support through a new tax credit for people with long-term care needs or their family caregivers.** This credit helps pay for the formal and informal costs associated with care for people with significant long-term care needs.
- \* **Direct service support through a new Family Caregivers Program** that provides information, education, counseling, and respite services directly to families that care for elderly, ill or disabled relatives.
- \* **Education for Medicare beneficiaries about long-term care issues and options.** Since most people who develop long-term care needs are Medicare beneficiaries, Medicare can be used to provide information on the limitations of its coverage, alternative sources of long-term care services and financing, and how best to choose the most appropriate options.
- \* **High-quality, affordable private long-term care insurance for Federal employees.** The Federal government would develop a model program to offer high quality, private long-term care insurance policies to its employees, retirees and eligible family members. By offering this coverage, the Federal government will both guide public policy by example and act responsibly as the largest employer in the nation.

## TAX CREDIT FOR PEOPLE WITH LONG-TERM CARE NEEDS OR THEIR CAREGIVERS

Eligible people with long-term care needs or their caregivers would receive a \$1,000 tax credit beginning in 2000. This would help about 2 million people, at a cost of ~~\$5~~ billion for 2000-04.

- \* **Goal:** This policy offsets some of the paid and unpaid long-term care costs incurred by people with chronic illness or the families with whom they live. A large proportion of long-term care costs are not covered by insurance, and studies suggest that the value of informal, unpaid long-term care provided by families is worth billions of dollars.
- \* **Amount of the credit:** The credit is \$1,000. It phases out for higher income tax payers (taxpayer with modified adjusted gross income exceeding \$110,000 for couples, \$75,000 for unmarried taxpayers, and \$55,000 if the taxpayer is married but filing a separate return; same phase-out as the child tax credit). This credit cannot exceed the total amount of tax liability except, however, it may be refundable for taxpayers with 3 or more dependents.

The flat \$1,000 credit would be given on the basis of a certified need for long-term care rather than expenses for long-term care. This means that families and people with chronic illness or disability do not have to collect and submit receipts for paid home health or respite care. It also recognizes the costs associated with informal, family caregiving. For example, a wife whose husband has had a stroke would not have a receipt for her reduced hours at work, time spent bathing and feeding her husband and other real costs associated with care.

- \* **Eligibility:** Three types of people could receive this tax credit: (1) taxpayers with long-term care needs; (2) taxpayers whose spouses have long-term care needs; and (3) taxpayers with dependents with long-term care needs.
- \* **"Person with long-term care needs":** For this credit, this includes:
  - People with 3 or more limitations in activities of daily living (ADL) (bathing, dressing, eating, toileting, transferring and continence management) who cannot perform these activities without substantial assistance from another individual due to a condition lasting for longer than 6 months, as certified by a licensed doctor in the previous 12 months.
  - People with severe cognitive impairments who require substantial supervision to be protected from threats to their health and safety due to this condition and have difficulty with one or more ADLs or one of four major instrumental ADLs.
  - Children ages 2 through 6 who have difficulty with 2 out of 3 ADLs (eating, transferring and mobility) or are under the age of 2 and require skilled caregiver in the parents' absence or specific durable medical equipment (e.g., a respirator) for over 6 months. Within one year, HHS and Treasury will report on whether these eligibility rules are appropriate and how to improve them if necessary.
- \* **"Caregivers":** Families would be eligible for the credit as caregivers if their relatives with long-term care needs can be claimed as dependents. Under current law, a "dependent" is

generally an individual who does not pay taxes, is related to the taxpayer, receives more than half of his or her support from the taxpayer, and has gross income less than \$2,750. For purposes of this credit, this definition would be expanded significantly in two ways. First, individuals with long-term care needs would not have to meet the support test if they live with a taxpayer who is a close relative for at least half the year (the entire year in the case of a distant relative and other persons). Second, the limit on gross income would be raised to the sum of the exemption amount, the standard deduction, and the additional deduction for the elderly and blind (to \$8,100 for single elderly person; in general, Social Security benefits are excluded from gross income for moderate to low-income individuals). Most people with income above this limit would file taxes and receive the long-term care credit themselves

Broadening the definition of dependency for the purposes of this credit is a major change that allows many more families that house and care for relatives to receive the credit. It does so by allowing caregiving relatives of individuals with long-term care needs to claim the credit when those individuals themselves have insufficient income to pay taxes.

\* **Who benefits:** About 2 million people would benefit from this credit: about 1.2 million elderly, about 500,000 nonelderly adults, and about 250,000 children. About three-fourths of people receiving the credit are expected to be spouses or family caregivers of these people with long-term care needs. Almost all recipients are middle class; about 75 percent of elderly taxpayers have income below \$50,000.

\* **Cost:** About \$5.5 billion over the five-year budget window.

<b>TAX CREDIT FOR PEOPLE WITH LONG-TERM CARE NEEDS: Examples Assuming 1999 Levels</b>					
<b>Elderly Single Person</b>		<b>Elderly Married Couple (1)</b>		<b>Caregiver of Elderly Person (2)</b>	
<b>INCOME</b>					
Social Security (3)	9,420	Social Security (4)	16,086	Senior's Soc Security (3)	9,420
Pensions	13,765	Pensions	14,370	Son's Income	46,000
Interest Income	1,000	Interest Income	1,500		
<b>Total Money Income</b>	<b>24,185</b>	<b>Total Money Income</b>	<b>31,956</b>	<b>Total Money Income</b>	<b>55,420</b>
<b>Adj. Gross Income</b>	<b>14,765</b>	<b>Adj. Gross Income</b>	<b>15,870</b>	<b>Adj. Gross Income</b>	<b>46,000</b>
<b>TAX LIABILITY</b>					
Exemption	-2,750	Exemption	-5,500	Exemption	-8,250
Standard Deduction	-4,300	Standard Deduction	-7,200	Standard Deduction	-7,200
Elderly Deduction	-1,050	Elderly Deduction	-1,700	Elderly Deduction	
<b>Taxable Income</b>	<b>6,665</b>	<b>Taxable Income</b>	<b>1,470</b>	<b>Taxable Income</b>	<b>30,550</b>
<b>Current Law Tax Liability</b>	<b>1,000</b>	<b>Current Law Tax Liability</b>	<b>221</b>	<b>Current Law Tax Liability</b>	<b>4,583</b>
				Current Law Child Tax Credit	-500
<b>Proposed LTC Credit</b>	<b>-1,000</b>	<b>Proposed LTC Credit</b>	<b>-1,000</b>	<b>Proposed LTC Credit</b>	<b>-1,000</b>
<b>Proposed Law Tax Liability</b>	<b>0</b>	<b>Proposed Law Tax Liability</b>	<b>0</b>	<b>Proposed Law Tax Liability</b>	<b>3,083</b>

Dept of the Treasury; Office of Tax Analysis. (1) Only one individual needs long-term care; both are older than 65. (2) Single elderly person moves in with son, his wife & teenage son; total income (including grandfather's) roughly equals the median income for a family of 4. (3) Weighted average of benefits paid to retired workers, and widows and widowers, in 1996 adjusted for inflation. (4) Average benefits paid to retired workers and their wives in 1996 adjusted for inflation.

## NEW FAMILY CAREGIVER SUPPORT PROGRAM

A new National Family Caregivers Support Program would support families who provide long-term care to elderly relatives with chronic illnesses or disabilities through state and local area agencies on aging. This \$125 million program would help approximately 250,000 families.

- \* **Goal:** This policy provides support for families who care for relatives with chronic illness in hope of easing the emotional, physical and financial strain of caregiving. Recent studies have found that services like respite care can relieve caregiver stress and delay nursing home entry, and that counseling and support for families of Alzheimer's disease patients can delay institutionalization for as long as a year.
- \* **Eligibility:** Families -- especially low-income families -- who provide care to elderly relatives with limitations in activities of daily living would be eligible for services.
- \* **Services provided:** Funding would be used to help families that take care of elderly relatives with significant long-term care needs. This assistance would include:
  - Connecting families with information on caregiver resources and local services (e.g., detailed information on the condition affecting their relative; names and numbers of local home care and respite services);
  - Providing counseling, training and peer support to teach families how to face the challenges of caregiving (e.g., how to bath people who have had strokes; what exercises work best for people with severe arthritis; how to cook meals for people with diabetes; how to manage the stress of caregiving);
  - Providing and paying for respite care (e.g., attendants so that the caregiver can shop or leave the house for other reasons, adult day care centers, and temporary care in an assisted living facility or nursing home). For people providing intense long-term care, these services provide necessary, temporary relief from caregiving responsibilities, allowing them to restore balance to their lives that strengthens their ability to continue to provide assistance. Most of the funding of this program would pay for respite services.

Additionally, a competitive grant program would test innovative interventions (e.g., use of computer information for distant caregivers) and challenges for subgroups of caregivers (e.g., minority caregivers; caregivers for people with severe conditions like brain injuries).

- \* **Administration:** All state agencies on aging would receive a grant from the Administration on Aging for distribution to local area agencies on aging. These Federal grants would be matched by the states and states could not reduce their current spending on such services. States would develop a sliding fee scale consistent with its other programs.
- \* **Who benefits:** Altogether about 250,000 families could be served by this program.

\* **Examples:** The following programs serve as models for this new, nationwide program:

- **California:** Its Department of Mental Health developed a program in 1985 to provide caregiver support services through eleven agencies statewide. These agencies target families caring for persons with Alzheimer's disease, Parkinson's disease, stroke, and traumatic brain injury. Services include needs assessment, information and referral, family consultation and training, support groups, and respite care.
- **New Jersey:** The Statewide Respite Care Program was established in 1988 to help unpaid caregivers of the stress arising from providing intensive personal assistance to a family member. Annually, over 2,000 families receive respite care provided through adult day care centers, short-term placement in the home of a trained individuals, or overnight nursing home stays. One quarter of the families helped by the program are caring for someone with Alzheimer's disease; heart disease, stroke and arthritis are the next most common chronic conditions of the program's care recipients. A recent evaluation found that families helped through its adult day care had much lower feelings of worry, strain and overload, and fewer experienced depression or anger. Depression is a major problem for caregivers, not only limiting their ability to help their relative but restricting their own lives and activities.
- **Washington:** Washington State Aging and Adult Services Administration established a program in 1989 to provide assistance to family caregivers. Through its area agencies on aging, it offers respite services to 2,800 families annually. Several thousand families receive caregiver training. Respite services are prioritized based on the caregiver's vulnerability, intensity of care provided by family members, and presence of other family and or community supports.
- **Wisconsin.** Since 1986, Wisconsin Bureau on Aging has funded county aging and social services offices to work with families to identify the types and amounts of assistance needed to care for relatives diagnosed with Alzheimer's disease or a related disorder. Covered services include respite care, provided in the home or in adult day care, and in-home help. In addition, assistive devices, caregiver training, and peer group supports are financed. Families share in the cost based on income. About 1,000 families benefit from funded respite care or in-home help and another 4,600 families are helped through caregiver training, information and peer group supports.

\* **Cost:** The total funding is \$125 million in FY 2000 and \$625 million over five years, most of which would be distributed among all states, and a small part of which would be used for the competitive grant program. Additionally, funds would be set aside for an evaluation of these efforts -- in an effort to identify what works and doesn't work so that future efforts are best targeted.

## **LONG-TERM CARE INFORMATION CAMPAIGN FOR MEDICARE BENEFICIARIES**

A National Long-Term Care Information Campaign will be conducted to help Medicare beneficiaries and their families better understand their long-term care options. All 39 million Medicare beneficiaries would receive this information through this \$10 million initiative.

- \* **Goal:** This policy provides information on long-term care to Medicare beneficiaries -- who comprise most of the people who have or will develop long-term care needs. Since nearly 60 percent of beneficiaries do not realize that Medicare does not cover most long-term care, this information is critical to educating them about their coverage and directing them to financing and delivery systems.
  
- \* **Information provided:** The Health Care Financing Administration (HCFA), working with other components of DHHS, would conduct this information campaign. It would include information about long-term care coverage under the Medicare and Medicaid programs; what to look for in a private long-term care insurance policy; how to access home and community-based care; and other consumer information. Components of the campaign would include:
  - Developing and distributing printed educational materials about long-term care options and resources to beneficiaries and their families;
  - Incorporating information about long-term care options and resources into the Medicare handbooks, toll-free phone numbers and the consumer internet site, [www.Medicare.gov](http://www.Medicare.gov);
  - Enhancing training on long-term care options in organizations that provide information to beneficiaries including state health insurance assistance programs, Medicare carriers and fiscal intermediaries, area agencies on aging and Social Security Administration offices;
  - Working with groups representing the elderly, people with disabilities, the long-term care industry, employers, states and others to disseminate information to their constituencies.

In addition, HCFA would conduct pilot information campaign projects focusing on the needs of particular populations such as people with disabilities, people who don't speak English, or the rural elderly. An evaluation component would be included to identify what works best in assisting beneficiaries in making informed long-term care decisions.

- \* **Who benefits:** All 34 million seniors and 5 million people with disabilities are covered by Medicare would receive this information. Since a large proportion of people with long-term care needs are elderly or adults with disabilities, Medicare is an extremely efficient way to target such people.
  
- \* **Cost:** \$10 million in FY 2000.

## **OFFERING PRIVATE LONG-TERM CARE INSURANCE TO FEDERAL EMPLOYEES**

This proposal would authorize the U.S. Office of Personnel Management (OPM) to make private long-term care insurance available to Federal employees, retirees, and eligible family members at negotiated group rates. The cost of administration of this benefit would be about \$15 million over 5 years and an estimated 300,000 people would participate.

- \* **Goal:** This initiative would educate Federal employees and retirees about long-term care options and encourage the purchase of high-quality, long-term care insurance at 15-20 percent below market rates. This is one in an ongoing series of efforts in which the Federal government has taken a leadership role by both guiding public policy by example and acting responsibly as the largest employer in the nation.
- \* **Eligibility:** People eligible to purchase this insurance would include: Federal employees and retirees, and their spouse; former spouses who are entitled to annuities under a Federal retirement system; and parents, and parents-in-law. In its first year, OPM would run a campaign to educate possible participants about long-term care insurance and solicit and evaluate potential insurers. In the second year, it would hold an open enrollment for all eligible participants. New employees and employees electing coverage during the open enrollment period would be subject to either minimal or no underwriting. All others will be required to disclose additional information about their health status in order to acquire coverage. Once enrolled, coverage would be guaranteed renewable and could not be canceled except for nonpayment of premium.
- \* **Types of insurance policies offered:** OPM would select a single qualified carrier, or a very small number of carriers, to provide one or more long-term care insurance policies. This selection of carriers would be based on quality, service and price. At a minimum, carriers must be licensed under state law, compliant with the Health Insurance Portability and Accountability Act standards, and offer guaranteed renewability of their policies. OPM would set a basic benefit package consistent with the National Association of Insurance Commissioners' standards (e.g., with a minimum benefit level; inflation protection; contingent nonforfeiture) and may offer plans with additional coverage (e.g., higher reimbursement levels for nursing home care or a more flexible benefit that can be used for whatever type of service the person needs). OPM would have the flexibility to administer the program as the market for long-term care services and protections evolves over time.
- \* **How much participants would pay:** The full cost of premiums would be paid by the participant. OPM would negotiate group rates that it expects will be 15 to 20 percent lower than the cost of individual long-term care policies. Employee and annuitant premiums would be withheld from salary or annuity and sent directly to respective contractors.
- \* **Cost:** The Federal administrative costs would be about \$15 million over 5 years.