

Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. list	re: Health Care Ceremony Accepts and No Responses (partial) (1 page)	12/31/1998	P6/b(6)
002. profile	re: personal medical (1 page)	n.d.	P6/b(6)
003. list	re: phone numbers (partial) (1 page)	n.d.	P6/b(6)

COLLECTION:

Clinton Presidential Records
Domestic Policy Council
Devorah Adler
OA/Box Number: 20469

FOLDER TITLE:

Long Term Care [Folder 5]

2012-0463-S

rc778

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
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C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

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- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

anca**American Health Care Association** 1201 L Street, NW, Washington, DC 20005-4014
FAX: 202-842-3860Facsimile Cover Sheet
Please Deliver Immediately Upon Receipt

To:

Chris Jennings

Company:

Fax #:

456-7431

From:

Bruce Yarwood

Tel #:

202-898-2858

Date:

1/4/99

Total pages (incl cover page):

4

Message:

If you did not receive a complete and legible transmission, please call
202-898-2826

The information contained in this facsimile is confidential information intended only for the use of the individual or entity named above. If the reader of this message is not the intended recipient, the reader is hereby notified that any dissemination, distribution or copy of this telecopy is strictly prohibited. If you have received this telecopy in error, please notify us by telephone or facsimile and destroy the original telecopy. Thank you.

() Fax delivered

Time

Operator

BRUCE YARWOOD

Chres

- Hue is
our statement -
- Ken - how do
the tax credit
work -

NEWS

ahca**American Health Care Association**

Contact: Tom Burke
202/898-2814

Immediate Release

**AMERICAN HEALTH CARE ASSOCIATION APPLAUDS
PRESIDENT'S LONG TERM CARE INITIATIVE
Tax Credits Key to Reforming Long Term Care Financing**

Washington, D.C. (January 4, 1999)--The American Health Care Association (AHCA) today lauded President Clinton for taking important steps in addressing the issue of providing long term care for our nation's elderly and chronically ill.

"The President and the Administration are demonstrating leadership with the introduction of this long term care initiative to assist the chronically ill and their caregivers. AHCA has long been an avid supporter of using tax credits to help ease the burden of long term care financing," said Dr. Paul Willging, president of AHCA.

As the baby boom generation ages over the next 30 years it will increase the need for long term care services and the current financing system will reach the breaking point. Adding tax incentives will help relieve pressure on individual consumers and provide access to more long term health care options.

"The Administration's plan also gives important visibility to long term care insurance. By providing this type of insurance to the federal workforce, all employers may be encouraged to examine this type of insurance for their employees," Willging said.

Willging further noted the wisdom of the President's plan, saying, "This plan goes well beyond just easing the financial burden. By providing badly needed public education about how to plan for and access long term care, the Administration takes on an important national public service."

--more--

Long Term Care/Add One

Most Americans do not realize the importance of planning for their long term care needs. "For example," added Willging, "virtually all homeowners carry fire insurance but face only a 1 in 1,200 chance of needing to make a claim. Meanwhile, only 3% of Americans carry long term care insurance, yet nearly half of all Americans will access long term care services at some point in their lives. Americans must be educated about how to plan for these services."

AHCA considers the Administration's announcement a major step toward guaranteeing access to quality health care for all Americans, but notes it is only the first step of many which will be required to truly provide reforms to our system for providing and financing long term care.

The population growth among the elderly over the next 30 years is staggering. Decisions on how to finance long term care must be made soon in order to ensure access to the system in the future. Both the public and private sectors must cooperate, innovate and develop policies which fill this growing need.

AHCA, a federation of 50 affiliated associations, represents over 11,000 non-profit and for-profit assisted living, nursing facility and subacute centers that provide care to more than one million elderly and disabled individuals nationally. Helpful information about long term care options can be obtained through AHCA's consumer information telephone line at 1-800-555-9414 or at the AHCA web site (www.ahca.org).

OWL PRESS RELEASE

666 11TH STREET, NW • WASHINGTON, DC 20001 • 202-783-6686 • FAX 202-638-2356

FOR IMMEDIATE RELEASE

January 4, 1999

CONTACT: Deborah Briceland-Betts

202-783-6686

Long Term Care Proposal Long-Awaited Help for Women

"Today's long term care proposal by President Clinton is a long-awaited step towards relief for America's caregivers, most of whom are women," said Deborah Briceland-Betts, the Executive Director of OWL (the Older Women's League). "The proposal comes at a time when Boomer women are stretching themselves across the generations to provide care for both aging parents and children. The proposal offers these women support and does not try to second-guess or replace them unnecessarily."

Caregiving support is important to women because:

- The majority of family caregivers, about 80 percent, are women caring for aging parents, children, or ailing spouses.
- Most women will be caregivers at some point in their lives; 89 percent of women over 18 years of age are caregivers. Women now in midlife, the Baby Boomer cohort, are projected to spend more time caring for their parents (18 years) than they have for their children (17 years).
- Women are also the primary recipients of long term care. Two-thirds of home care consumers are women (10 million) and 70 percent of those in nursing homes are women.

"Caregivers are often still in the workforce and are trying to work and care for a family member at the same time, or they live far away from their parents and are long-distance caregivers," said Briceland-Betts. "Finding needed services in either situation is often difficult and frustrating."

"The National Family Caregiver Support Program proposed by the President fills an information gap for caregivers," said Briceland-Betts. "Many caregivers lose precious time and energy searching for help. They don't know where to go and some simply never find it." The one-stop-shops created by the states under the proposal would provide information about available services and provide training and counseling support to family caregivers. "Providing support to family caregivers will help them do their jobs longer and more effectively. When that happens, we all benefit," said Briceland-Betts.

OWL is the only national membership organization to work solely on issues unique to women as they age. OWL has 75 chapters and 15,000 members across the nation.



For Release at 11 AM
January 4, 1999

Contact:
Scott Treibitz
703/276-2772

Reaction To Clinton Caregiver Proposals

**Statement of Stephen McConnell
Senior Vice President, Alzheimer's Association**

**Spokespeople are Available for News Interviews and Talk Shows
B-Roll Available**

"With the proposal he is putting forth today, President Clinton gives a powerful recognition of the incredible role that family caregivers play in providing long-term care in this country."

"Family members are the heart and soul of our caregiving system. They provide at least 70% of the care for people who have Alzheimer's disease, and they do so at enormous personal cost -- physical, emotional and financial."

"Every family struggling today to keep a spouse or a parent or grandparent at home will understand and appreciate the importance of what the President is doing today."

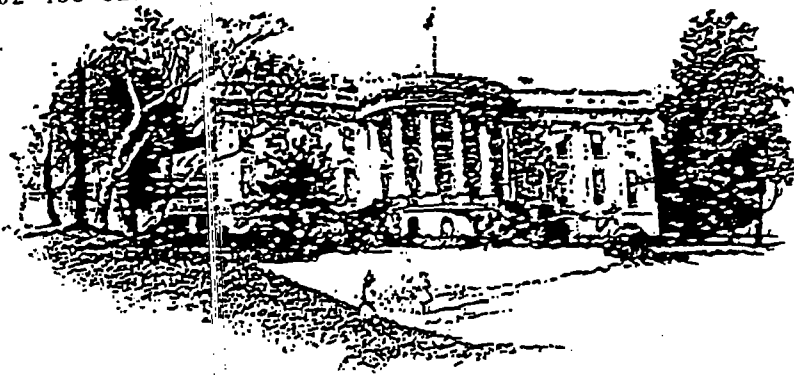
"This initiative will help millions of hard working families address a real problem and should draw strong and immediate bipartisan support. The Alzheimer's Association will work aggressively with the President and Congress to see these proposals enacted into law this year."

-30-

CAREGIVERS STUDY

The Alzheimer's Association and the National Alliance of Caregiving will soon release a national report on *Caregivers of those with Alzheimer's*.

**For details and a general overview
contact Scott Treibitz at 703/276-2772**



OFFICE OF CAPRICIA PENAVIC MARSHALL
SOCIAL SECRETARY
THE WHITE HOUSE

TELEPHONE NUMBER: 202-456-7136

FAX NUMBER: 202-456-6771

NUMBER OF PAGES, INCLUDING THIS PAGE _____

DATE _____

To Debra K

FAX NUMBER _____

FROM Sharon Kennedy Gail

MESSAGE _____

The names w/o an "A or R"
have not responded yet

OMB
Treasury

Sonia
Connolly

NOT FOR Distribution
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 President's List

HEALTHCARE CEREMONY - Monday JAN 4 1999 - 10:00 AM White House - Business - East Visitors Entrance

Page 1

THE PRESIDENT AND FIRST LADY

REPORT DATE: December 31, 1998
 REPORT TIME: 1:35 PM

Accepts and No Responses

A **Mr. Daniel C. Adcock**
 Assistant Legislative Director, National Association of Retired Federal Employees
 Washington, DC

A **Ms. Linda Anthony**
 Executive Director, Pennsylvania Coalition of People's With Disabilities
 Harrisburg, PA

disability
groups

X **Mr. Howard Bedlin**
 Vice President for Public Policy & Advocacy, National Council on The Aging
 Washington, DC

A **Mr. Robert B. Blancato**
 Chairman of the Advisory Board, National Silver Haired Congress
 Washington, DC

X **Ms. Deborah Briceland-Betts**
 Executive Director, Older Women's League
 Washington, DC

A **Ms. Maria Cordone**
 Director of Community Service & Older Workers, IAM & Retirees
 Upper Marlboro, MD

A **Mr. Lawrence Crecy**
 Executive Vice President, National Caucus & Center on Black Aged
 Washington, DC

Ms. Hilda L. Crespo
 Hispanic Working Group on Healthcare
 Washington, DC

A **Ms. Jean Daniel**
 Policy Director, National Association of Area Agencies on Aging
 Washington, DC

A **Mr. Justin Dart**
 Founder, Justice for All
Guest: Mr. Tim Yazawa

A **Dr. Jane L. Delgado**
 President and CEO, COSSMHO
 Rockville, MD

Ms. Beth Foley
 Executive Director, Council for Exceptional Children
 Reston, VA

A **Mr. Marty Ford**
 Assistant Director, Association of Retarded Citizens
 Washington, DC

X **Mr. Burton Fretz**
 Executive Director, National Senior Citizens Law Center
 Washington, DC

left msg.

202 289
6972

ASK
ed Flynn
re: Fed camp.

~~AARP~~

~~NCOA~~

~~National
(Max
Richtman)~~

~~Sam
Simmons~~

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X max Richtman

Withdrawal/Redaction Marker

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Page 2

REPORT DATE: December 31, 1998
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Accepts and No Responses

Mr. Timothy Mark Fuller
Executive Director, Gray Panthers
Washington, DC

Ms. Helen Gibson
Supervisor for Special Programs, CWA Retirees
Washington, DC

A **Mr. Val John Halamandaris**
President & CEO, National Association for Homecare
Washington, DC

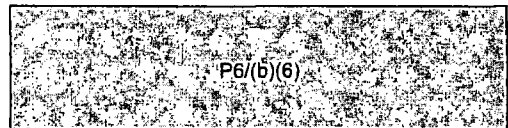
Mr. Robert Kafka
ADAPT

Ms. Carmela LaCayo
President & CEO, National Association for Hispanic Elderly
Pasadena, CA

A **Mr. Paul Arthur Marchand**
Chairman, Consortium for Citizens with Disabilities
Washington, DC

~~X~~ **Mr. Stephen R. McConnell**
Senior Vice President, Alzheimer's Association
Washington, DC

] knows



[601]

A **Mr. Mike Oxford**
Executive Director, National Council on Independent Living

~~X~~ **Mr. Stephen Protulis**
National Council of Senior Citizens
Silver Spring, MD

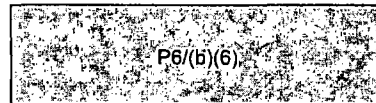
] left msg

A **Mr. Stephen Regenstreif**
Director, AFSCME Retiree Program
Washington, DC

~~X~~ **Mr. Max Richtman**
Executive Vice President, National Committee to Preserve Social Security and Medicare
Washington, DC

~~X~~ **Ms. Judith Asemus Riggs**
Director for Federal Policy, Alzheimer's Association
Washington, DC

] knows



Dr. Elena Rios
President, National Hispanic Medical Association
Washington, DC

A **Mr. Michael Rodgers**
Senior Vice President for Government Relations, American Association of Homes & Services for the Aging
Washington, DC

~~X~~ **Mr. John Charles Rother**
Director of Legislation & Public Policy, American Association of Retired Persons (AARP)
Washington, DC

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Page 3

REPORT DATE: December 31, 1998
REPORT TIME: 1:35 PM**Accepts and No Responses**

Mr. Daniel Schulder
National Council of Senior Citizens
Silver Spring, MD

A **Mr. Gerry Shea**
Assistant to the President for Government Affairs, AFL-CIO
Washington, DC

~~X~~

Mr. Samuel J. Simmons
President, National Caucus & Center on Black Aged
Washington, DC

A **Dr. Marta Sotomayor**
President & CEO, National Hispanic Council on Aging
Washington, DC

A **Ms. Victoria Wagman**
Policy Associate, National Council on the Aging, Inc.
Washington, DC

Ms. Roberta Weiner
Older Women's League
Washington, DC

A **Mr. Bruce Yarwood**
Legislative Counsel, American Health Care Association
Washington, DC

A **Mr. Tony Young**
Senior Policy Analyst, United Cerebral Palsy Association

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Page 4

REPORT DATE: December 31, 1998
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Regrets

- R **Ms. Polly Arango**
Director, Family Voices
Algodones, NM
- R **Mr. Todd A. Crenshaw**
Organizational Specialist, National Education Association Retirees
Washington, DC
- R **Mr. Jonathan D. Dauphine**
Chief Program Officer, Long Term Care Campaign
Bethesda, MD
- R **Mr. Horace B. Deets**
Executive Director, American Association of Retired Persons
Washington, DC
- R **Ms. Martha A. McStein**
President & CEO, National Committee to Preserve Social Security and Medicare
Washington, DC
- R **Dr. Galen Miller**
Vice President and Director of Professional Development and Research, National Hospice Association
Arlington, VA
- R **Ms. Patricia McGill Smith**
Executive Director, National Parent Network on Disabilities
Washington, DC
- R **Mr. Frank Stella**
Deputy Assistant to the President for Operations, American Federation of Teachers Retirees
Washington, DC
- R **Ms. Rosalie W. Whelan**
Coordinator, Retired Members Department, Service Employees International Union Retirees
Washington, DC

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Page 5

REPORT DATE: December 31, 1998
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TOTAL COUNTS

Number of Accepts:	30
Number of Regrets:	9
Number of No Responses:	10
Number of Unknown Guests:	0
Number of Expected Attendees:	40

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11:15 am-
12:05 pm

HEALTHCARE EVENT**GRAND FOYER**

Remarks: Jeff Shesol

Staff Contact: Bruce Reed, Capricia Marshall

Event Coordinator: Laura Schwartz

POOL PRESS

- **The President** and the First Lady, accompanied by Secretary Robert Rubin, Secretary Donna Shalala, Director Janice LaChance and Person TBD, are announced into the Grand Foyer.
- The First Lady makes remarks and introduces Person TBD.
- Person TBD makes brief remarks and introduces **the President**.
- **The President** makes remarks and introduces the Vice President via satellite.
- **The President** proceeds to his seat.
- The Vice President and Mrs. Gore make remarks and begin a discussion.
- Upon conclusion of discussion, the Vice President makes concluding remarks and bids farewell.
- **The President** makes concluding remarks and departs.

12:10 pm

THE PRESIDENT proceeds to the Oval Office

12:15 pm-
1:15 pm

MEETING**CABINET ROOM**

Staff Contact: Gene Sperling

CLOSED PRESS**DOWN FOR THE DAY AT 1:15 PM****BC/HRC RON****THE WHITE HOUSE
WASHINGTON, DC**

Fax Transmission
Del Oro Caregiver Resource Center
5713A Marconi Avenue
Carmichael, CA 95608
916-971-0893/ Fax 971-9446

To: Sarrah Bianci

Fax #: 202-456-5557

From: David Baker

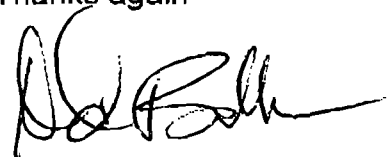
Pages (including cover sheet): 2

December 31, 1998

Sarrah,

Here's the list.

Thanks again

A handwritten signature in black ink, appearing to read 'David Baker', with a stylized, cursive script.

David Baker
Gerontologist
Community Resource Specialist

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Profile Phone List

Jim Burns
Ruth Burns

P6/(b)(6)

w 928-7079

Barbara Cepeda-Adams
Jesus Cepeda

P6/(b)(6)

[003]

* Bill Griffith
Vesta Griffith

Nora McGuinness
Arthur McGuinness

P6/(b)(6)

w 530-752-9906

* Genevieve Nauman
Dick Nauman

P6/(b)(6)

w 653-1694

~~Vernon Peasenell~~
~~Barbara Peasenell~~
~~Joseph Peanenell~~

P6/(b)(6)



DEL ORO CAREGIVER RESOURCE CENTER

The Del Oro Caregiver Resource Center was founded to establish a coordinated resource system to meet the needs of brain impaired adults through assistance to their families, professionals and other caregivers.

The Del Oro Caregiver Resource Center supplies information and referral services to caregivers of brain impaired adults; and provides contractual services for legal and financial advice, family counseling, respite care and diagnostic assessment. Del Oro Caregiver Resource Center identifies, refers to and assists in the development of support groups.

BRAIN IMPAIRMENT

Each year, millions of adults suffer brain damage from a variety of complex and puzzling diseases. And each year, the families of these adults are faced with the demanding task of caring for loved ones who can no longer care for themselves.

The loss of brain function resulting from brain impairment affects the behavior, personality and ability to perform independent tasks. Brain impairment, occurring in adulthood, has many causes including:

- *Alzheimer's, Parkinson's, multiple sclerosis, Huntington's and other degenerative diseases of the brain;*
- *Stroke and other cerebrovascular accidents;*



- *Traumatic brain injury and post infectious damage;*
- *Brain tumors and permanent damage as a result of seizures, substance toxicity and other such disorders.*

PROGRAM GOALS

- Coordinate and network with organizations and other professionals serving brain impaired adults and their families to reduce fragmentation of services.
- Document local service needs through data collection for program development and improvement.
- Support the development of enabling resources meeting short term and long term needs of brain impaired adults, their caregivers and families.
- Assist in the identification of local resources and the development of appropriate services.

PROGRAM SERVICES

- *Information and referral:* Toll-free phone line available to those desiring current information regarding impairment with referral to community resources.
- *Support Groups:* Referrals to existing support groups; assistance in establishing needed support groups.
- *Education and Training:* Provision and/or coordination of training and other professional educational programs in subjects related to



research, diagnosis, behavioral management, stress reduction, etc.

■ *Family Counseling:* Short term counseling with referral to local resources and professionals serving family members.

■ *Legal/Financial Consultation:* One time consultation provided by a lawyer (community property, estate planning, etc.).

■ *Diagnostic Evaluation:* Referral for medical diagnostic evaluation for eligible individuals with suspected brain impairment.

■ *Respite Care:* Time limited substitute care to alleviate caregiver stress. Available through contracted services and with a participant's share of cost based on a sliding scale.

ELIGIBILITY

Family members or concerned professionals living in the 13-county Del Oro Caregiver Resource Center service area are eligible for information and referral services, family support groups, caregiver training and conferences.

Other services are available to those providing care for a person whose brain impairment occurred during adulthood (age 18 and older) and who is not eligible for assistance from other publicly supported programs or similar benefits.

Information about eligibility for respite care and other services may be obtained by contacting Del Oro Caregiver Resource Center at **(916) 971-0893 or 1 (800) 635-0220.**

Respite

Recreation

Recognition

Does Your Loved One Have Memory Problems Or Confusion?

Are you looking for a friendly and secure place where he or she can enjoy enriching activities with others? Has your family or your doctor suggested that you need a break from caregiving so you can take care of your own health?

Triple "R" Can Help.

Our social companionship and recreation program for older adults with memory loss runs each day, Monday through Friday, from 7:30 a.m. to 5:30 p.m. We're located at the Ethel MacLeod Hart Multipurpose Senior Center, 27th and J Streets, in a beautiful park.

You'll find free parking nearby, and a circular drive provides easy access for persons with limited mobility.

Caregivers are invited to our monthly get-togethers to share experiences, and learn new ways to handle difficulties. Fees for part or full days are kept as low as possible and discounts are available to regular participants.

Benefits of The Triple "R"

A safe, friendly environment

Activities designed to meet the individual's recreational, intellectual and social needs

A cost effective approach to help families keep their loved ones at home

Individual and group support for caregivers

Come Visit Triple "R."

Bring your loved one, and experience the fun and caring that makes Triple "R" unique. Join in our sing-alongs, exercises, walks, and discussions. Sip coffee outside on the patio. Try our Country Western dance class, the art table, or balloon volleyball. Enjoy listening or even dancing to old favorite tunes on the piano. Just call in advance so we can expect you.

Meet the Staff.

Your loved one will feel special at Triple "R." As a caregiver of her 90-year-old mother said, "Mama never wanted to go to any group before. Now, Fridays at Triple "R" are the highlight of her week." Individual attention is assured by a ratio of approximately one staff person or volunteer for every two participants.

The Program Coordinator, with a master's degree in social work, offers support to caregivers, supervises staff, and develops the program. The Activity Leader plans and coordinates daily activities. Personal care is supervised by the Care Coordinator, an experienced C.N.A. Program Aides assist with activities and participants' personal needs.

We Welcome Volunteers.

Whether for one hour or eight, for skills such as music, sports, crafts, or simply listening and offering companionship, volunteers make a big difference at Triple "R." Training is provided.

For more information, call 264-5462.

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Fact Sheet: Selected Caregiver Statistics

Definitions

The term **caregiver** refers to anyone who provides assistance to someone else who needs it: A husband who has suffered a stroke; a wife with Parkinson's disease; a mother-in-law with cancer; a grandfather with Alzheimer's disease; a son with traumatic brain injury from a car accident; or a child with muscular dystrophy. **Informal caregiver** is a term used to refer to unpaid individuals such as family members and friends who provide care. These persons can be primary or secondary caregivers, full time or part time, and can live with the person being cared for or live separately. **Formal caregivers** are volunteers or paid care providers associated with a service system.^{1,2}

Magnitude

How many family caregivers are there in the U.S.?

- Estimates vary on the number of caregivers in the U.S., depending on the definition used.
- Nearly one out of every four U.S. households (23% or 22.4 million households) is involved in caregiving to persons aged 50 or over.³¹
- An estimated 15% of U.S. adults are providing care for seriously ill or disabled relatives.³
- There are an estimated 13.3 million Americans who have a parent or spouse who is elderly and disabled and have the potential responsibility for their care.⁵
- More than 7 million spouses, adult children, other relatives, and friends or neighbors provide unpaid help to disabled older adults living in the community.⁵

Long-distance caregiving

- Nearly 7 million Americans are long-distance caregivers for older relatives (i.e., a travel distance of one hour or more between the caregiver and older adult needing assistance).³⁴
- The average travel time for these caregivers to reach their relatives is 4 hours.³⁴

How many persons are being cared for?

- Nearly 100 million Americans have one or more chronic conditions.³³
- An estimated 12.8 million Americans of all ages need assistance from others to carry out every day activities (such as eating, dressing, bathing). Of those, about 57%

- are aged 65 and older (7.3 million); 40% are working-age adults aged 18-64 (5.1 million); and 3% are children under age 18 (400 thousand).⁶
- Between 10.3 and 14.7 million Americans age 18 and over are afflicted with adult-onset brain disorders^{1,2} to 1.8 million of these adults reside in California.⁷

Who Are the Caregivers?

- 85% of all home care is provided by family members and friends; 71% of all long-term care is provided in the community. Only 14% of home care is rendered by paid providers.⁶
- About 70% of all caregivers are married. However, female caregivers are twice as likely as their male counterparts to be widowed.⁸

Age and Gender

- The average age of a caregiver is 57 years old, however, one quarter are between 65 and 75 years of age and another 10% are 75 and older.¹⁰
- One recent national survey found the average caregiver of a loved one 50 years and older to be 46 years of age.³¹
- Approximately 72% of caregivers are female.¹⁰
- When considering family caregivers who live with the care recipient, about 53% of **primary** caregivers (those with the principal responsibility to provide care for a family member) and 45% of **secondary** caregivers are female.⁴

Ethnicity

- Research suggests that for African-American and Latino families, adult children comprise about 75% of caregivers compared to 40% to 60% in white families.⁴⁸
- A recent survey indicates that caregiving may be more prevalent in non-white families ranging from 32% of Asian families to 29% for African Americans and 27% for Latinos compared to 24% for white families.³¹

Kin relationship

- 85% of care recipients are relatives of the caregiver.⁹
- Approximately 23% of caregivers are the wives of the care recipient while 13% are husbands, 29% are daughters, and 9% are sons.¹⁰
- In a national sample of caregivers who live with their care recipient, spouses accounted for about 62% of **primary** caregivers while adult children comprised 26%. **Secondary** caregivers were more likely to be adult children (46%) than spouses (16%).⁴
- One-third of primary caregivers assume the role

because they live closer to the care recipient than other family members.¹

Working caregivers

- An estimated 14.4 million full- and part-time workers are balancing caregiving and job responsibilities.³⁶
- About one-third to nearly two-thirds of family caregivers are employed outside the home.^{8,9,10,11}
- Between 7.4% to 11.8% of the workforce is involved in providing care for an older person.³⁵
- 33% of full-time employees and 37% of part-time workers have lost time from work due to caregiving responsibilities. In addition, 15% of caregivers previously employed chose early retirement and 12% reported giving up work entirely while they were helping their older relative.⁹
- In California, over half (53%) of family caregivers under the age of 65 those most likely to be in the labor force—juggle work and caregiving responsibilities. 18% of not-employed caregivers of brain-impaired adults had quit their jobs in order to provide care for their family member. Another 42% reduced their work hours in the previous year to provide care for their relative.³⁰

The "Sandwich Generation"

- Between 20% and 40% of caregivers have children under age 18 to care for in addition to their disabled relative.^{1, 10, 12}
- About 60% of adult child caregivers live with their disabled parent and 20% of all adult child caregivers have both their disabled parent and at least one child under the age of 18 living in their home.¹⁰

How long are they caregivers?

- The duration of caregiving can last from less than a year to over 40 years. The majority of caregivers provide unpaid assistance for one to 4 years; 20% provide care for 5 years or longer.¹⁰
- The average woman can expect to spend 17 years caring for a child and 18 years caring for an elderly parent.¹³

Time spent caregiving

- 80% of caregivers provide unpaid assistance 7 days a week.¹⁰
- On average, caregivers provide personal care assistance and household maintenance chores for 12 hours per week. 28% give care for 8 hours or less, while 36% provide help for 21 hours or more. 11% provide "constant" care.⁹

- Caregivers of persons living in institutions or residential care facilities provide an average of 36 hours per month or 8.5 hours per week of care, while caregivers of community-dwelling patients provide an average of 286 hours per month or 66.5 hours per week of care.¹⁴
- Time spent caregiving varies by type of impairment. FCA's statewide study found caregivers of cognitively impaired adults spending an average of 13 hours per day providing care—more than a full-time job outside the home.⁴⁵

Extent of caregiving duties

- About 66% of caregivers assist older persons with activities of daily living (ADLs), such as bathing or dressing. Of these, approximately 68% assist with one or more ADL: about 19% assist with one ADL, 15% with two ADLs, and 33% assist with three or more ADLs.⁹
- 75% of all caregivers help with grocery shopping, transportation, and housework, and about 66% prepare meals or manage finances. 50% help administer medicines.⁹

Who Is Being Cared for?

Age

- An estimated 40% of all Americans who need long-term care are **under** age 65.⁶
- 14 million working age adults have "severe" disabilities.⁴⁷
- About two-thirds of caregivers help aging parents or others over age 65, but the remainder care for non-elderly persons such as children, spouses, or other relatives and friends.¹⁵
- As more elderly persons live to "old old" age, more also face chronic illnesses and disabilities. There were 33.9 million Americans age 65 and over in 1996—about 1 in every 8 Americans. By 2030, there will be about 20 million older adults, more than twice their number in 1996.⁴⁶
- 22% of persons 85 years and older live in a nursing home and 45% need help with everyday activities. Those 85 and over will be the fastest growing part of the elderly population in the next century.¹⁶

Ethnicity

- No ethnic group is exempt from needing care for its disabled, ill, or elderly family members. Recent research suggests that Alzheimer's disease, which affects at least one person in five after age 75, strikes with rates undifferentiated by ethnicity.¹⁷

Caregiver Strain

Physical Health

- 25% of care receivers either are bedridden or use wheelchairs. Their need to be lifted and carried can result in muscle strain and back pain for the caregiver.⁹
- 16% of caregivers indicate that their health has worsened since becoming a caregiver. Caregivers are more likely than other persons of the same age to report themselves as in poor health, and they are significantly less likely than other persons to report that their health is good or excellent.²⁴
- About 8% of primary caregivers who live with their care recipient are themselves limited in their ADLs or require ADL assistance.⁴
- Working caregivers are especially prone to headaches, weight changes, frequent anxiety, and depression. 60% report physical strain as a result of caregiving.^{25,26, 37}

Mental and Emotional Effects

- Up to half of primary caregivers caring for someone with Alzheimer's develop significant psychological distress.⁴³
- Studies show that among caregivers, an estimated 46% are clinically depressed. Approximately 49% of female caregivers and 31% of male caregivers experience depression as a result of caregiving. Among spouse caregivers 21-25% of husbands and 50-52% of wives are depressed.^{27,28}
- Caregivers use prescription drugs for depression, anxiety and insomnia two to three times as often as the rest of the population.²⁹
- Approximately 80% of workers who also have responsibilities at home for caregiving reported experiencing emotional strain as a result of caregiving, with more than 10% reporting "a great deal" of emotional strain.²⁶

Financial Issues

- About 76% to 80% of caregiving costs for disabled older adults at home are attributed to unpaid labor by family members.⁴⁰
- Research findings suggest that unpaid caregiver support saves the American taxpayers \$33.3 billion in the cost of caring for persons with Alzheimer's alone.⁴¹
- When the combined costs of medical, long-term care, home care and lost productivity for caregivers are totaled, the direct and indirect costs of caring for persons with Alzheimer's approaches \$100 billion.^{41, 44}
- The value of unpaid caregiving for someone with Alzheimer's disease is about \$31,000 to \$35,000 per year.^{41, 42}

- 40% of caregivers incur additional financial expenses for care-related products, services, and activities. 26% of caregivers spend up to 10% of their monthly income on caregiving; 31% have incurred bills due to travel; 24% due to special diets for the care recipient; and 25% due to telephone and utility charges.¹⁰
- The public sector currently is financing only a small proportion of the care for people with Alzheimer's disease 12.5% of the care provided to community-based care recipients and 34% to residents in skilled nursing facilities.¹⁴
- Medicare and private insurance pay less than five percent of the nation's long-term care bill. Under the current system individuals pay almost half of all nursing home costs out-of-pocket.⁶
- The aggregate costs of caregiving in terms of lost productivity from caregivers who are employed full time is an estimated \$11.4 billion per year. When part-time and long-distance caregivers are considered, this rises to an annual cost of \$29 billion.³⁶

Caregiver Assistance

- About one-half of primary caregivers provide care with no outside assistance whatsoever.⁹
- Contrary to popular belief, only an estimated 10% to 20% of family caregivers use formal services through public or private agencies.^{9,21,22}
- Support services for caregivers, including counseling, information and on-going support, have been shown to deter institutionalization of care recipients with moderate dementia by nearly a year.³²

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Resources

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Family Caregiver Alliance supports and assists caregivers of brain-impaired adults through education, research, services and advocacy.

FCA's information Clearinghouse covers current medical, social, public policy and caregiving issues related to brain impairments.

For residents of the greater San Francisco Bay Area, FCA

provides direct family support services for caregivers of those with Alzheimer's disease, stroke, traumatic brain injury, Parkinson's and other debilitating brain disorders that strike adults.

Prepared by Family Caregiver Alliance in cooperation with California's Caregiver Resource Centers, a statewide system of resource centers serving families and caregivers of brain-impaired adults. Funded by the California Department of Mental Health.
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NATIONAL ALLIANCE FOR CAREGIVING

A National Resource for Caregivers of Older Americans

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ASA, VA, and NARAA,
in affiliation with
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NAPGCM, NCOR, NASW,
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Gail Hunt
Executive Director

FAX

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Jeanne,
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Gail Hunt

Executive Director

The National Alliance for Caregiving (NAC) is a non-profit joint venture, created in 1996 to support family caregivers of the elderly and the professionals who serve them. There are three NAC partners - the American Society on Aging, the Department of Veterans Affairs, and the National Association of Area Agencies on Aging - and founding sponsor Glaxo Wellcome. There are also 11 affiliate organizations: AARP, American Academy of Home Care Physicians, American Association of Geriatric Psychiatry, Assisted Living Federation of America, Children of Aging Parents, Gray Panthers, National Association of Professional Geriatric Care Managers, National Association of Social Workers, National Council on the Aging, United Seniors Health Cooperative, and the Well Spouse Foundation.

According to the 1997 national caregiver survey, 22.4 million US households—nearly one-quarter of the population—contain someone caring for an older relative or friend. The value of family caregiving to society is estimated conservatively to represent nearly \$200 billion per year. Yet these caregivers often feel isolated and experience stress from the burden of caregiving itself and from balancing caregiving, work, and other family responsibilities. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of older Americans, the Alliance was created to conduct research, develop national projects, and increase public awareness of the issues of family caregiving.

Since 1996, the Alliance has completed the following projects:

- a national caregiver survey to identify the profile of the caregiver, the care recipient, and the impact of caregiving, including minority caregivers; and a public awareness campaign that highlights the value of caregiving to society and promotes resources available to families;
- a follow-up survey of Baby Boomer women caregivers to find out how the experience of caregiving has changed their own planning for long term care; and
- the LinkAges project, which included a training package and caregiver brochure for healthcare professional organizations whose members come into contact with caregivers and who can help link them to services: American Occupational Therapy Association, American Nurses Association, and American Society for Consultant Pharmacists. Also, working with the American Library Association, the Alliance disseminated lists of selected books and videos, websites, and caregiving guidelines for aging services, and a reproducible caregiver brochure to all 10,000 US public and hospital libraries.

The Alliance also is developing projects to support employed caregivers, to educate caregivers of those in managed care, and to establish a network of caregiver training programs available around the country.

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For Immediate Release/June 17, 1997

NATIONAL CAREGIVERS' SURVEY SHOWS CAREGIVING'S IMPACT ON MILLIONS OF AMERICANS

NAC and Its Partners Release Full Findings from First Study in a Decade

Bethesda, MD (June 17, 1997) - In nearly one in four U.S. households (23 percent or 22.4 million), there is at least one person over the age of 18 who is caring for someone aged 50 or older, according to a new survey released today by the National Alliance for Caregiving (NAC).

The survey, conducted by the NAC and AARP and sponsored by Glaxo Wellcome, Inc., ManorCare Health Services, Metropolitan Life Insurance Company and the Archstone Foundation, was released today at a Senate Aging Committee briefing in Washington, D.C.

"This survey shows that there has been a dramatic increase in caregiving over the last 10 years," said Gail Hunt, NAC Executive Director. "And given that America's elderly population is certain to more than double to 80 million by 2050, businesses, the government and individuals need to begin working together now to find creative ways to support caregivers," she added.

Key survey findings include:

- The average caregiver is a 46-year-old working woman who cares for her 77-year-old mother who lives nearby.
- Caregivers spend an average of 18 hours per week caring for a loved one; and almost half of them devote at least eight hours per week to helping older relatives/friends with transportation, grocery shopping, medication management and personal care, including bathing, feeding and toileting.
- More than 40 percent of caregivers are also caring for children under the age of 18.
- Almost two in three caregivers are employed full- or part-time -- about half reported that their caregiving responsibilities result in their arriving late for work, leaving early or taking time off.

(more)

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Caregivers/Page Two

A more in-depth analysis of the survey results on the part of MetLife yielded a very conservative estimate that the annual aggregate cost of caregiving to U.S. businesses, in terms of lost productivity among employees providing hands-on care, is \$11.4 billion. When all employed caregivers are included in the analysis, the estimate soars to \$29 billion per year.

"The results of the survey translate into millions of individuals who are doing their best each day to provide support to someone they care about," said Hunt. "With luck, each one of us will grow old, so we pave the way for our own futures when we all work together on innovative changes to public and corporate policy to help caregivers. We also need to work on educating caregivers about the considerable array of options that are available to assist them in their own communities."

Many types of services are being developed in the U.S. to meet the health and personal needs of the nation's growing number of older persons. However, these services are not available in all areas of the country or to people of all income levels. The range of long-term care options available for seniors through both the public and private sectors includes: independent living; continuing care retirement/senior living communities; home and community-based care programs, including home health, personal care and chore services and adult foster care; senior day care; assisted living; and skilled nursing and rehabilitation and post-hospital care. In addition, there is a range of similar programs and services designed specifically for individuals with Alzheimer's disease. A relatively underutilized service, respite care programs, can provide today's caregivers with a reliable, short-term alternative care solution.

The NAC is a non-profit partnership of four national aging organizations -- the American Society on Aging, the National Council on the Aging, the Department of Veterans Affairs and the National Association of Area Agencies on Aging -- and six affiliate groups, including AARP, Gray Panthers, Children of Aging Parents, National Association of Social Workers, United Seniors Health Cooperative and the Well Spouse Foundation. The mission of the NAC is to develop national programs to support both family caregivers and the professionals who serve them.

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CONTINUUM OF CARE FACT SHEET

An Overview of Senior Care Options Across the Public and Private Sectors

Today there is a continuum of care developing in the U.S. to meet the complete range of seniors' health and personal care needs. Programs and services along this continuum may exist in the public and/or private sectors. Funding for public sector programs comes from the Older Americans Act, states (in only some parts of the country) and Medicaid, which is limited to people with low income and assets or high medical costs.

Oftentimes, caregivers are not aware of the variety of reliable and appropriate long-term care options available to assist them and their loved ones. More than ever before, it is critical to educate and inform the public about the range of senior care options that exist today, which include the following:

Home and Community-Based Services

A wide range of home and community-based services is available to assist older persons who wish to live independently in their own homes or with family members. However, these services are not available in all areas of the country. They include: "Meals-on-Wheels;" homemaker and chore services, such as shopping, cooking, cleaning, home repair and yard work; health care services, such as visiting nurses, dispensing medication, physical and other types of therapy; personal attendant services, such as assistance with bathing, feeding and walking; and help with financial and legal issues. For seniors who are able to leave their homes, other services available include: transportation to medical appointments and shopping, meal programs in senior centers or other community settings and adult day care.

Independent Living (or Senior Housing)

Group house, townhouse and apartment-style living especially designed to accommodate the needs and preferences of independent adults best describes this senior housing option, which provides a secure, comfortable and residential environment. Many of these settings also are architecturally designed to alleviate some of the physical limitations that growing older may bring.

Respite Care

Respite care provides the caregiver who is caring for a loved one at home with a temporary break from caregiving duties. Respite care can last for as little as one day, and for as long as a month or more. Respite care is used for a variety of reasons—a weekend away, family emergency, long-awaited vacation or business travel that interferes with caregiving. Caregiving families can also use respite care as a way to "try out" full-time nursing care or assisted living services without making a commitment to a long-term placement decision. Respite care is flexible, and can be tailored to meet the needs of the caregiver. It can be provided in the home or in a long-term care facility.

Senior Day Care

These programs are designed for seniors who live at home, but require care, support or socialization during the day on less than a 24-hour basis. Programs vary, and may include the following services: counseling and health assessment; health education; personal care; therapy; social activities; meals; and transportation.

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Continuing Care Retirement Community (or Senior Living Community)

This senior care setting offers a long-term contract that provides housing, personal and health care services and nursing care, usually all in one location, as needed by each resident as he/she grows older. These communities provide a comprehensive array of services tailored to meet individual residents' needs, abilities and preferences.

Assisted Living

These residential facilities are an option for seniors who want to maintain their independence and privacy, but who require some supervision and support. They may include services such as housekeeping, linen service and meals, as well as activities of daily living such as medication management, bathing, dressing and toileting. Emphasis is placed on socialization and activities, and charges usually reflect the level of individual service required.

Nursing and Rehabilitation

Appropriate for people who need round-the-clock nursing services, these facilities offer 24-hour skilled nursing care. Oftentimes they will also offer physical, occupational and/or speech therapies to the chronically ill and frail elderly. Many of these facilities are federally certified, which means they may participate in Medicare or Medicaid programs.

Specialized Alzheimer's Services

There are a number of different care settings that have been developed especially for individuals with Alzheimer's disease and related memory disorders. Due to the progressive nature of the disease, an individual's stage of affliction often will determine the level of care required. The continuum of specialized Alzheimer's care mirrors that of the traditional continuum of care, and includes senior day care, Alzheimer's assisted living and Alzheimer's Special Care Units (SCU) in skilled nursing centers.

For More Information on Senior Care Options

For more information on publicly funded home and community-based services for older adults, members of the public can contact the Eldercare Locator, which will provide them with contact numbers for the local Area Agency on Aging and other community services to assist the older person in need. Call toll-free Monday through Friday, 9 a.m. to 11 p.m. (Eastern) at 1-800-677-1116. Members of the media can contact the National Association of Area Agencies on Aging, (202) 296-8130.

For more information on the range of senior care options available from ManorCare Health Services and a directory of the company's more than 200 facilities nationwide, members of the public can contact the nearest facility by checking their local telephone book. Members of the media can contact Leslie Keenan, (301) 979-4738, or Kathy Lanza, (301) 979-4753.



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FAMILY CAREGIVER FACT SHEET

In the fall of 1996, the National Alliance for Caregiving, together with the American Association of Retired Persons, and with funding from Glaxo Wellcome, conducted a national random dial telephone survey to identify the prevalence, demographics, impacts, and needs of family caregivers of the elderly. The survey database of 1,509 respondents includes an oversampling of Hispanic, African American, and Asian American caregivers.

The full survey report, with analysis and charts, is available in May 1997, from the National Alliance for Caregiving, S. 642, 4720 Montgomery Lane, Bethesda, MD 20814.

- * There are 22.4 million US households--nearly one in four--involved in family caregiving to elderly relatives or friends.
- * Profile of the typical caregiver of an elderly person: a 46-year-old woman who is employed and also spends around 18 hours per week caring for her mother who lives nearby.
- * Profile of the typical care recipient: a 77-year-old woman who lives alone and has a chronic illness.
- * 72% of caregivers are women; 28% are men.
- * 15% of caregivers are caring for a friend or neighbor.
- * Over 30% of caregivers are caring for two or more elderly relatives or friends.
- * Almost three-quarters of caregivers report that someone else--usually a daughter or son--helps with the caregiving.
- * About one-quarter of caregivers report helping someone who has dementia.
- * Transportation, grocery shopping, and household chores are the most common tasks caregivers perform.
- * More than half of all caregivers help with at least one activity of daily living (e.g., bathing, dressing, eating) and nearly a quarter are helping with at least two.

1 Additional funding was obtained from the Archstone Foundation, Manor Care Health Services and MetLife.

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- * 37% of caregivers help their friends or relatives with medications, pills or injections.
- * While the average caregiver provides care for 18 hours per week, "intense" caregiving is going on in a quarter of the 22.4 million households, with 4.1 million households providing at least 40 hours per week of unpaid, informal family assistance to an older relative and another 1.6 million households providing 20-40 hours per week.
- * 64% of caregivers are working full or parttime. Half of them report making some adjustment in their schedule (taking time off, coming in later, working fewer hours). Those caregivers providing the most intense care for the most hours are most likely to have made changes.
- * 6% of caregivers who were working report that they gave up work entirely due to caregiving and 3.6% said that they took early retirement.
- * A little less than half report that caregiving has caused them to have less time for other family members; 43% had to give up vacations, hobbies or other activities.
- * Only 15% of caregivers report experiencing physical or mental health problems due to caregiving.
- * Caregivers are spending out-of-pocket about \$2 billion per month for groceries, medicine, and other cash supports for their relatives. (Half of all caregivers are spending their own money, at an average of \$171 per month.)
- * 41% of caregivers are caring for children under 18 at the same time as elderly relatives or friends.
- * The number one coping mechanism mentioned (74%) to cope with stress was prayer. Talking with friends (66%), exercise (38%) and hobbies (36%) were also mentioned. Only 16% of caregivers get help from counselors or other professionals.
- * Only 7% of caregivers have participated in a support group.
- * Besides using nursing/home health services (38%) and wheelchairs or walkers (47%) for their relative, caregivers were most likely to have used home modification (28%).
- * When asked what kinds of help or information caregivers could use most, survey respondents requested "free time; time for myself" most frequently (17%). Help with housekeeping was mentioned by nearly 10%. Eighteen percent said they needed nothing, while 38% said that they didn't know what help or information they could use.
- * Nearly 70% of caregivers used a positive word to describe how they personally felt about being a caregiver.
- * 11% of caregivers are providing long-distance care (one hour or more from the caregiver's residence).

WORKING CAREGIVERS FACT SHEET

- Overall profile of caregiver: 46 year-old baby boomer woman, married and working, who spends 18 hours a week caring for her 77 year-old mother who lives nearby.
- Sixty-four percent of caregivers work full or parttime.
- Working caregivers spend an average of 12 hours per week doing caregiving. About half provide instrumental activities of daily living only (e.g., transportation, managing finances, housework, home repair).
- Fifty-two percent of employed caregivers report that caregiving had the following negative effects on their work lives:

Go in late, leave early, take time off	49.4%
Take leave of absence	11.0
Drop from fulltime to parttime	7.3
Leave work entirely	6.4
Lose job benefits	4.2
Take early retirement	3.6
Turn down promotion	3.1

- Eighty percent of employed caregivers report that their supervisors are either very or somewhat understanding about the ways caregiving affects their work. Only seven percent report their supervisors are unaware of their caregiving responsibilities.
- MetLife analysis indicates conservatively—taking only those working caregivers doing personal, hands-on care—that employers lose \$11.5 billion annually. Counting long-distance caregivers and those doing IADLs, the estimate is \$29 billion in lost productivity.

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MINORITY CAREGIVERS FACT SHEET

- There are an estimated 22,411,200 caregiving households nationwide with English speaking caregivers, of which there are approximately,
 - 18,290,000 White, non-Hispanic households
 - 2,380,000 Black, non-Hispanic households
 - 1,050,000 Hispanic households and
 - 400,000 Asian households
- Asian and Hispanic caregivers are significantly younger than Whites and Blacks, with average ages of 39 and 40 respectively, compared with 47 for Whites and 45 for Blacks. More than one-third of Asian and Hispanic caregivers are under 35, compared with just over one in five White caregivers and just under one in five Black caregivers.
- Asian caregivers are most evenly split among female and male caregivers: 52 percent of Asian caregivers are women (in contrast with 77% of Blacks, 74% of Whites, and 67% of Hispanics, and 48 percent are men).
- Asian caregivers are more highly educated than caregivers of other racial/ethnic groups, with 39 percent being college graduates and 21 percent having had graduate education. In contrast, only 15 percent of Blacks and 18 percent of Hispanics are college graduates and fewer than seven percent of either group have had graduate education.
- Asian caregivers also report considerably higher annual household incomes than other groups (averaging more than \$45,000 compared with just under \$28,000 for Blacks, for example).
- While 41 percent of caregivers have one or more children under age 18 living in their households, more than half of all Black, Hispanic, and Asian caregivers report having one or more children under age 18 in their households in contrast with 39 percent of White caregivers.
- Asian caregivers are more likely to be employed full- or part-time (77%) than Whites (65%), Blacks (66%), or Hispanics (65%).
- Asians are least likely to be caring for a spouse (1%) and most likely to be assisting a father (18%). Hispanic caregivers are more likely to be caring for a grandparent (22%) than other caregivers (15%). Black caregivers are most likely to be taking care of a relative other than an immediate family member or grandparent - 14 percent, in contrast with nine percent of White, seven percent of Hispanic, and six percent of Asian caregivers.
- White caregivers, on average, care for persons who are older than those cared for by caregivers of other racial/ethnic groups: The mean age of care recipients of White caregivers is 77.6 years, compared with 75.2 for Blacks, 74.7 for Hispanics, and 74.4 for Asians.
- Asian caregivers are more likely to live in the same household with their care recipient (36%) than Blacks (26%) or Whites (19%).
- Asian caregivers spend significantly less time providing care per week, on average, than other minority caregivers: 15.1 hours, in contrast with 20.6 hours for Blacks, 19.8 hours for Hispanics, and 17.5 hours for Whites.

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ALZHEIMER'S CAREGIVER FACT SHEET

The following facts were derived from the national caregiver survey, Family Caregiving in the US: Findings from a National Survey, a national random digit dial telephone survey with 1,509 respondents. The survey was published by the National Alliance for Caregiving and AARP in June 1997, and a free copy can be obtained by writing the National Alliance for Caregiving, 4720 Montgomery Lane, Suite 642, Bethesda, MD 20814.

- 22% of all caregivers of those 50+ are caring for a relative or friend with Alzheimer's or dementia--nearly 5 million US households.
- The mean age of the Alzheimer's caregiver is 49 years old--three years older than the average family caregiver.
- A greater percentage (25.5%) of Alzheimer's caregivers are co-resident than the average caregiver (20.6%). Co-residence is often a marker for stress. But 17% of Alzheimer's care recipients live in either assisted living or a nursing home.
- A much higher percentage of Alzheimer's caregivers spend 21 hours per week or more caring for their relative or friend--nearly 40%--versus 26% of all caregivers.
- Of those caregivers whose relative or friend lives in a facility, 28% said that the care recipient lives in a special Alzheimer's facility.
- Excluding "constant care," those caring for someone with Alzheimer's spent on average 17.5 hours per week versus 13 hours per week for caregivers overall.
- Looking at IADLs, Alzheimer's caregivers spent much more time preparing meals, managing finances, arranging for outside services, and managing medications. Looking at ADLs, nearly 70% provided ADL support versus 51.5% of caregivers overall.
- A much greater percentage of Alzheimer's caregivers (51% versus 23%) reported problems with getting their relative or friend to take medications on time, in the right amount, and as directed. On the other hand, the caregivers themselves report greater knowledge of what each medicine is for, possible side effects, and possible medicine interactions.

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- More Alzheimer's caregivers report being the only one who cares for their relative or friend, while only 41% (versus 49%) report that other relatives are doing their fair share of helping with caregiving and 37% (versus 26%) report family conflict over caregiving.
- On the topic of balancing work and family, 63% of the 60% of Alzheimer's caregivers who work full or part-time say that they have had to make some accommodations in the workplace to meet their need to provide care. Nearly 58% say that they have to go in late, leave early, or take time off during the day to provide care, and 10% have taken a leave of absence (about the same as other caregivers). But twice as many Alzheimer's caregivers (13%) have had to drop back to part-time or choose early retirement (7%) and nearly 10% said that they had to give up work entirely.
- A slightly higher percentage of Alzheimer's caregivers (83% versus 81%) report that their employer's attitude toward the demands of their caregiving was somewhat or very understanding.
- Twice the percentage of Alzheimer's caregiver (21% versus 10.8%) say that caregiving represents a physical strain. Forty-three percent versus 25% report that caregiving is emotionally stressful. Twelve percent versus 6.6% say that caregiving represents a financial hardship.
- Alzheimer's caregivers say that the biggest difficulty they face is watching the deterioration of their loved one.
- A higher percentage of these caregivers (83%) has used formal services versus 73.5% of caregivers overall. Nursing and personal care services, respite care, meals-on-wheels, and adult day care services were used the most.
- Services that Alzheimer's caregivers say that they would use include help in understanding how to pay for nursing homes, adult day care or other services, time for oneself, and help with ADL care. Only 11% thought they would use a support group.
- About 57.5% of overall caregivers used a positive word to describe how they feel about caregiving. Fifty-one percent of Alzheimer's caregivers used a positive word.