

# CAREGIVING in the USA

A few facts and figures about the lives of  
caregivers in the United States

While this set of information primarily relates to families and other informal caregivers, there is also some information about paraprofessional caregivers, home health aides and hospital and hospice professionals.

Compiled by Lynn Kable in 2007

# WHAT IS CAREGIVING? WHO ARE CAREGIVERS?

- Caregivers provide continuous care over a long period of time in homes, institutions and long term care facilities for persons with physical or mental illness or disability requiring assistance with activities of daily living (Barbara Hogan, PhD, SAH Conference on Caring for Caregivers in the USA and Japan, Gainesville, Florida, April, 2002)

## Dr. Hogan said about USA Caregivers

- Family, friends, and neighbors, called “informal caregivers” provide between 70% and 80% of care outside of institutions.
- “Formal caregivers” are primarily home health aides and nursing assistants.

# Who Receives Care in the USA?

- More than half of those receiving long term care are over the age of 65.
- The fastest growing age group is over 85.
- Only 5% receiving LTC are institutionalized at any one time in nursing homes, etc.

(Facts from Hogan, Barbara, PhD, op.cit. 2002)

# Who Gives Care in the USA?

- **An estimated 52 million informal and family caregivers provide care to someone over the age of 20 who is ill or disabled.** (Health and Human Services, *Informal Caregiving, Compassion in Action*. Washington, DC)
- **Of these, at least 44 million are over 18 and providing unpaid assistance to older adults and adults with disabilities living in the community.** (National Alliance for Caregiving and AARP 2004)

# Who are Informal Caregivers

- According to the family Caregiver Alliance in 2007, many people in all ethnic groups are currently informal caregivers, (Asian-American 16% African American 21% Latino 16%, White 21%)
- At least two-thirds of all caregivers are women according to the National Alliance for Caregiving most recent estimates.
- Women also spend 50% more time care giving than their male counterparts, and handle the most difficult caregiving tasks. ([www.owl-national.org](http://www.owl-national.org) and [www.caregiver.org](http://www.caregiver.org))

# Time and Travel

According to the Family Caregiver Association:

- 1 in 5 informal caregivers provide care more than 40 hours per week, while nearly half of caregivers provide less than 8 hours of care per week. 1/3 of caregivers providing more than 40 hours of care per week are over 65 years old.
- Caregivers in 2003 were found to spend an average of 4.3 years in caregiving, while another study said 40% of caregivers had been at it for more than 5 years, and nearly 20% for more than 10 years.
- 42% of caregivers live within 20 minutes of the care recipient but 15% are classified as long distance caregivers who may spend from four to seven hours traveling.

# Paraprofessional (Formal) Caregivers

Nursing assistants and Home Health Aides most often:

- Are Middle-aged woman
- Have a low educational level
- Live below or near poverty
- Receive low wages, few benefits

(Hogan, Barbara, op cit.)

# Age, Relationship of Caregiver to Person Receiving Care

(from [www.caregiver.org](http://www.caregiver.org))

- The majority of caregivers are middle-aged (35-64)
- Family caregivers over 75 years old spend an average of 35 hours per week in care giving.
- 22% of persons over 65 are caregiving for a spouse.
- The person most likely to be providing care to an older person is an adult child, but the person most likely to be primary caregiver for someone they are living with is a spouse. Adult children are often secondary caregivers.
- 17-24% of informal caregivers are estimated to be friends or neighbors.

# INFORMAL CAREGIVERS ARE VALUABLE TO SOCIETY

- **Assessing values & costs of informal care giving in the USA from a societal perspective, there was an estimated annual \$306 billion value to the U.S. economy in 2006 – and some studies suggest higher.** (Peter S. Arno, PhD. *Prevalence, Hours and Economic Value of Family Caregiving, Updated State-by-State Analysis of 2004 National Estimates*. Kensington, MD )
- **If informal caregiver services had to be replaced by paid workers, the cost was estimated at the very least to be \$257 billion annually (in 2000 US\$).**
- **By contrast, the annual cost for all nursing home care is now \$92 billion and for home health care is \$32 billion.** (Hogan, Barbara Op Cit, nursing home figure updated from Family Caregiver Website)

# Informal Caregiver Employment Statistics

- According to the Family Caregiver Association, between 25 and 34% of workers report that they are also now or have recently been, caregivers.
- 48% of caregivers are employed full time, another 11% are employed part-time.
- Women who are caregivers during working years are 2.5 times more likely to live in poverty in old age than their counterparts without care giving roles.
- The Older Women's League says many midlife women find themselves caring for children, mothers and grandmothers ([www.owl-national.org.factsheets/poverty.html](http://www.owl-national.org.factsheets/poverty.html))

# COST OF INFORMAL CAREGIVING IS BORNE PRIMARILY BY THE CAREGIVERS AND THEIR EMPLOYERS

- According to Dr. Hogan (op.cit.) the estimated losses to the informal caregiver in 2002 including lost wages, social security and pension or opportunity to invest in pension plans, averaged \$659,139 over each caregiver's lifetime.
- Hogan said unplanned loss to businesses had a \$11.4 billion annual cost in 2002. More recent estimates from [www.caregiver.org](http://www.caregiver.org) go as high as 29 billion annually.

# Identified Problems of U.S. Caregivers

- The Older Women's League (OWL) says care giving is identified as one of the main determinants of the health of an aging woman.
- According to the World Health Organization (WHO) Global Commission on Women's Health Caregivers in general suffer from low income and high stress. (Organizations quoted by Barbara Hogan, PhD, op.cit)
- Elderly spousal caregivers (age 66-96) experiencing caregiver stress have 63% high mortality rate than non-caregivers the same age.  
(Covinsky, K.E. et al. Patient and Caregiver Characteristics Associated with Depression in caregivers of Patients with Dementia in Journal of General Internal Medicine, 18,1006-14)

# Physical Health Problems of Caregivers

According to [www.caregiver.org](http://www.caregiver.org):

- Caregivers have increased levels of high blood-pressure, cardio-vascular disease, diabetes.
- Women who spend nine hours per week or more caring for a spouse double their chance of developing cardio-vascular disease.
- 60% of caregivers report that their exercise and eating habits have gotten worse.
- More than half of caregivers reported missing doctors appointments, and 72% report not going to the doctor as often as they should. In rural areas, access to medical care is a big problem for caregivers.
- Women caregivers are twice less likely to fill prescriptions because of the cost.

# Mental and Emotional Health

- 40-70% of caregivers show signs of clinical depression, while 1/4 to 1/2 of these meet clinical criteria for major depression. (Zarit, S. *Assessment of Family Caregivers: A Research Perspective (2006)*. In Family Caregiver Alliance Caregiver Assessment. Vol II pp.12-27)
- Depressed caregivers are more likely to suffer from Substance Abuse or Chronic Disease.

# POSSIBLE REMEDIES FOR INFORMAL AND PARAPROFESSIONAL CAREGIVERS

- **Increased Compensation for lower paid paraprofessional workers**
- **Educational and Instrumental Support**
- **Health screening & monitoring.**
- **Social Support**
- **Stress reduction activities.**

# Hospital and Hospice Professional Caregivers

- In Medical Centers and Hospices, caregivers are defined as people who take care of patients.
- Caregiver stress has been identified as a major reason for physicians, nurses, and other staff leaving their fields, and suffering “burnout.”
- Hospitals, institutions, and hospices have begun to identify and address, formally and informally, the needs of their staff attributed to “caregiver stress.”

# Hospital and Hospice Professional Staff

- Because of the high cost of staff turnover and training new personnel in hospitals, many arts, exercise, stress reduction, peer support, counseling & recreation programs credited with retaining one nurse or doctor are said to have “paid their own way.”

## 7 “R’s for Caregiver Relief that Can Include Arts and Design

- Respite - a time to do what needs doing
- Retreat – a time to get away and relax
- Rage – a time to let it all hang out
- Religion/meditation – a time to ask for help
- Recreation/arts – a time to follow one’s own interests
- Renewal/Education – an opportunity to learn new skills
- Remembering/Grieving – expressing respect and caring for someone who has passed away