

World Wide Home Care Statistics, Trends and the Four Pillar Solution to Caregiver/Carer Challenges



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Definition of a caregiver [Baroness Pitkeathley, *It's my Duty Isn't it?* 1989]

Someone whose life is in some way restricted by the need to be responsible for the care of someone who is mentally ill or handicapped, physically disabled or whose health is impaired by sickness or old age.

Caregiving is a global phenomenon

- No nation is without family caregivers
- Carers function as low- or unpaid healthcare workers yet policymakers don't include them in healthcare decision-making and doctors don't include them in discussions
- Nations have a variety resources for caregivers
- Every nation's healthcare system is struggling to meet demands

What is the profile of a typical caregiver?



In Africa: According to a 2006 study done by USAID: HIV/AIDS is having a devastating effect on households. It has orphaned more children in Africa than in any other part of the world. Studies show that up to 60% of orphaned children, including those orphaned by AIDS, live in grandparent-headed households.

Country Statistics:

- Population: 680 million and the population is rapidly expanding
- The UN Secretary-General's Task Force on Women and AIDS in Southern Africa found 2/3 of caregivers were female
- 1/4 were 60+

- Households headed by older women in sub-Saharan Africa are 2x as likely to include orphans as households headed by older men
- Children orphaned by AIDS has risen from one million in 1990 to 15 million in 2008; by 2010, the number could exceed 25 million.
- Women caregivers need support and training. Men only assume the responsibility if there are no women available.



In China: Chinese caregivers are influenced by the Confucian norm, where obedience, provision and care towards the parents and/or other close relatives have always been emphasized (Zhan, 2004).

Country Statistics: (From a 2008 article called *The Aging Giant* by Dr. Joseph H. Flaherty, associate professor of geriatric medicine at Saint Louis University)

- Population: 1.3 billion
- Their tradition of caring for family members is strong, but will it be strong enough to counterbalance society's pressures?
- In 2005 and 2006, homes, universities, hospitals and nursing homes in three major cities with populations of more than 10 million were studied.
- Everything is fine today because older Chinese had five or six children. They have many caregivers. But their children were limited to one child in 1979. What happens in 30 years when their children turn 80?
- By 2030, 336 million Chinese will be 60+. If the burden of their care shifts from family to nursing homes, the country would be unprepared.
- China has fewer nursing homes than most developed countries. Beijing alone will have to construct 48 new nursing homes yearly to keep up with the aging population.



In Israel: The caregiver is usually a woman, either unpaid because she is the spouse, daughter or daughter-in-law or remunerated if she is an Israeli or foreign provider of nursing care.

Country Statistics:

- Population: 6 million

- In 2000, the number of people age 65+ represented 10% of the population
- Most primary caregivers are women (66%)
- About 40% are spouses
- About 50% are adult children; most are married with families of their own
- Primary caregivers invest between 20-45 hours of caregiving weekly



In Japan:

Country Statistics:

- Population: 127 million
- In 2005, 17% of the population was 65+.
- By 2020, it is expected 26% of the population will be 65+
- According to a 2005 national survey, the proportion of male caregivers has increased steadily over time from 11.2% in 1984 to 17.9% in 1986 and 22.7% in 2004.
- Japanese life expectancy is the longest in the world (77 male; 84 female)
- About 1/2 of the elderly live with their children, the highest rate of industrialized nations.



In Australia: She is caring for her spouse and loves to play Carrie the Caregiver, a shockwave game.

Country Statistics:

- Population: 19.6 million
- 2.3 million are caregivers (nearly 2 million are between 15-64)
- 20% are primary caregivers
- 70% are female
- 43% care for a spouse; 25% for a child; 21% for a parent
- 20% are 65+
- 5% are under 18



In the U.S.: According to a 2004 Survey conducted by the National Alliance for Caregiving and AARP: She is 46, works, has at least some college education and cares for her 75-year-old widowed mother who lives nearby.

Country Statistics:

Population: 306 million

- A 1997 AARP and National Alliance for Caregiving survey reported 27% of caregivers were men (By 2004, it was almost 40%)
- 60% of male caregivers worked full time. 41% of female caregivers worked full time
- Males and females face the same challenges (depression, stress, exhaustion and reduced personal time); however, men approach the role differently. “Men approach caregiving as work, tasks that must be accomplished,” says Edward H. Thompson, coeditor of *Men as Caregivers*
- Men delegate and are more comfortable seeking outside help

2008 US Bureau of Labor Statistics

- In-home caregiving for the elderly is one of the fastest growing industries in the new millennium
- Home care aides increased by 138% from 1992 through 2005, to almost 1 million employees
- A National Alliance for Caregivers study estimates family caregivers suffer a financial loss of \$650,000+ in lost wages, pensions and Social Security benefits

UnitedHealth Group's Evercare® organization and the National Alliance for Caregiving (NAC) studied Hispanic Households in the U.S.

- 36% of Hispanic households have at least one family member caring for an older loved one
- More than eight million Hispanics provide care to older loved ones
- This is a larger percentage than all U.S. caregiving households (21%)
- Becoming a family caregiver caused a major shift in the working situation that could have dramatic implications as the current fiscal crisis continues

The Four Pillar Solution

Pillar IV: Governments

- Pass laws to provide funds and respite to support the caregivers/carers
- Expand support by increasing caregivers' access to affordable basic shelter, land to grow crops or raise animals and other income-generating opportunities, including microcredit programs
- Encourage males in sharing the responsibility of caregiving
- Address the overall health and specific psychosocial needs of caregivers through the counseling and other assistance
- Ensure caregivers have information on HIV prevention, treatment, care, support, supplies and training

For example:

- **The United Kingdom-Pioneers of the Caregiver Movement** has contributed to the passage of three acts of parliament and two national caregiver strategies.
- **United Nations International Day of Older Persons 2008: Global Perspectives on Family Caregiving.** On Oct. 1, 2008, family caregiving advocates from around the world shared challenges and progress hosted by AARP, the National Alliance for Caregiving and the United Nations Programme on Ageing
- **In the US, the Lifespan Care Respite Act was passed in 2006;** however, it has not been funded (maybe in 2009?). In 2007, 24 bills were introduced in Congress to help caregivers, but have not been acted upon.

Pillar III: NGOs

- In 2006, the National Alliance for Caregiving invited teams from eight Latin American countries to a conference on caregiver issues. One year later, Chile approved legislation to provide financial support to family caregivers looking after bedbound loved ones. Peru introduced legislation to create a national day recognizing caregivers and Argentina is working on convening a second Pan American conference on caregiving.

- International Forum on Ageing-in-Place to be held in Akita, Japan from October 10-12, 2009 will provide an international platform for information exchange and knowledge transfer based on the themes: Models of Ageing in Place, Age Friendly Cities and Technology. Sponsored by the International Federation on Ageing. Hosted by Friends of IFA Japan in partnership with the Hong Kong Council of Social Services.

Pillar II: Private Sector

- In the US, doctors, employers, state and federal policymakers, private insurers and Medicare are experimenting with the Medical Home concept that has a physician or nurse lead a team who tend to the patient's health care and education. Its goal is to make primary care attractive to doctors and boost the nation's shrinking supply of family physicians, internists, pediatricians and geriatricians
- Business owners, especially those in the home health industry, must share resources and best practices globally, especially to developing countries

For example:

- MetLife Foundation recently announced plans to sponsor an updated national caregiver survey this year which the National Alliance for Caregiving that will include people caring for children with disabilities
- I am in the home health care industry and have recently reached out to several international caregiving organizations and offered to share resources from the California Association for Health Services at Home (**CAHSAH**), the leading statewide home care association in the U.S.

Pillar I: Individual

- Adopt/maintain a healthy lifestyle
- Reach out to a friend, neighbor or family member who is a caregiver and offer respite
- Don't wait for the government, NGO or business to address a need. Women are known for the grassroot approach!
- We are global citizens and cannot ignore what happens worldwide. But these tasks seem daunting. We can begin in our community.
- Gandhi: Be the change you want to see in the world

Caregiving tips from around the world

- Care of yourself. Maintain your relationships
- Chronic illness can be forever. Most are unprepared for another's lingering
- Adopt a "wait and see" attitude for what can and cannot be done
- Don't say, "You look tired, you need to rest." Say, "You look tired. What can I do to help?"
- A chronic illness means you will always have an illness in your home
- Do not assume decision-making roles for your loved one. Your loved one is responsible for his/her life
- Caregiving is not always selfless love transferred to another. It can be difficult and exhausting
- Develop a personal support system
- Ask for help from friends and family
- Keep your sense of humor and develop new interests
- Have flexible expectations
- Don't think of your loved one as "the patient"
- Create a telephone support network
- Spend your energy wisely
- Set priorities together
- Protect your relationship and work together
- Join a support group. None around? Put an ad in the paper. They'll come!
- Adapt. Maybe you cannot go out to eat, but you can have a picnic in bed or bring in a meal
- Your relationship will require new skills. If you think just because you have had a great relationship, all will be well, and you will be kidding yourself
- Do not allow the illness to become the focus of your relationship – You, Your Spouse and "IT"
- COMMUNICATE, COMMUNICATE, COMMUNICATE!

Caregiving tips specifically for men:

- List what you need in case someone asks how they can help
- Plan something for yourself—whether it's a trip or a movie at home. Tell yourself you will get through this
- Acknowledge your emotions. You're human, not a robot
- Set up a group e-mail to keep family and friends in the loop
- If you care for your spouse, don't put off taking a trip if you have always dreamed of it. If it's feasible, do it!
- Discuss issues and find what works for you both
- Learn about your patient's disease, even if it's scary

Conclusions:

- Caregivers are neglected everywhere
- Most caregivers/carers are women. Men must assume more caregiving responsibilities
- As the population ages, more caregivers will be needed
- Most caregivers do not receive proper training
- Caregiver burnout is a common problem. Loved ones assume the role with the best of intentions; however, have no training and cannot do it 24/7.
- Most caregivers need respite.
 - 9% of the population reports they are in poor health
 - 17% of caregivers report they are in poor health
 - 35% report fair health
- Many times caregivers ignore their own health issues
- There are resources available; caregivers must learn where to look
 - 29% find caregiving information on the Internet
 - 28% ask doctors
 - 10% ask a nurse or other health professional

International Resources:

- **England** : www.pdsg.org.uk
- **France**: Send an email to flandrealzheimer@wanadoo.fr
- **Germany**: Send an email to info@deutsche-alzheimer.de
- **Carer for the Caregiver Training Video**
<http://www.youtube.com/watch?v=6YtjAQNIGUU>
- **Family Caregiving 101: help for new caregivers**
<http://www.familycaregiving101.org>
- **Carers Australia: includes news, resources and articles**
www.carersaustralia.com.au
- **Carers Australia The Princess Royal Trust for Carers: advice and help forums –**
www.carers.org
- **Direct Government Caring for Someone: guide to caring**
www.direct.gov.uk/en
- **Alzheimer's Caregiver Support Online**
<http://alzonline.php.ufl.edu>

International Organizations:

- **Eurofamcare** surveys family carers of seniors regarding the familiarity, availability, use and acceptability of services
- In 2003, Germany, Greece, Italy, Poland, Sweden and the UK formed a trans-European group
- **The Pan-European Group** consists of 23 countries (including the aforementioned six countries)
- **Eurocarers**, launched in June 2007 and comprised of 18 organizations and research bodies from nine countries , provides a united voice to influence policy
- On February 27, 2004, **International Alliance of Carers (IACO)**, in London, was launched by Australia, UK, Sweden, the Netherlands and US family caregiving organizations. Their mission is to:
 - Increase visibility of family caregiving as an international issue;

- Promote the sharing of best practices in caregiving programs between countries; and
- Encourage and provide assistance to countries interested in developing family carer organizations.