



Home Caregiving Strategies for Health Professionals and Home Caregivers

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Objectives



- Identify the primary providers of long term care
- Identify aspects of family caregiving that influence patient outcomes
- Discuss ways to be a caregiver advocate

There are only four kinds of people in the world:



1. Those who have been caregivers
2. Those who currently are caregivers
3. Those who will be caregivers
4. Those who will need a caregiver

First Lady Rosalyn Carter

What is Caregiving?



Helping someone out, assisting someone,
nurturing them...

Providing assistance to a person who is ill,
disabled, or needs help with daily activities

The provision of healthcare services

Who are the Caregivers?



**FORMAL
CAREGIVER**

**INFORMAL
CAREGIVER**



The Invisible Caregiver



The Primary Family Caregiver: (Informal, not paid)

Does not think of self
as a “caregiver”

Thinks in terms of
relationships



The Invisible Caregiver



The Primary Family Caregiver:

Typically is not recognized by the formal healthcare system as part of the care team



Family Caregiver Stats



- 29 % of households in the U.S. provide care to a chronically ill, disabled or elderly person in any 12-month period

National Alliance for Caregiving, AARP 2009

- Spend an average of 20 hours/ week providing care for their loved one

13% of family caregivers spend 40 hours +

National Alliance for Caregiving, AARP 2009

- 62 % rearrange work schedules, decrease their hours or take leave

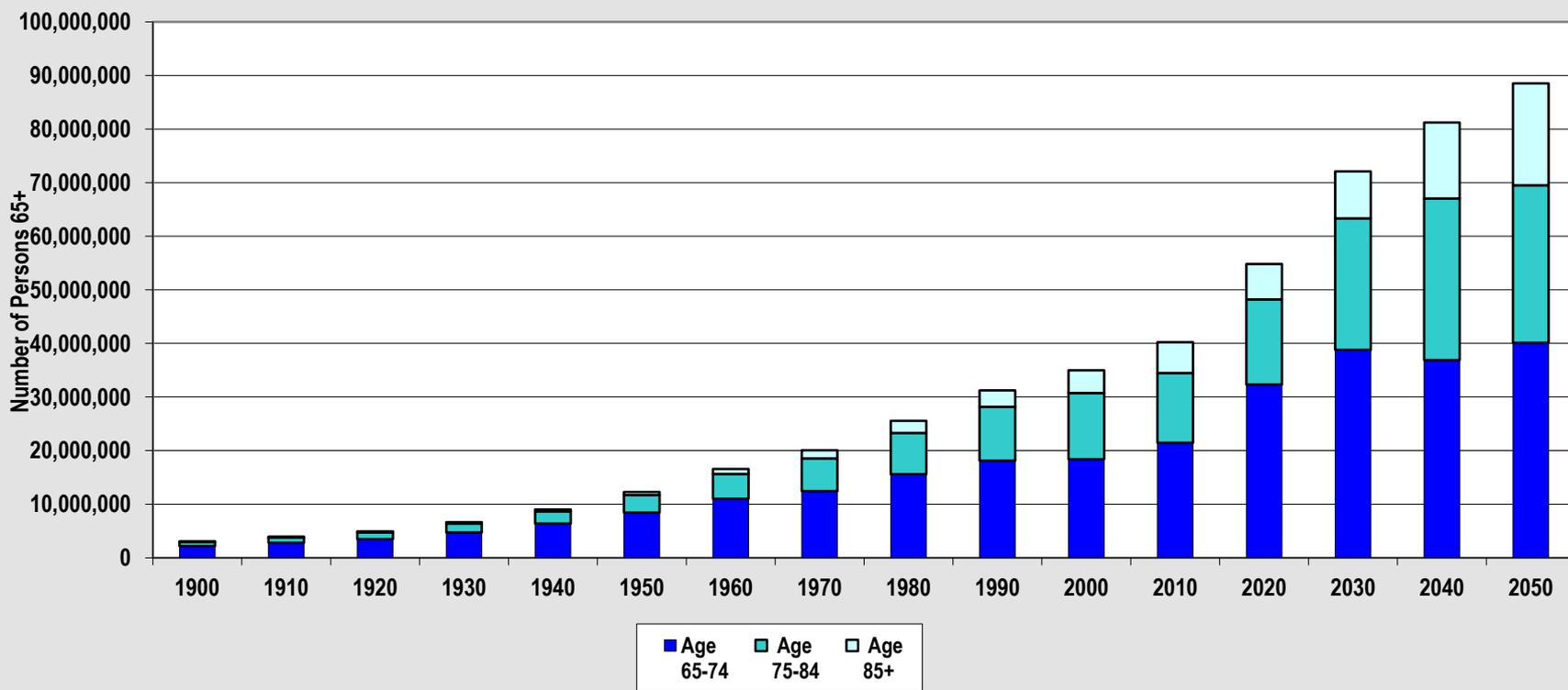
MetLife, 2010



Aging in America

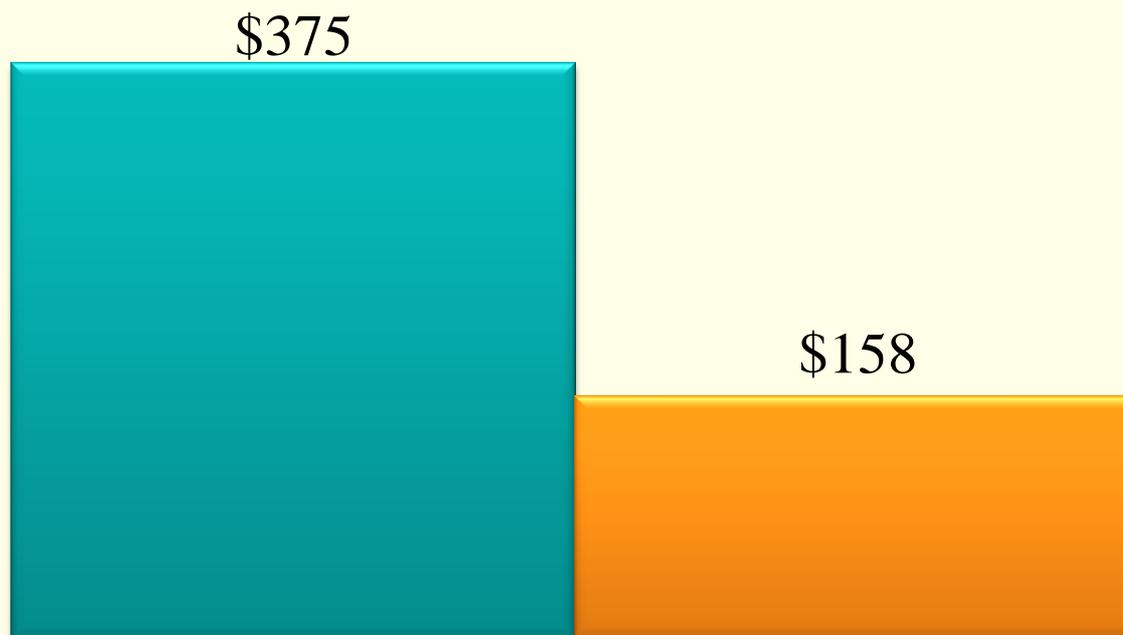
Population 65+ by Age: 1900-2050

Source: U.S. Bureau of the Census





Value of “free” care



(in billions)

- Services Provided by Family Caregiver
- Services Provided by Government



Cost to the Family Caregiver

Financial:

- Personal loss of about \$659,139 over a lifetime
- Spend an average of \$5,531 a year on caregiving expenses

Government Assistance



Services Provided	Medicaid	Medicare
■ Homemaker-laundry, shopping, errands	YES	NO
■ Home delivered meals	YES	NO
■ Electronic Personal Emergency Response System	YES	NO
■ Adult Day Health Care	YES	NO
■ Respite-temporary relief for the primary caregiver	YES	NO
■ Nursing Home care	YES	LIMITED

Becoming a Caregiver



“The Call”

Sudden

Gradual-chronic

Tag, You're It



1. The spouse/partner

2. The adult child

Caregiver by choice

Caregiver by default

3. Other relative or friend



Caregiver Profile



49 year old woman, married, employed
Cares for her widowed mother
37% have children or grandchildren under
18 years old living with them



The Care Recipient



An adult with a chronic illness or disabling condition

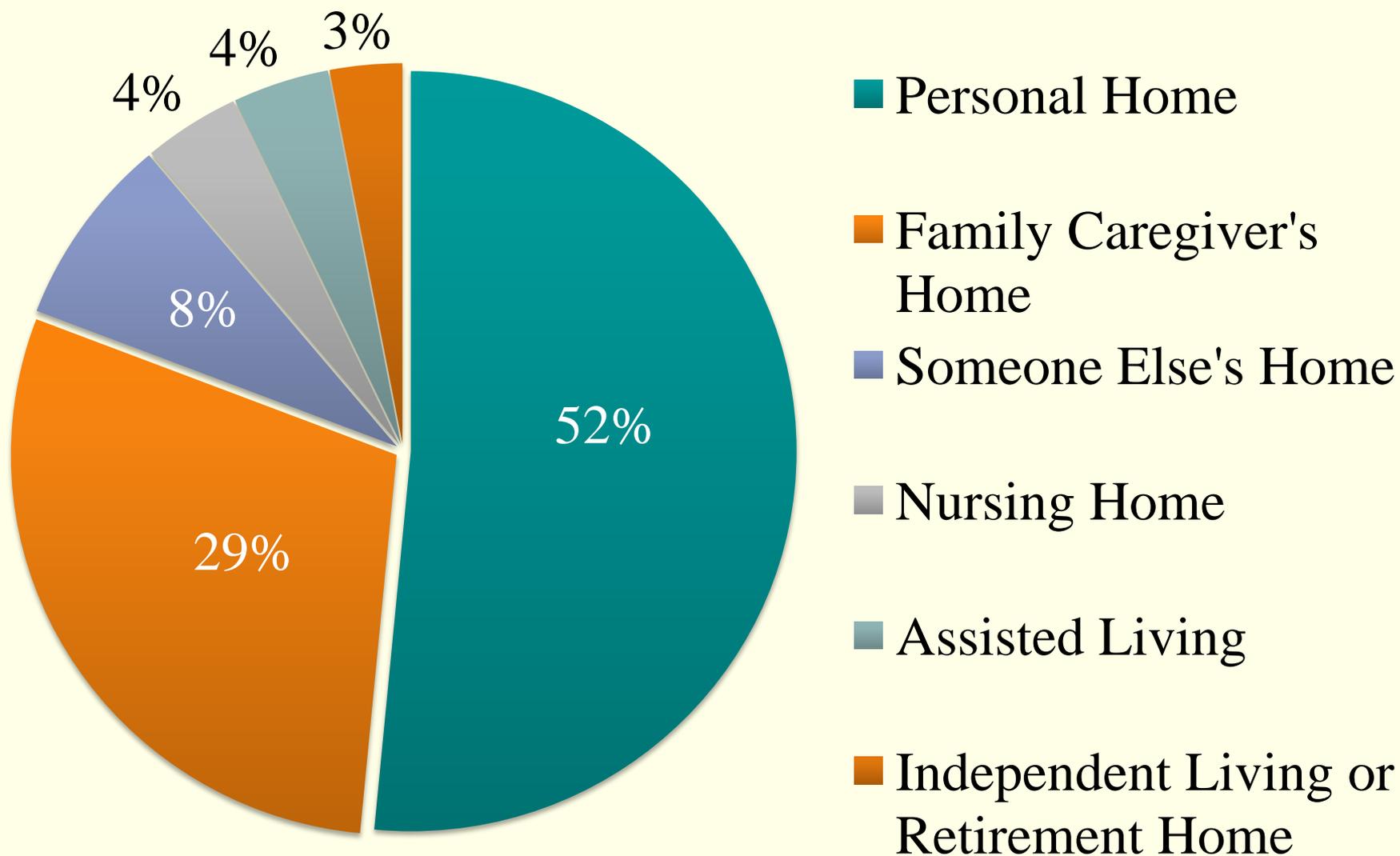
An older person who needs ongoing assistance with everyday tasks to function on a daily basis (frail elder)

3/4 have one chronic illness

1/2 have at least two chronic illness



Care Recipient Residence



Family Caregiving



Early Stage:

Responsibilities are often assumed gradually, especially if the illness is chronic

Family Caregiver Strategies



Early Strategies:

Ask the professionals questions

Seek information

Prepare

Health Professional Support



Early Stage:

Help the primary family caregiver recognize
he/she is *a caregiver!*

Awareness : diagnosis + *interaction with the health care system*

Over 90% become more proactive after they self-identify

Health Professional Support



Early Stage:

- Address the concerns of both the client *and* the primary caregiver
- Provide disease/ condition specific resources
- Be informed of local and internet resources for education and caregiver support

Family Caregiving



Middle Stage: Responsibilities increase

- Buy groceries
- Prepare meals
- Clean house
- Do laundry; mow yard
- Talk to doctors, care managers and others to understand what to do
- Become the financial manager



Family Caregiver Strategies



Middle Stage:

- Learn caregiving skills
- Practice self-care!
- Attend a support group
- Identify ways for others to help and
Let Them!!



Health Professional Support



Middle Stage:

- Suggest a family meeting facilitated by a neutral party to create a long term care plan
- *Listen* and validate the caregiver's concerns
- Be sure the caregiver understands all home care instructions; use lay language
- Continue to provide resources for education and support
- Promote caregiver respite and self-care

Family Caregiving



Late Stage:

Family member quits working to become a full time caregiver and patient advocate

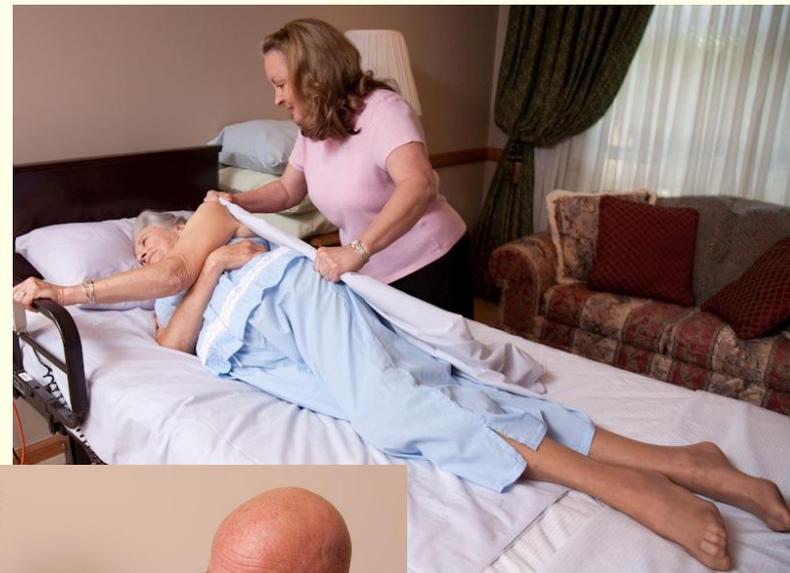
Typically one family member is on call 24/7

Family Responsibilities



Late Stage: Assists with ADL's

- Transfers
- Bathing and dressing
- Toileting; incontinence care
- Feeding, including tube feeding
- Med administration including injections



Impact



Health Challenges:

Mental Health -High rate of mental health problems

Physical Health –

- 72% of family caregivers report not going to the doctor as often as they should
- 55% say they skip doctor appointments for themselves

Impact



■ Financial Challenges:

- Six in 10 family caregivers are employed

MetLife Study of Working Caregivers and Employer Health Costs;

National Alliance for Caregiving and MetLife Mature Market Institute. February 2010

- 66% make adjustments to their work life
- 1 in 5 family caregivers take a leave of absence

Caregiving in the United States; National Alliance for Caregiving in collaboration with AARP. November 2009



Cost to Businesses

American businesses can lose as much as \$34 billion each year



MetLife Caregiving Cost Study: Productivity Losses to U.S.; MetLife Mature Market Institute and National Alliance for Caregiving Business. July 2006

Family Caregiver Strategies



- Self-care!
- Respite
- Support group
 - understanding
 - safe environment
 - creative solutions



Family Caregiver Advocate



- Assess for caregiver burnout or depression
- Inquire about the caregivers health, coping, assistance from others
- Continue to provide education to the caregiver as well as the client



Challenges



- One out of five Medicare patients are readmitted within 30 days

Re-hospitalizations among Patients in the Medicare Fee-for-Service Program

Stephen F. Jencks, M.D., M.P.H., Mark V. Williams, M.D., and Eric A. Coleman, M.D., M.P.H.

N Engl J Med 2009; 360:1418-1428

- MedPAC estimated that in 2005 readmissions cost the Medicare program \$15 billion, \$12 billion of which could have been avoided

Strategies-Project Red



Project Re-Engineered Discharge

- *Educating the patient about his or her diagnosis throughout the hospital stay*
- Asking the patient to explain in their own words the details of the discharge plan
- Making appointments for follow-up and testing
- Confirming the medication plan and making sure the patient understands changes in the routine and side effects to watch for
- Phoning the patient 2 to 3 days after discharge to identify and resolve any problems

Transitions of Care



Improve communication during transitions between providers, patients, and caregivers

Establish points of accountability for sending and receiving care, particularly for hospitalists, physicians practicing in skilled nursing facilities, primary care physicians, and specialists



Transitions of Care



- Increase the use of case management and professional care coordination
- Expand the role of the pharmacist in transitions of care



CAPS



Consumers Advancing Patient Safety

“At the heart of safe discharge is clear communication and education for patients and families”

- Importance of prompt follow-up care
- What to expect and what to do when they leave the hospital
- How to plan for their immediate and longer-term needs



Evidence-Based Programs



New York University Caregiver Intervention

Provides counseling and support interventions for rural elder spousal caregivers of Alzheimer's disease patients

Caregivers reported:

- **Better physical health**
- **Fewer depressive symptoms**
- **Higher satisfaction with social support network**
- **Less troubled by spouses memory and behavior changes**
- **Delay nursing home placement and as-needed telephone counseling sessions to family caregivers**

Evidence-Based Programs



Environmental Skill Building Program

Occupational Therapists instruct caregivers of persons with dementia to:

- Manage functional decline
- Manage challenging behaviors
- Enhance home safety
- Enhance caregiving efficacy

Caregiver Advocacy



Discussion



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