

# Caregiver Basics

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# Caregiver

*Informal caregiver* and *family caregiver* are terms that refer to:

- unpaid individuals such as family members, friends and neighbors who provide care.
- These individuals 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

## Who are the AD Caregivers?

- Spouses – the largest group. Most are older with their own health problems.
- Daughters – the second largest group. Called the “sandwich generation,” many are married and raising children of their own. Children may need extra support if a parent’s attention is focused on caregiving.
- Grandchildren – may become major helpers.



- Daughters-in-law – the third largest group.
- Sons – often focus on the financial, legal, and business aspects of caregiving.
- Brothers and Sisters – many are older with their own health problems.
- Other – friends, neighbors, members of the faith community.


# Caregiving Population

- During any given year, more than **50 million people** provide care for an aging family member or friend often with chronic illness or disability.

*National Family Caregivers Association, Random Sample Survey of Family Caregivers, Summer 2000, Unpublished*

- The typical family caregiver is a 46-year-old woman caring for her widowed mother who does not live with her. She is married and employed. Approximately **60%** of family caregivers are women.

*National Alliance for Caregiving and AARP, Caregiving in the U.S., 2004.*

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- ▶ The need for family caregivers will increase in the years ahead. People over 65 are expected to **increase at a 2.3% rate**, but the number of family members available to care for them will only increase at a 0.8% rate.

*Mack, K., Thompson, L., & Friedland, R. Data Profiles, Family Caregivers of Older Persons: Adult Children. The Center on an Aging Society, Georgetown University, page 2, May 2001.*

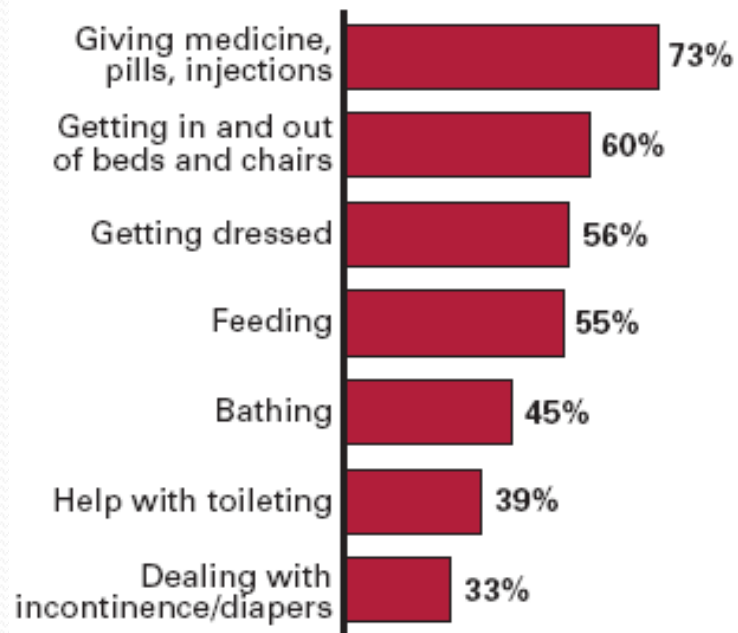
# Joy of Caregiving

- (1) Bringing family members closer together
- (2) Enriching lives
- (3) Expanding personal sense of efficacy
- (4) Expression of love and caring
- (5) Engagement in successful advocacy

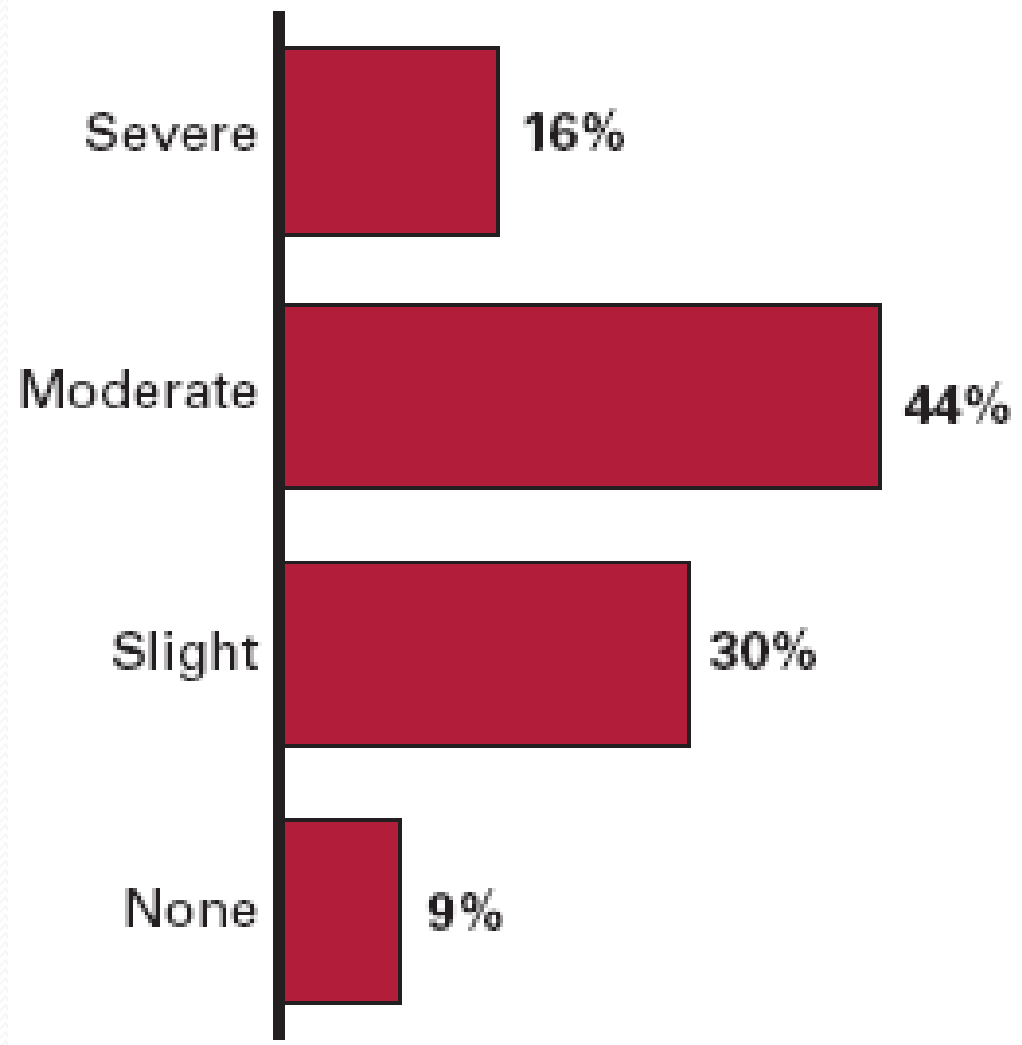
# Stressors Experienced by Family Caregivers

- (1) Emotional strain,
- (2) Marital discord,
- (3) Conflicts with other family members,
- (5) Unresponsive service delivery systems,
- (6) Transition planning concerns,
- (7) End of life planning concerns

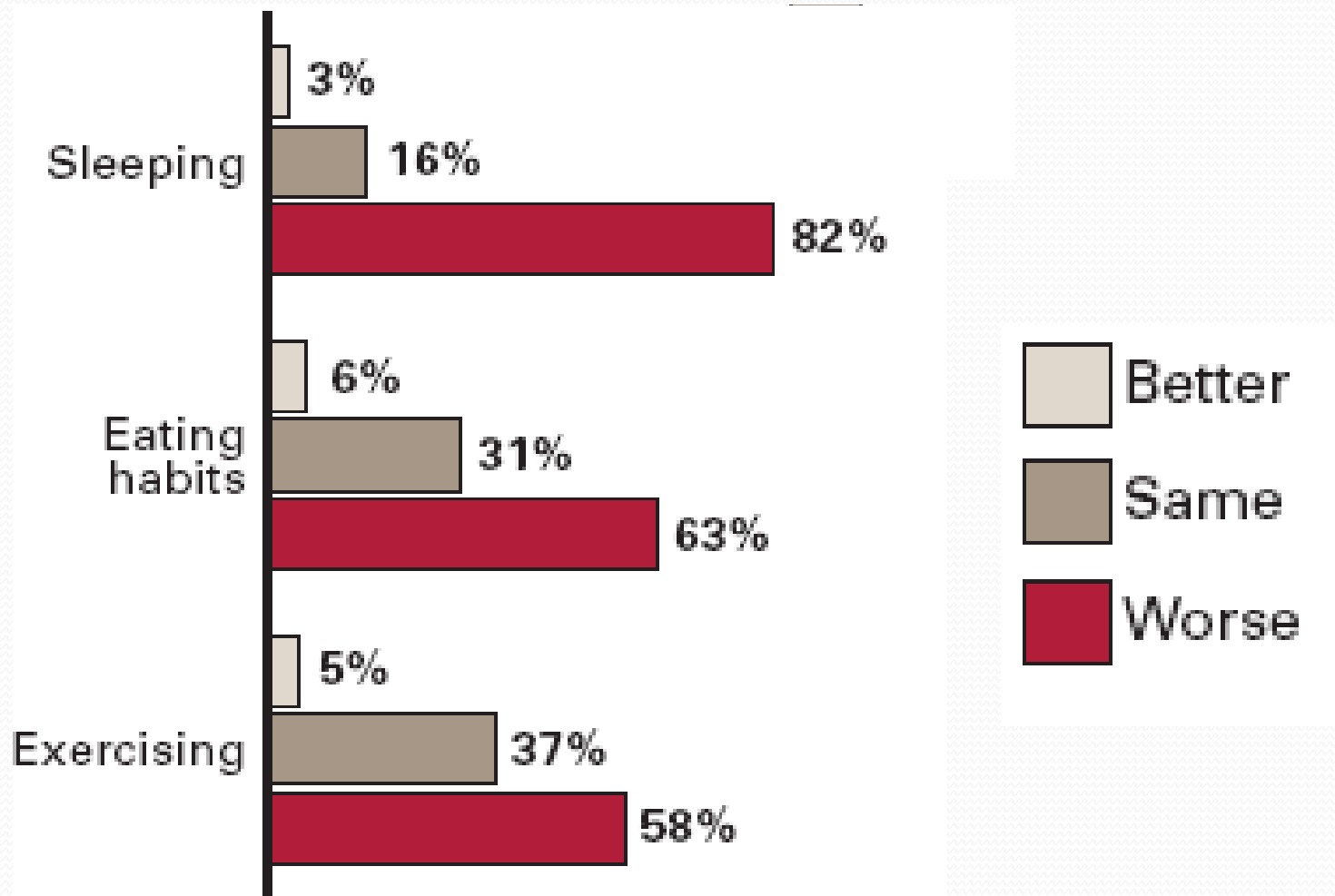
# Type of Help Provided



# Caregiving and Depression



# Types of Self Care Better, the Same, or Worse than before Caregiving?




# Significant Caregiver Problems

- Coping with increased needs of the dependent family member
- Coping with disruptive behaviors
- Isolation and loneliness
- Lack of sleep
- Disruption of household routines
- Conflicted multiple role demands

# Caring for the caregiver

- Learn about the disease
- Setting aside time for own needs
- Involve other family members
- Daily relaxation time
- Counseling services
- Outside resources
  - Adult day service center
  - Long-term care
  - In-home help
- Support group

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- Stress
  - Appraisal
  - Coping
  - Objective burden
  - Subjective burden
  - Resiliency
  - Problem solving

# Stress

## The physical and emotional cost of caregiving

- One in five caregivers: greatest challenge is the demand on personal time and lifestyle.
- Other reasons: inadequate training,
- financial concerns,
- frustration of dealing with the health care and social service systems
- caregivers don't take advantage of community services that could help reduce their stress - too busy to use them, don't even know they are available or can't afford them.

# Stress

- Stress is not just unpleasant; it can negatively affect health, well-being, and ability to provide care.
- Stress appears to increase the risk of serious illnesses such as heart disease and cancer, and intensifies problems such as asthma and insomnia.
- In extreme cases Stress may lead to inadequate care and even the verbal or physical abuse of an older parent.

# Appraisal & Coping

**Appraisal:** Not just the experience but how I feel about it and my ability to cope

## Coping

- **Confrontive Coping:** aggressive efforts to alter the situation and suggests some degree of hostility and risk-taking.
- **Distancing:** cognitive efforts to detach oneself and minimize significance.
- **Self-Controlling:** efforts to regulate one's feelings and actions.
- **Seeking Social Support:** seeking informational support, tangible support, and emotional support.

# Coping

- **Accepting Responsibility:** acknowledging one's own role in the problem and trying to put things right.
- **Escape-Avoidance:** wishful thinking and behavioral efforts to escape or avoid the problem.
- **Planful Problem Solving:** deliberate problem-focused efforts to alter the situation, coupled with an analytic approach to solving the problem.
- **Positive Reappraisal:** efforts to create positive meaning by focusing on personal growth. It also has a religious dimension.

# Objective and Subjective Burden

- Objective: adverse effects from disruption to family life and relationships, actual day-to-day demands of caregiving and financial burden
- Subjective: Loss, grief, guilt and anxiety related the changes in the cared for family member

# Resiliency

- The ability of a caregiver to maintain equilibrium in the midst of crisis
- Often the caregiver is seen as functioning at a higher level than before the crisis

# Problem Solving

- Problem Definition.
- Problem Analysis.
- Generating possible Solutions.
- Analyzing the Solutions.
- Selecting the best Solution(s).
- Planning the next course of action (Next Steps)

# Evidence based Caregiver Support Programs

[http://www.aoa.gov/AoARoot/AoA\\_Programs/HCLTC/Alz\\_Grants/compendium.aspx#evidence](http://www.aoa.gov/AoARoot/AoA_Programs/HCLTC/Alz_Grants/compendium.aspx#evidence)

- Coping with Caregiving (Gallagher-Thompson)
- Home Environmental Skill-Building Program (Gitlin)
- Brief Occupational Therapy Intervention (Dooley and Hinojosa)
- New York University Caregiver Intervention (Mittelman)
- Nine-Week Cognitive-Behavioral Intervention to Reduce Anxiety in Caregivers of People with Dementia (Akkerman)
- Progressively Lowered Stress Threshold (PLST) Model (Buckwalter)
- STAR-Caregiver (Teri and Logsdon)
- Psycho-educative Group Intervention Program for Caregivers of People with Dementia (Hébert)
- In-Home Behavioral Management Program (Gallagher-Thompson)
- Project CARE (Gonyea, O'Connor, and Boyle)
- Savvy Caregiver (Hepburn)

# *Savvy Caregiver*

- A 12-hour training program usually delivered in 2-hour sessions over a 6-week period.
- Materials for the program include a detailed trainer's manual, a caregiver manual, a training videotape, and a CD-ROM.
- Program focuses on helping caregivers think about their situation objectively and providing them with the knowledge, skills, and attitudes they need to manage stress and carry out the caregiving role effectively.

# *Savvy Caregiver*

- An evaluation of *Savvy Caregiver* found statistically significant positive outcomes for caregivers who participated in the program vs. those in the control group with respect to the caregivers' beliefs about caregiving, their reactions to the behavioral symptoms of their care recipient, and their feelings of stress and burden (Ostwald et al., 1999; Hepburn et al., 2001).

# Home Environmental Skill-Building Program

- Five 90-min home visits and one 30-min telephone contact.
- In an initial home visit, the occupational therapist reviews intervention goals and conducts a systematic needs assessment to identify which of 11 areas are difficult for the caregiver to manage and for which he or she wants to learn new strategies.

# Home Environmental Skill-Building Program

- Domains
  - Caregiver-centered concerns (feelings of upset, being overwhelmed, guilt, fatigue, concern for the future, and body aches and pains)
  - Communication issues with the care recipient
  - Coordinating care with formal providers or other family members
  - Difficulties assisting in bathing, dressing, toileting, eating or getting around
  - Home safety
  - Distracting or engaging care recipient in meaningful activity
  - Wandering
  - Managing incontinence
  - Managing catastrophic reactions
- Needs assessment, development of a targeted plan and identification of initial problem area to target.
- Observation of the caregiver or engagement in role-playing to evaluate approach to the identified problem.
- A walk-through of the home to examine environmental setups and assess how these may affect the problem areas.

# NYU Counseling and Support Intervention

- Three approaches:
  - (1) individual and family counseling sessions that took place within the first four months of enrollment,
  - (2) weekly support groups,
  - (3) “ad hoc counseling”
- The intervention is available to participants and their families indefinitely
- Significant impact on decreasing depressive symptoms in spouse caregivers, reducing spouse caregivers’ negative appraisals of behavior problems and delayed nursing home placement of the person with dementia

# The Star-C Intervention

- One hour meeting with a family caregiver in the caregiver's home once a week for eight weeks .
- STAR-C manual lays out a plan for each meeting.
- First meeting - provide information about behavioral symptoms and work with the family caregiver to identify three behavioral symptoms that are currently causing difficulty, describe symptoms precisely, and rate how often they occur.

# The Star-C Intervention

- Second and third meetings, teach the caregiver the “ABC” approach to behavioral symptom change:
  - identify Antecedents or triggers that precede the Behavioral symptom and observe Consequences that follow the symptom.

Consultant and caregiver then brainstorm strategies to modify identified antecedents and consequences with the objective of reducing behavioral symptoms.

They also agree on a behavior change plan for the following week.

# The Star-C Intervention

- Remaining five meetings focus on how to communicate with a person with Alzheimer's disease, how to create pleasant events for the person, and issues that concern the caregiver.
- “Homework” is assigned between meetings, including reading materials and a diary to record behavioral symptoms and strategies tried.
- After the in-home meetings, the consultant follows up with the caregiver through four monthly telephone calls.

# Support Groups

- Mutual Support
- Psychoeducational
- Peer-led
- Professionally-led
- Short versus long-term

# Benefits

- A respite
- Reduces isolation and loneliness
- Ventilation of pent up feelings
- Instilling hope
- Validating role and experiences
- Education about disease process
- Strategies for problem solving
- Developing plans

# Evidence based Health Promotion Programs

- Chronic disease self management program
- Active choices
- A matter of balance

Meet health needs of both caregiver and person with dementia

Can be combined with respite supports

# Respite

- Short or longer term
- In and out of home
- Day (to support working caregivers)
- Evening and weekends (to give caregivers more of a life and to reduce stress)
- Volunteer/family/staff

# Family Dynamics

- Primary and secondary caregivers
- Disagreements about diagnosis
- Not helping enough or interfering too much
- Not agreeing about care needs
- Past relationship issues