



## FAMILY CAREGIVING FOR OLDER ADULTS: CAREGIVER SUPPORT NEEDED

 ARGEC  
Atlanta Regional Geriatric Education Center

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## Objectives



- ☐ Provide prevalence rates for family caregiving
- ☐ Describe the tasks associated with caregiving in long-term care
- ☐ Discuss the consequences of caregiving and associated risk factors
- ☐ Describe the benefits of family caregiving
- ☐ Identify the challenges and issues with caregiving
- ☐ Locate resources to support family caregivers

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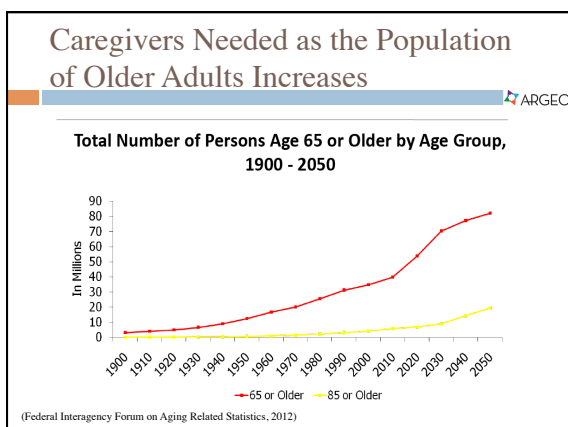
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## Becoming a Caregiver



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- May happen
  - Slowly over time as older adult's needs increase
  - Suddenly with illness (e.g. stroke)
  - Without choice – spouse or women (e.g. daughter, daughter-in-law) often expected to assume the role
- Regardless of how one becomes a caregiver, people are often unprepared for the long trajectory of chronic illness.

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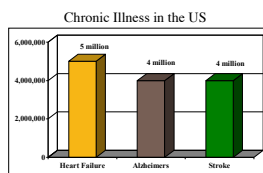
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## Diseases Requiring Long-Term Care

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- Researchers have examined the experiences of family caregivers caring for older adults with:
  - Alzheimer's Disease
  - Dementia
  - Heart Failure
  - Stroke
  - Parkinson's Disease
  - Depression
  - Cancer
  - Medically ill




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## Caregiving Tasks

(Tasks from Oberst Caregiver Burden Scale, 2004)

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- Medical/nursing treatments
- Personal Care
- Household task
- Assistance with mobility
- Emotional support
- Surveillance of symptoms and progress
- Transportation
- Structuring/planning activities
- Managing behavior problems
- Finding and arranging care while away
- Communication
- Coordinating, arranging, and managing services and resources
- Seeking information and talking with healthcare providers




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## Consequences of Caregiving

- Burden, stress, physical and psychological strain
- Poor health habits (i.e. neglecting health care, eating a poor-quality diet)
- Impact on work – (e.g. late arrival, leaving early, taking time off or leave of absence, retire early.
- Financial burdens
- Difficulty in finding time for themselves
- Family conflict

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## Factors Associated with Increased Caregiver Stress

- Caregivers health problems
- Working outside the home
- Negative attitudes towards caregiving
- Greater functional needs of the family member
- Higher frequency and time spent caregiving
- Limited informal and formal support

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## Benefits of Caregiving

- Get to know family member better, develop closeness
- Opportunity to resolve past conflicts/hurt
- Payback for care the family member (e.g. parent) provided
- Satisfaction in providing comfort to someone
- Family humor and working together
- Gift of time

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## Caregiving Case Study



- Phyllis is a 78-year-old, widowed woman living independently in her own home in a small town. She has four adult children, all married who live at a distance. The closest adult child is her daughter who lives 1½ hours away. The other adult children live several states away.
- In talking to one of her sons one day, Phyllis mentions that she has “done it again”. She has had another small accident hitting a guard rail. She says her car is not damaged that much and the policeman did not give her a ticket. As her son thinks about it, this is the fifth accident that his mother has mentioned in the previous year. She has hit guard rails before, almost pulled her car door off at a gas pump, and once fell asleep while driving. Luckily, she has not had any major injuries or caused injury to others. Phyllis always has a reason that she explains about why the accident happened.

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## Caregiving Case Study cont.

- Although she lives in a small town, his mother does not have a lot of close friends, which has been typical throughout her life, and her daughter does not get down to visit that often as she has two teenage children. Generally, she can get to where she wants to go without getting on major highways, but she does have to take a major interstate to get to the large shopping mall or if she drives up to see her daughter.
- She also has made recent comments about how much work needs to be done on her house and how she does not know who to call to make repairs. Her son becomes concerned and talks with his siblings. One brother thinks something might be wrong as well, but another brother thinks she's fine and that the brothers worry too much.

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## Caregiving Case Study Questions

- Is there cause for concern?
- How should the family approach the mother?
- What options do they have?

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## Challenges for Family Members



- ☐ Managing the medical condition
- ☐ Dealing with family issues
- ☐ Communicating effectively
- ☐ Identifying community services
- ☐ Long-term planning

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DEAR ABBY



### Siblings in denial about Alzheimer's

**DEAR ABBY:** For years now, my dad's health has slowly deteriorated. He has good days when he kind of knows what's going on, and bad days when his whole world is off balance. Recently he suffered some mini-strokes, and last September the doctor diagnosed him with Alzheimer's.

I was there when Dad was diagnosed. You could see the look of relief on his face to finally have a name for what was going on inside him. He told the doctor, "Well, at least now I know I'm not going crazy" because it was a medical condition he could comprehend.

The problem is his siblings. They get angry at Mom when she tells the doctor how Dad is at home and accuse her of exaggerating. They get upset with us for not letting Dad drive, even though he doesn't see well and has been known to get lost. They have even gone behind our backs and told Dad he does not have Alzheimer's, which only compounds the problem.

Some of Dad's siblings see him

### Problematic Interactions with Family Members



*"The problem is his siblings. They get angry at Mom when she tells the doctor how Dad is at home and accuse her of exaggerating...they have even gone behind our backs and told Dad he does not have Alzheimer's...they all insist he is 'fine' and blame Mom for his lack of spirit."*

(UExpress, 2004)

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## Common Late Life Family Issues - Starting the Conversation about...



- ☐ Living arrangements
- ☐ Issue of Driving
- ☐ Financial and legal concerns
- ☐ End-of-life health care decisions

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## Living Arrangements



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- Home
  - ▣ Coordination of services
- Living with children
  - ▣ Who will provide the social interaction for older adults?
- Other settings (independent living, assisted living, adult day care etc.)
  - ▣ Cost, variety of services, turnover of staff

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## Resources about Living Options

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- Click on or copy and paste the weblink below to access Eldercare.gov's Housing Options for Older Adults brochure:
  - ▣ [http://www.eldercare.gov/Eldercare.NET/Public/Resources/Brochures/docs/Housing\\_Options\\_Booklet.pdf](http://www.eldercare.gov/Eldercare.NET/Public/Resources/Brochures/docs/Housing_Options_Booklet.pdf)
- Click on or copy and paste the weblink below to access the AARP's "Which Housing is Best for You?" guide:
  - ▣ [http://www.aarp.org/home-garden/housing/info-08-2009/ginzler\\_housing\\_choices.html](http://www.aarp.org/home-garden/housing/info-08-2009/ginzler_housing_choices.html)

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## Issues of Driving

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- Extremely important to one's independence
- Safety has to take priority
- AARP 55 Alive Driving Program
- Independent Driving Evaluation
  - ▣ Not covered by insurance, expensive, simulated in lab and road tests




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## Resources for Older Drivers



- Click on or copy and paste the weblink below to access this article: Carr, D. B., & Ott, B. R. (2010). The older adult driver with cognitive impairment. *JAMA*, 303(16), 1632-1640.
  - <http://jama.jamanetwork.com/article.aspx?articleid=185732>
- Click on or copy and paste the weblink below to access the NHTSA's older drivers education resources: <http://www.nhtsa.gov/Senior-Drivers>
  - Adapting motor vehicles for older drivers
  - How to understand and influence older drivers
  - Driving safely while aging gracefully

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## Financial And Legal Concerns



- Families
  - Often are unaware of benefits associated with Medicare (<http://www.medicare.gov/>)
  - Have different "rules" about discussing finances/money
  - Often do not understand the difference between wills, living wills, and health care power of attorney
- Click on or copy and paste the weblink below to access a case study from the New York Times about what can happen when families do not have "the talk"
  - [http://www.nytimes.com/2013/05/25/your-money/aging-parents-and-children-should-talk-about-finances.html?pagewanted=all&\\_r=0](http://www.nytimes.com/2013/05/25/your-money/aging-parents-and-children-should-talk-about-finances.html?pagewanted=all&_r=0)

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## End of Life Decisions



- Living wills
  - Health Care Power of Attorney
  - How much treatment a person wants relative to the risks
  - Extending life with little quality
- RESOURCES:**
- Click on or copy and paste the weblink below to access the Family Caregiver Alliance website:
    - [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=401](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=401)
  - Click on or copy and paste the weblink below to access the National Hospice and Palliative Care Organization website:
    - [http://www.caringinfo.org/files/public/brochures/End-of-Life\\_Decisions.pdf](http://www.caringinfo.org/files/public/brochures/End-of-Life_Decisions.pdf)

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## A Discussion about Family Caregiving



- Laura J. Bauer is the Director of National Initiatives at Rosalynn Carter Institute (RCI) for Caregiving. She is a co-author of the Institute's signature training program, *Caring for You, Caring for Me – Education and Support for Family and Professional Caregivers, 2nd Edition*
- Laura will talk about the challenges family caregivers face, evidence based programs to support family caregivers, and the role of the RCI.
- Click on or copy and paste the weblink below to listen to the podcast
  - <https://gsu.sharestream.net/ssdcms/i.do?u=4fb8fd52d79545b>

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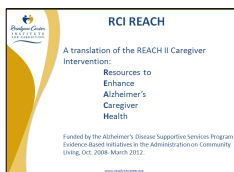
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## Resources Mentioned in Podcast

- A report entitled “**State of the Science: Professional Partners Supporting Family Caregivers**” was published through the *American Journal of Nursing* and the *Journal of Social Work Education* and includes 17 articles on assessment and support of caregivers. Click on or copy and paste the weblink below to access the above:

□ <http://www.nursingcenter.com/lnc/static?pageid=809507>



- Click on or copy and paste the weblink below to access the REACH II:

□ <http://www.edc.gsp.h.pitt.edu/Reach2/>

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## Tools for Assessing Caregiver Burnout

- Click on or copy and paste the weblink below to access the Caregiver Self Assessment Questionnaire
  - [http://www.amaassn.org/ama1/pub/upload/mm/433/caregiver\\_english.pdf](http://www.amaassn.org/ama1/pub/upload/mm/433/caregiver_english.pdf)
- Click on or copy and paste the weblink below to access the Zarit Caregiver Stress Self Assessment Tool
  - [http://www.aging.emory.edu/documents/caregiver\\_stress\\_self\\_assessment.pdf](http://www.aging.emory.edu/documents/caregiver_stress_self_assessment.pdf)
- Click on or copy and paste the weblink below to access the Montgomery-Gorgotta Caregiver Burden Scale
  - <http://www.aging.emory.edu/documents/MontgomeryGorgottaCaregiverBurdenScale.pdf>

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## Caregiver Support Resources



- Click on or copy and paste the weblink below to access the ARCEC Transitions in Care Toolkit
  - <http://www.aging.emory.edu/arcec/toolkit/index.html>
- Click on or copy and paste the weblink below to access the Rosalynn Carter Institute for Caregiving – Caregiver Intervention Database
  - [http://www.rosalynncarter.org/caregiver\\_intervention\\_database/](http://www.rosalynncarter.org/caregiver_intervention_database/)
- Click on or copy and paste the weblink below to access the Family Caregiver Alliance Tools and Multimedia
  - [http://www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=2324&chcategory=52](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=2324&chcategory=52)

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## Caregiver Support Resources con't



- Click on or copy and paste the weblink below to access the HELPGUIDE.org Tips for Making Family Caregiving Easier.
  - [http://www.helpguide.org/elder/caring\\_for\\_caregivers.htm](http://www.helpguide.org/elder/caring_for_caregivers.htm)
- Click on or copy and paste the weblink below to access the Atlanta Area Agency on Aging AgeWise Connection – Services for Caregivers
  - <http://www.agewiseconnection.com/services/svcsforcaregivers>

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## Planning Ahead & Asking for Help



- Have a family meeting and develop a plan
- Conference calls can be used to include family members at a distance
- Recognize that some family members may not be comfortable in some aspects of caregiving
- Acknowledge the individual's right to set limits on what he/she can do
- Use a calendar to schedule activities

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## Planning Ahead & Asking for Help

(continued)



- Make environmental changes that may facilitate providing care (safety bars, raised toilet seat, raising chairs)
- Get to know your resources – especially for those in you local community
- Seek support of church groups or friends
- Ask for specific types of help (respite time, help with household chores, help with paperwork, help with transportation, emotional support, etc.)

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## References



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