



# The Sandwich Generation

## *Caregiving Includes Caring for Me*

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# Institute for Human Caring

- Team of clinicians, educators, health systems experts
- Change within Providence St. Joseph Health → people of every age and stage of illness can get the best care possible
- Physical, emotional, spiritual, interpersonal and social well being
- To improve Quality → Care for the Whole Person
- Quality Improvement engine
  - Collaborate with clinicians across disciplines and specialties to drive measurable improvement in patient-centered whole person care



# Family Caregiver Resource Center: Serving OC since 1988

## **Mission:**

**“To Increase the  
Quality of Life of  
Caregivers by Helping  
Families and  
Communities Master  
the Challenges of  
Caregiving”**



# “Silver Tsunami”

10,000 people a day are turning 65!



- “In 2015, 40 million caregivers in the United States provided unpaid care to older relatives and friends. Almost three in 10 people who are caring for someone say their life has changed, often negatively. More than one in five says *her* weight, exercise habits, and/or social life have suffered. And emotionally, one in five says *she* is generally unhappier – with one in three saying *she* feels sad or depressed.” (AARP)



# Crisis

- Let's face it, we are in a caregiver crisis!



# Definition of a Caregiver

- ***Informal or family caregiver:*** is an ***unpaid individual*** (for example, a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living and/or medical tasks.
- ***Formal caregivers*** are ***paid care providers*** providing care in one's home or in a care setting (adult day care, residential facility, long-term care facility).



# Caregiving

- May involve:
  - helping with medical care, procedures and therapy
  - assisting with meals, personal care and transportation
  - providing emotional, mental and spiritual support
  - devoting just a few hours a week or around the clock care





# Startling Statistics

- Approximately 44 million Americans have provided **unpaid care** to an ***adult or child*** in the last 12 months
- Approximately 40 million caregivers provide care to adults (**aged 18+**) with a disability or illness. This represents 17% of Americans
- About 16 million adult family caregivers care for someone who has **Alzheimer's disease or other dementia**



# Age & Gender

- 65% of **care recipients** are female
- 60% of **caregivers** are females
- Spousal caregivers are the oldest: 63 years old
- Males share more caregiving tasks than in the past
- Females still shoulder the major burden of care



# CG & Care Recipients

- Parent care continues to be the primary caregiving situation for mid-life caregivers with 70% of the caregivers between the ages of 50 and 64



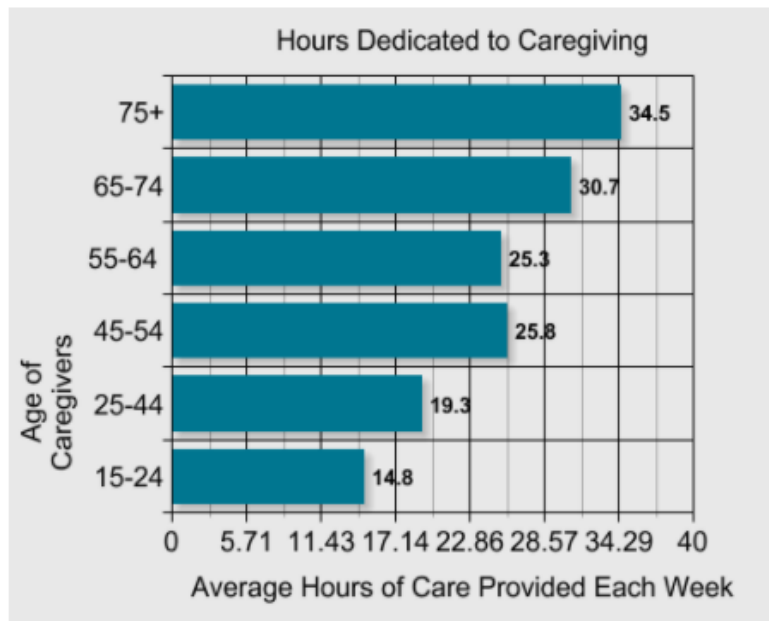
- **Unpaid caregivers** provide complex chronic care:
  - 46% perform medical and nursing tasks
  - More than 96% provide help with activities of daily living (ADLs)



# Time Spent Caregiving

- Average of 24 hours per week for 4 years
- Older= more hours of CG

Number of Hours Dedicated to Caregiving by Age of Family Caregiver



[The Partnership for Solutions. (2004). Chronic Conditions: Making the Case for Ongoing Care.]



# What is the Sandwich Generation?

- The **Sandwich** Generation is a generation of people who care for their aging parents while supporting their own children.
  - Younger parents (30-40's) caring for their own minor children and aging parents
  - Middle aged parents (50-60's) caring for their grown children (more financial) and aging parents
- Club Sandwich: Those in their 50's-60's sandwiched between aging parents, adult children and grandchildren, or those in their 30's-40's, with young children, aging parents and grandparents.



# Sandwich Generation: Contributors

- Increase in aging population
- Generation of young adults struggling to achieve financial independence
- Grandparents Raising Grandchildren
  - 2.4 million grandparents raising 4.5 million children



# The Cost

- Services provided by unpaid caregivers: estimated economic value of \$470 billion in 2013
  - up from \$450 billion in 2009 and \$375 billion in 2007
- The value of unpaid caregiving exceeded the value of paid home care **and** total Medicaid spending in the same year, and nearly matched the value of the sales of one of the world's largest company, Wal-Mart (\$477 billion)
- The economic value of the care provided by unpaid caregivers of those with Alzheimer's disease or other dementias was \$217.7 billion in 2014





# The Burden

- Unpaid caregivers : positive activities in their respective daily lives are reduced by 27%
- Burdens and responsibilities of middle-aged Americans are increasing:
  - Nearly half (47%) of adults in their 40s and 50's have a parent age 65 or older and are either raising a young child or financially supporting a grown child (age 18 or older).
  - About one-in-seven middle-aged adults (15%) is providing financial support to both an aging parent and a child
- Pew Research: burden is more from grown children rather than aging parents
  - Boomerang children
  - Factors: recession and sluggish economy



# Help for the Family CG



**Family Caregiver Resource Center**  
**Phone (800) 543-8312 or (714) 446-5030**  
**[www.caregiveroc.org](http://www.caregiveroc.org)**



# California Caregiver Resource Center System est. 1984

<https://www.caregiver.org/californias-caregiver-resource-centers>



# 11 Caregiver Resource Centers



# Family Caregiver Resource Center

## *Orange County*

- Serving all of Orange County since 1988
- Grant funded non-profit program of St. Jude Medical Center.
- Part of the California Caregiver Resource System (CA Dept Health Care Services)
- Contract Agency for Older American's Act, Title III-E, Family Caregiver Support Program (Federal Grant via CA Dept. of Aging)



# Serving OC since 1988

## **Mission:**

**“To Increase the  
Quality of Life of  
Caregivers by Helping  
Families and  
Communities Master  
the Challenges of  
Caregiving”**



# For unpaid family caregivers

## **Education, Support and Counseling**

- Professional staff focusing on issues specific to successful family caregiving and self care.
- Services are provided in a variety of modalities i.e., individually, in groups and through a variety of events and classes.
- Grants for respite and other services



## Our Mantra

*“Caregiving includes  
caring for me.”*



## **-Eda LeShan-**

**When we truly care for ourselves, it becomes possible to care far more profoundly about other people. The more alert and sensitive we are to our own needs, the more loving and generous we can be toward others.**





# 3 Underlying Beliefs for Self-Care

- Caring for yourself will also benefit the person you care for
- You can “thrive” not just “survive” as a caregiver
- Feeling alone is a choice – support and help is available



# Health Consequences

Caregivers can suffer tremendous negative physical health effects

- As the care receiver's health deteriorates, so does the potential for the caregiver's.



# Emotional Consequences

- Caregivers potentially suffer tremendous negative emotional health effects
  - Stress
  - Anxiety
  - Depression



# Managing Stress

- Recognize
- Take time out
- Sensory cues
- Humor
- Conflict reduction



# Start with a Dx

- Learn as much as you can about your loved one's condition
- Activities of daily living (ADL's) are no longer "routine" for your loved one
- Establish a "new normal" for yourself



# Home Care Needs

- Gather as much information about your loved ones condition and the care required.
  - Detail the daily schedule of care and decide how much you are able to provide.
  - Make sure the space you have is appropriate and equipped for you and your loved one.
  - Think about getting an in-home assessment.



# Caregiver Hacks:

<https://careconnection.aarp.org/en/connect-and-share/tips-and-hacks.html>

The screenshot displays the CareConnection website interface. At the top, there is a navigation bar with a 'MENU' button, the 'CARECONNECTION' logo (Part of AARP Family Caregiving), and links for 'Register | Sign In', 'Type Size AA', and a search icon. A sidebar on the left contains navigation options: Home, Guides, Information, Tips & Community (selected), Overview, Dementia Decision Tool, Caregivers in the Community™ (CINC) App, Caregiving Tips & Hacks, and Caregiver Assessment Tool. The main content area features the article title 'Crafty Ways to Re-engineer Simple Household Items' and a sub-header 'Caregiving Tips and Hacks are crafty ways to re-engineer simple household items to solve everyday problems, from opening jars to holding a hand of cards. Browse through these DIY (do it yourself) ideas to find clever ways to work around day-to-day obstacles.' Below this is a 'FILTER BY' section with two columns: 'Environment' and 'Refine By'. The 'Environment' column includes checkboxes for Kitchen Dining, Bathroom, Living Room, Bedroom, and Office. The 'Refine By' column includes checkboxes for Mobility, Personal Care, Daily Tasks, Meal Time, and Dementia Care. A 'DONE' button is located at the bottom right of the filter section. To the right of the filter section is a 'Share your ideas!' box with the text 'Are you the handyman/handywoman of your household – able to jury-rig common items to meet your needs? Share with us your caregiving tips and hacks.' and a 'SUBMIT IDEA' button. At the bottom, there are three preview cards for specific hacks: 'Computer Mouse Aid', 'Modify a TV remote for ease of use', and 'DIY Button Aid'. A vertical 'Feedback' button is on the right edge of the page.

**MENU** CARECONNECTION Part of AARP Family Caregiving Register | Sign In Type Size AA

Home Guides Information Tips & Community Overview Dementia Decision Tool Caregivers in the Community™ (CINC) App Caregiving Tips & Hacks Caregiver Assessment Tool Products & Services

Share This: [Twitter] [Pinterest] [Facebook] [Email]

## Crafty Ways to Re-engineer Simple Household Items

Caregiving Tips and Hacks are crafty ways to re-engineer simple household items to solve everyday problems, from opening jars to holding a hand of cards. Browse through these DIY (do it yourself) ideas to find clever ways to work around day-to-day obstacles.

**FILTER BY**

**Environment**

- Kitchen Dining
- Bathroom
- Living Room
- Bedroom
- Office

**Refine By**

- Mobility
- Personal Care
- Daily Tasks
- Meal Time
- Dementia Care

**Share your ideas!**

Are you the handyman/handywoman of your household – able to jury-rig common items to meet your needs? Share with us your caregiving tips and hacks.

**SUBMIT IDEA**

**Computer Mouse Aid**

**Modify a TV remote for ease of use**

**DIY Button Aid**

<https://careconnection.aarp.org/en/home.html>

Feedback



# Costs to providing care

- Is your loved one eligible for public funded or subsidized care.
- Understand the benefits of their current health plan and any supplemental health insurance policies (i.e. LTC Insurance).
- What other resources are available and what are you and/or others willing to pay for?





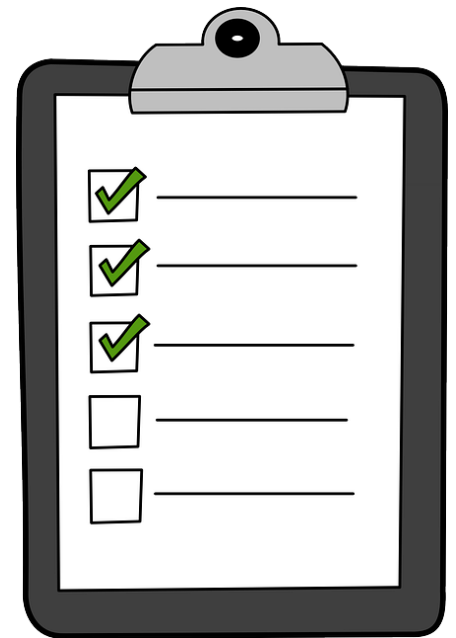
# Communication Foundation

- Keep everyone informed
- Focus on the present
- Be honest about the toll of caregiving on you - physical, emotional & spiritual
- Recognize your limitations
- Learn to ask for help



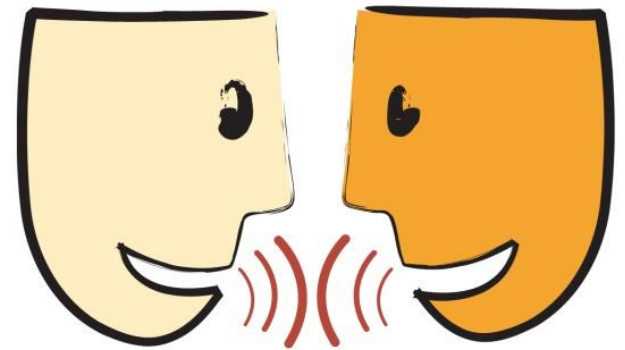
# Accept and Ask for Help

- Develop the “LIST”
  - Honor those offering to help.
  - Help does not have to be directly related to care, but something that needs doing.



# Communicate

- Talk to your loved one
  - Health care wishes –  
Advanced Directives
  - Finances – Estate  
Planning, Powers of  
Attorney



# Advance Care Planning Resources

The Center for Advance Care Planning and Advocacy: 714-712-7050

- [www.TalkAboutWhatMatters.org](http://www.TalkAboutWhatMatters.org)
- Home visits to assist with advance care planning, completion of an advance direction and uploaded to electronic health record

Family Caregiver Resource Center: 714-446-5030

- ACP workshops
- [www.caregiveroc.org/](http://www.caregiveroc.org/)



# Communicate

- Talk to family and close friends and bring them together to discuss your loved one's care.
  - A family meeting



# Family Dynamics

- Expectations/Promises
- Family Personality
- Sibling issues
- Proximity
- Decision-making style
- Emotions



# Conflict Management

- Put your past behind you - stay in the present
- Understand underlying reasons for behavior
- What's your part?
- Listen...Listen...Listen
- Acknowledge their worries/requests, but remain firm
- Problem solve & negotiate when appropriate
- Respect their position in the family
- Pick your battles



# Tips to Remember

- Be realistic with each other
- Active listening - reflect/paraphrase
- Use “I” statements
- Use outside resources - use a third party
- Develop an agreed upon plan with clear steps
- Re-evaluate the plan periodically





# Avoiding Stress

If the one you are caring for is cognitively impaired...please avoid:

- Arguing **A**
- Reasoning **R**
- Explaining **E**



# Respite Planning

Respite: “...a usually short interval of rest or reprieve...”

- Get used to planning time for yourself.
- Make it meaningful and guilt free.



# Self Care Action Plan

- Make a commitment to yourself
- Write it down
- Share it with others
- Make your plan meaningful



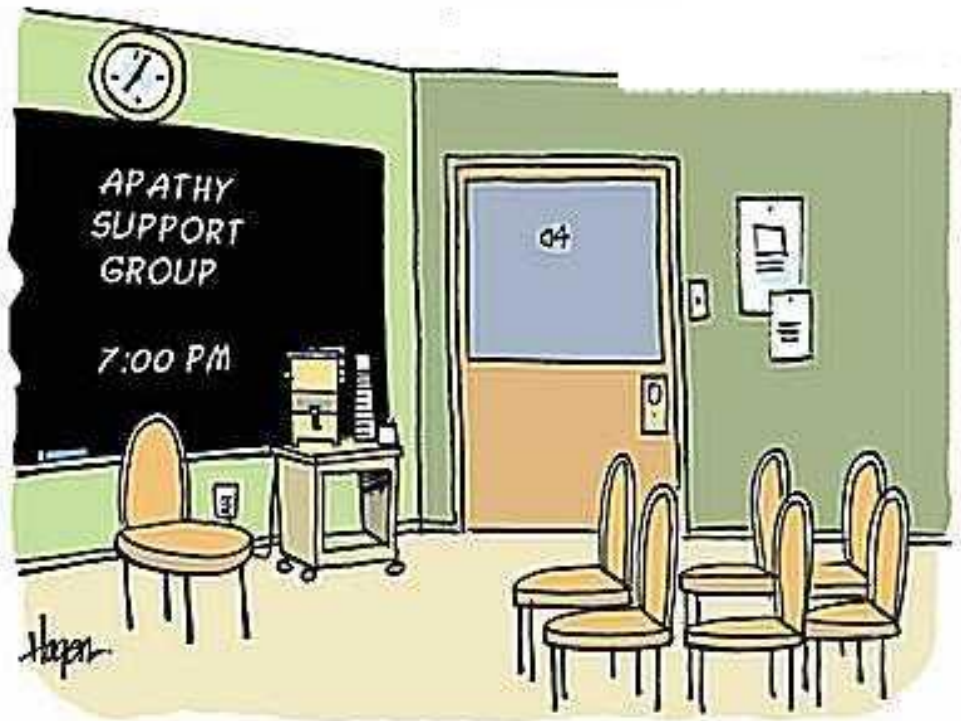
# Self Care Action Plan

- It's something you want to do
- It's reachable (accomplish during the next week)
- It answers: What? How much often?
- It has a high confidence level



# SUPPORT GROUPS

Find one  
that fits  
you.



# Former First Lady Rosalynn Carter

"There are four kinds of people in this world:

- those who have been caregivers,
- those who currently are caregivers,
- those who will be caregivers,
- and those who will need caregivers."



# Resources

- Family Caregiver Resource Center
  - [www.caregiveroc.org/](http://www.caregiveroc.org/)
  - 714-446-5030
- National Alliance for Caregiving
  - [www.caregiving.org/](http://www.caregiving.org/)
- Caregiver Action Network
  - [www.caregiveraction.org/](http://www.caregiveraction.org/)
- AARP
  - [www.careconnection.org](http://www.careconnection.org)
  - [aarp.org/caregiving](http://aarp.org/caregiving)



# Questions?





# Sources for Stats

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