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**FEARLESS CAREGIVING:  
STAGES, SUPPORT, AND  
SELF-CARE**

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**OBJECTIVES**

- Identify the different roles of caregivers and who makes this population in the US
- Understand the Economics of Caregiving
- Learn the stages/"turning points" of caregiving and how to cope during each stage
- Discuss the "Caregiving Crisis" and how it is an important health and medical issue
- Understand the impact of caregiving on a person's mental and physical health so that self-care becomes a priority

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**DEFINITION OF A CAREGIVER**

- Dictionary: A person who provides direct care. A family member or paid helper who regularly takes care of a child or a sick, elderly, or disabled person
- Informal: family/friend



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**JOB DESCRIPTION OF THE CAREGIVER MAY INCLUDE BUT IS NOT LIMITED TO THE FOLLOWING:**

- Untrained friend or family member
- Act as advocate, researcher, case manager, accountant, and psychologist
- Make difficult medical decisions
- Manage financial affairs
- Must not be easily stressed, angered, or brought to tears
- Must want to "live on the edge" because you will not know what is coming next
- Expect patient backlash
- Guilt, fear, and loneliness
- Assist with medication management, showering, toileting, lifting, transporting, and other back breaking duties
- Hours are as needed AND when demanded.
- Daytime and/or evening shifts - Sometimes both back to back for several days.
- Annual Salaries: \$0
- Benefits: \$0
- Appreciation varies depending on the person you're caring for and the people in their life
- Sacrifice required

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### CAREGIVERS IN THE UNITED STATES

- There is someone serving as an unpaid family caregiver in close to one-third of all American households
- 66% are women (typically middle aged)  
The number of men is increasing
- More than 37% are married, employed and have children or grandchildren under the age of 18 living with them
- More than half are living with the care recipient
- 78% of adults in the community and in need of long-term care depend on family and friends as their ONLY source of help
- 83% of caregivers are related to the care recipient

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### THE ECONOMICS OF CAREGIVING

- The value of the services family caregivers provide for "free" when caring for older adults is estimated to be \$375 billion a year.  
The annual cost spent on homecare and nursing home services COMBINED is \$158 billion
- Women who are caregivers are 2.5 times more likely than non-caregivers to live in poverty
- Half of working caregivers indicate that an increase in caregiving expenses has caused them to use up all or most of their savings

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**THE CAREGIVING CRISIS**

- Longevity and growth of our aging population
  - Since January 1<sup>st</sup> 2011, 10,000 baby boomers turn 65 EACH DAY
  - 85% of people over 65 will require caregiving assistance at some point during their life
- Eldercare in the workplace is becoming just as an important issue as childcare in the work place
  - Employees caring for elderly loved ones cost employers 8 percent more in health care expenses each year

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**TURNING POINTS**

1. Shock and Mobilization
2. The New Normal
3. Boomerang
4. Playing God
5. "I can't do this anymore!"
6. Coming Back
7. The In-Between Stage
8. The Long Good-bye

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**CASE EXAMPLE**

- Mary works full-time as the director of nursing at Club Med Nursing and Rehab
- She has a 15 year old son and a 12 year old daughter
- Her parents live in a 55+ community that is a thirty minute drive from her home
- Mary is divorced and her ex-husband lives out of state and has minimal contact with their children

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**SHOCK AND MOBILIZATION**

- The Call
  - Mary gets a call from her father, Bill, during her shift at work. Mary's mother, Faye, went for a walk that morning and hasn't come home.
  - The police are called and able to find Faye within two hours. They take Faye to the hospital where she is admitted.
  - The social worker calls Bill the next day stating that Faye is being discharged and has been diagnosed with dementia. He takes her home with discharge instructions and a list of "resources" for people diagnosed with dementia.

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## SHOCK

- How can this have happened to my mom?
- What am I supposed to do?
- I have no one to talk to.
- My Dad can't handle this.
- This is only going to get worse.
- This isn't really happening.
- Who can I trust?
- What does this all mean?



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## STRATEGIES

- Write down every question you have
  - Prioritize by number the most pressing questions and then research to find answers
- Make a list of what needs to get done
  - Prioritize by number the most pressing actions
- Create a simple, step-by-step, action plan
- Interview and research physicians
- Get a second opinion
  - Consider treatment options available
  - Educate yourself about the diagnosis



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**THE NEW NORMAL**

- Mary realizes that she has a new responsibility - family caregiver
- Strategies:
  - Don't be the lonely hero
  - Look at finding a mental health therapist and/or support group
  - Identify the people in your life that you can trust
  - Care for yourself: Do things you LIKE to do
    - Commit to doing one pleasing activity per day
    - Look for ways to laugh
    - Find an activity that completely takes your mind off of your role as a caregiver
    - Exercise, monitor your own physical health, maintain healthy diet

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**BOOMERANG**

- *The illness suddenly becomes worse or the care plan falls apart.*
- Mary and Bill were able to get Faye into a local day care center where she could be monitored. They found a memory disorder center where Faye had a complete work-up and was stabilized on medications that helped with Faye's confusion, anxiety, and agitation. The memory disorder center also provided educational classes for Mary and Bill so that they could better understand dementia.
- Mary gets a phone call from the hospital that Bill had a stroke and was admitted for treatment
- Faye has to move in with Mary while her father is being treated



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**STRATEGIES**

- ◉ RESPITE CARE
- ◉ Reach out to your therapist and/or support group
- ◉ Talk with people you trust
- ◉ Breathe
- ◉ Continue self - care: Diet, exercise, regular check-ups, etc.
- ◉ Meditate, pray, or anything that silences the mind DAILY
- ◉ Reward yourself - massage, mani/pedi, movie, outing with friend, concerts, sporting event etc.

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**PLAYING GOD**

- ◉ *The caregiver believes that they hold their loved ones life in their hands*
- ◉ This creates a wall around the caregiver and their life becomes defined by the caregiver role
- ◉ Mary's father is placed in the rehab center where she works after he discharged from the hospital due to his stroke. The social worker there knows Mary well and tries to encourage her to look at assisted living placement for Faye. Mary is defensive insisting that she is the only one who can care for Faye.

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**STRATEGIES**

- Reality check
  - Do you expect your loved one to get better?
  - Discuss with another caregiver
  - Has your loved one come to terms with loss and frailty?
  - Do you see your loved one's recovery as your sole responsibility?
  - Can you accept the truth?
- Set Boundaries
  - Introduce other family members, friends, care helpers early before you are seen as the solitary caregiver
- Revise your Attachment
  - "Caregivers must connect with people in the healthy world so they can be less anxious and angry and lonely when they visit the world of dementia." Pauline Ross

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**I CAN'T DO THIS ANYMORE!!!!**

- Faye spends three nights in a row up and agitated. She paced the house and became verbally abusive when Mary tried to re-orient her. Mary is sleep deprived, worried about her father, and losing touch with her children. She feels like she can't go another day like this.
- Anger is commonly felt among caregivers and is triggered by fatigue, frustration, and resentment. These are all exacerbated by guilt the caregiver has for feeling these feelings.
- Strategies
  - Seek out a social worker, caregiving organizations, and community resource hotline
  - Know that there are resources to help you cope
  - Reach out to therapist/support group/people you trust

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### COMING BACK

- Mary realizes that Faye is progressively getting worse and will become more and more dependent. She researches assisted living facilities in the community and places her mother to a facility close to her home.
- When the caregiver anticipates the decline of their loved one they can begin to imagine the possibility of their own comeback to life
- Strategies:
  - Feel the fear
  - Seek serenity
  - Find joy - reconnect to friends, hobbies, and passions put on hold
  - Give yourself permission to let go

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### THE IN-BETWEEN STAGE

- Faye had lost her ability to chew and swallow her food due to the progression of her dementia. The attending physician recommended that Faye either be put on a feeding tube or under hospice care.
- The care-recipient can't be cured in a hospital but is not yet ready to die
- Often comes with frequent emergency room visits and readmissions to the hospital
- Strategies:
  - Palliative care
  - Hospice care
  - Utilize support system

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### THE LONG GOOD-BYE

- ◉ Mary had Faye complete an advanced directive before she was ill. Faye clearly stated that she did not want to be kept alive by artificial means, including a feeding tube. Mary asked for a hospice evaluation and had Faye placed under hospice care in the assisted living facility.
- ◉ Death becomes real
- ◉ Strategies
  - Palliative care vs. Hospice
  - Grief and loss support groups
  - Individual counseling
  - Self-care

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### THE FIRST STRATEGY IS ALWAYS SELF-CARE

- ◉ Many studies reflect that the health among many caregivers declines once they take on this role
- ◉ Caregiver burn-out
  - Physical
  - Mental



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**MODERATING CAREGIVER STRESS**

- ◉ Caregiving can provide a deeply rewarding sense of purpose, a source of great pride, and can be a cathartic experience for both caregiver and care-receiver
- ◉ Factors that moderate stress include
  - Emotional support
  - Instrumental support
    - Routine assistance with the day-to-day
  - Prayer, hobbies, exercise, or an activity that allows the caregiver to disengage from the intensity of their caregiving responsibilities

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**CAREGIVER SUPPORT GROUPS**

- ◉ Provides emotional support and concrete suggestions for making caregiving tasks more efficient and rewarding.
- ◉ Caregivers get acknowledgement of their mixed feelings
- ◉ Can help a new caregiver navigate through the new demands of their life
- ◉ It is impossible to fully understand the role of caregiver unless you've been a caregiver

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**CAREGIVER SUPPORT GROUP**  
SHARE, LEARN, AND SUPPORT ONE ANOTHER  
INFORMATION  
GUEST SPEAKERS  
REFRESHMENTS



JOIN US ON THE FIRST TUESDAY OF EVERY MONTH AT  
2:30PM.  
IMPERIAL POINT MEDICAL CENTER  
6401 N FEDERAL HIGHWAY  
FT. LAUDERDALE, FL 33308  
PRIVATE DINING ROOM (IN THE CAFETERIA)  
RSVP'S ARE APPRECIATED BUT NOT NECESSARY. CALL  
BONNIE AT 954-776-8961.  
GROUP IS FACILITATED BY BONNIE PETRIE, LCSW WITH THE  
IMPERIAL CARE MANAGEMENT PROGRAM.

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**TEN TIPS FOR  
CAREGIVERS**

1. Choose to take charge of your life, and don't let your loved one's illness or disability always take center stage.
2. Remember to be good to yourself. Love, honor, and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
3. Watch for signs of depression and don't delay in getting professional help when you need it.
4. When people offer to help, accept the offer and suggest specific things that they can do.
5. Educate yourself about your loved one's condition. Information is empowering.

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**TEN TIPS FOR CAREGIVERS**

6. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved ones independence.
7. Trust your instincts. Most of the time they'll lead you in the right direction.
8. Grieve for your losses and then allow yourself to dream new dreams.
9. Stand up for your rights.
10. Seek support from other caregivers. There is great strength in knowing you are not alone.

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**AFFIRMATIONS**

- I make the best decisions that I can.
- My choices may be limited and beyond my control.
- There are no perfect elder care solutions and no perfect families.
- If I had selected another course of action, I might now be having doubts about that as well.
- New problems are not necessarily related to what I did or didn't do.
- I know it's easy to second guess or criticize from a distance.
- It isn't possible to compare how one person handles things to how another relative would handle it, if their positions were reversed. Choices, options and lives are different from what they were 30 years ago.
- I can't do it all but I do my best.
- I must consider "good-enough-for-now" solutions.
- Compromise is necessary for each to get some of what they need and want.
- My care receiver is not unhappy or upset because of what I have done. She/He is living with unwanted dependency, loss and/or pain. She/he still needs to feel useful, dignified and loved.
- We must continue to celebrate good times as a family and feel good about what we have been able to do for and with each other.

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**POSITIVE EFFECTS OF CAREGIVING**

- Caregiving provides a sense of purpose
- Supporting and helping others prevents social isolation and can actually increase longevity
- Can allow the caregiver to feel good about themselves, learn new skills, and strengthen family relationships
- Life lessons are learned from the caregiving experience
  - Knowledge gained from the care receiver
  - Attitude towards change
  - Compassion and gratitude
  - Importance of self care

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**SOME CORPORATIONS ARE STARTING TO CARE**

- Prudential Financial - Employees can pay a \$100 co-pay to hire a geriatric care manager
- McGraw-Hill: Employees can enroll another adult family member on their health insurance plan at regular family rates
- Verizon Communications: Offers emergency in-home care
- Freddie Mac: Offers caregiving support groups and emergency home care costing employees on \$15/day
- AstraZeneca: Employs can work with a geriatric care expert for six hours every year to help them with their caregiving situation
- IBM: Offers discounted long-term care insurance and free software to help employees find caregiving resources

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WHAT CAN WE DO AS HEALTHCARE PROVIDERS?

- Ask questions
  - Do you feel like you are under a lot of stress?
  - What aspects of your day are the most stressful?
  - Have you been feeling down?
  - Are you feeling more anxious or irritable?
  - How often do your friends and family visit?
  - Do you have anyone that can help watch your loved one so you can have some time for yourself?
  - Do you have any outside help?

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WHAT CAN WE DO AS HEALTHCARE PROVIDERS?

- Listen, Listen, and Listen
  - Caregivers often times just need to vent
- Validate the caregiver's feelings
- Help the caregiver understand the care receiver's behavior
- Advocate
- Be aware of personal biases if the caregiver is male
- Help where you can and refer when you can't
  - Social worker
  - Local area agency on aging
  - Geriatric care managers
  - Geriatricians
  - Mental health practitioners
  - Support groups
  - Websites
  - Provide educational literature

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**"THE LIVE OAK DEFINITION OF AN ELDER" BARRY BARKAN**

An Elder is a person  
Who is still growing,  
Still a learner  
Still with potential and  
Whose life continues to have within it  
Promise for and connection to the future.  
An elder is still in pursuit of happiness,  
Joy and Pleasure  
And her or his birthright to these  
Remains intact.  
Moreover, an elder is a person  
Who deserves honor  
Whose work it is  
To synthesize wisdom from long life experience and  
Formulate this into a legacy  
For future generations.

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**QUESTIONS?**



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