The Forgotten Patient

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Learning Objectives

The Learner Will Be Able To:
- Accurately identify the caregiver
- Define and identify caregiver stress
  - Symptoms
  - Signs
- Recommend interventions and support for caregivers
Definitions

- **Caregiver burnout** is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude -- from positive and caring to negative and unconcerned.

- Compassion fatigue—also known as secondary traumatic stress (STS), is a condition characterized by a gradual lessening of **compassion** over time.

All Encompassing Job

- Caregiving is a marathon, not a sprint
- It is a long term investment with an inevitable end but no definite timeline
- The caregiver gives assistance with activities of daily living (ADL’s), medical services coordination, medical supervision, administration of medications and assistance with financial, legal, spiritual and emotional concerns.
Who are the Caregivers?

- Boomers
- Millennials
- The sandwich generation
  a generation of people, typically in their thirties or forties, responsible for bringing up their own children and for the care of their aging parents.

Some Statistics

- Research from the National Family Caregiver Support Center reports
- 45-65 million people provide care for a chronically ill, disabled or aged family member or friend during any given year
- Caregivers spend an average of 25 hours per week providing care for their loved one.
- 87 percent of them are not getting enough sleep
It Costs Money!

- At an estimated $470 billion annually, family caregivers deliver twice the amount of care as is delivered by paid care for nursing home and home care services.

Special Note: The Rural Caregiver

- Removed from readily available and professionally organized supportive services and care networks
- Faced with challenges such as geographic barriers to resources and isolation from other caregivers, family members or informal supports.
- This lack of service availability, care networks, and isolation from other caregivers and family members can add to and magnify caregiver stress, burnout, and depression.
Concerns for the Caregiver

- Lack of Time
- Isolation
- Grief

The Signs of Caregiver Burnout

- Denial
- Anger
- Social withdrawal
- Anxiety
- Depression
- Exhuastion
- Sleeplessness
- Emotional reactions
- Lack of concentration
- Health problems
Denial

- Denial about the disease and its effect on the person with the disease.
- Unrealistic hope for the future

Anger

- Anger is directed at the patient
- Caregivers can become impatient with the patient
- Having unrealistic expectations from the patient demonstrated by overestimation of their abilities
- Lack of recognition regarding condition and the patient’s limitations
Social Withdrawal

- Caregivers find that they no longer want to stay in touch with friends or participate in activities once enjoyed.
- Everyone needs a break from time to time.
- Caregivers — motivated by a mix of love, loyalty and a dash of guilt — rarely take a break.

Anxiety

- The caregiver may not feel up to facing another day and what the future holds.
- Feeling overwhelmed.
Depression

- Feeling sad and hopeless much of the time.

Exhaustion

- Difficulty with their own ADLS
  - Mental
  - Physical
  - Spiritual
Sleeplessness

- Difficulty falling asleep
- Nightmares
- Stressful or vivid dreaming
- Difficulty staying asleep or frequent awakening
- The bewitching hour

Emotional Reactions

- Crying at minor upsets; you are often irritable.
- Feeling furious one minute, sad and helpless the next
- Emotional rollercoaster
- Over reacting
- Under reacting
Lack of Concentration

- Trouble focusing
- Difficulty completing complex tasks
- When distracted, trouble returning to task at the point where the task was interrupted

Health Problems

- The caregiver may lose or gain weight, get sick more often (colds, flu), or develop chronic health problems (backaches, high blood pressure)
- Stress takes a toll on the immune system
Why Do We Care About Caregivers?

- **Double Win** when we take care of our unpaid family caregivers they in turn take better care of their loved ones.
- Doctor days go DOWN significantly when caregivers are healthy and prepared to give their best care to their loved one.

Tips For the Caregiver

- **Seek support** from other caregivers. You are not alone!
- **Take care of your own health** so that you can be strong enough to take care of your loved one.
- **Accept offers of help** and suggest specific things people can do to help you.
- Learn how to **communicate effectively** with doctors.
- Caregiving is hard work so **take respite breaks** often.
Tips For the Caregiver

- **Watch out** for signs of depression and don't delay getting professional help when you need it.
- **Be open** to new technologies that can help you care for your loved one.
- **Organize** medical information so it's up to date and easy to find.
- **Make sure** legal documents are in order.
- **Give yourself credit for doing the best you can in one of the toughest jobs there is!**

Questions?
References: Resources

- [www.webmd.com/women/caregiver-recognizing-burnout](http://www.webmd.com/women/caregiver-recognizing-burnout)
- [www.caregiveraction.org/](http://www.caregiveraction.org/)