Issues Related to Family Caregiver

- >40 million US adults are family caregivers of someone >18 years of age who is ill or has a disability

- ~25% of all US households affected by someone who is a family caregiver.

Emotional & Physical Challenges of this Role

- Caregiver Burnout
  - Feelings of distress/ helplessness/being overwhelmed/ angry
  - Changes in sleep/ eating patterns
  - Emotional exhaustion
  - Physical exhaustion

- Physical Challenges:
  - Providing physical care: bathing, feeding, taking to appointments, paying bills, managing care. Can be physically draining—take time away from work, friends, activities that you enjoy.
  - Managing work outside the home: may have to put in longer work hours, or (for many) reduce work or lose job because of caregiving responsibilities.
  - Not all caregivers have physical challenges.

- Emotional Challenges:
  - Regardless of type of caregiver (distance, local, caregiver of someone who lives in your own home, etc), the research shows that there are emotional stressors in all of these situations.
  - Our work showed that caregivers of individuals in an institutional setting had higher levels of depression for a longer period of time than those who cared for someone at home. One reason: individuals living in an institutional setting are often more ill—the caregiver has the stress of trying to navigate an unfamiliar environment (NH), talk to healthcare providers, and often is having to make more medical and treatment decisions which can be stressful.

- Regardless of the setting, research shows that caregivers are at high risk for emotional distress, depression, anxiety all of which have been shown to increase their risk for death. In Shultz’ group at the University of Pittsburgh, he showed that caregivers who were providing care AND experiencing mental/emotional strain (or burnout) were greater than 60% more likely to die within 4 year compared to caregivers who were not experiencing emotional strain.
Tips for Avoiding Caregiver Burnout/Strain

• **Ask others to help you with specific tasks of caregiving.** **START THIS EARLY IN THE PROCESS OF CAREGIVING.**

• Need to start asking for help EARLY in the process of caregiving.....even if you don't feel as if you really need help (Mittleman’s work re: support system). Get assistance for things that are important sources of stress to you.
  o Consider paid help if that would be of assistance.
  o Consider asking family/friend to help. Often time, people want to help---they just don’t know what you need help with. The sooner you start asking for assistance, the sooner you can get a system in place that will be of help to you and potentially reduce the emotional strain associated with being the primary family caregiver.
  o Remember: most likely, over time, your loved one will have increasing needs for assistance. The sooner you share the workload, the better equipped you will be to not only care for yourself but have the emotional and physical energy needed to make important healthcare decisions and provide support to your loved one.

• **EARLY in the process of caregiving….talk directly with the person you are caring for to find out what their goals of care are.** **Is it living at home as long as possible?.....or living close to family?....**
  o Find out what is important to them==is it living at home at all cost? Or is it being able to enjoy seeing family?....or comfort at all cost—not length of life? You will be their advocate for the quality of life that is important to them—especially as the illness progresses.
  o By knowing what is important to your loved one you will not only be a better advocate in making decisions for them but you will reduce a major source of emotional distress that family caregivers often experience towards their loved ones end of life. By knowing what your loved one wants in terms of care planning, you will reduce your own source of emotional strain.

• **EARLY in the process of caregiving, let YOUR healthcare provider know that you are a family caregiver.**
  o Often, caregivers do not see the untoward effects of caregiving upon themselves early on. Your healthcare provider can monitor your physical and emotional status to detect physical or emotional changes early on.
  o Early identification of issues can lead to earlier treatment. A benefit for you as well as your loved one.

Some people find support groups of help. If you do, you can find local chapters online (Alzheimer’s association, United Way, Gathering Place, Agency on Aging, National Alliance for Caregiving).

Not everyone finds benefit from a support group➔ do what works for you.