

Cultivating Resilience while providing care

☞ Susan Hedlund, LCSW,
Director

☞ Patient/Family Services
Knight Cancer Institute
OHSU



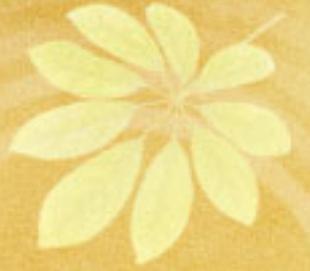


❧ They number in the thousands. They move with matter of fact purpose. Occasionally they rage. Sometimes with guilt. Almost always with love. Rarely with recognition. They are the caregivers. Spouses, parents, children, close relatives, and friends who have the responsibility of caring for a loved one.

The background is a textured, light beige color. In the top-left and top-right corners, there are decorative floral motifs consisting of several overlapping, light green leaves or petals arranged in a circular pattern.

☞ “There are four kinds of people in the world-those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers.”

☞ Rosalyn Carter



“Caregiver”

- ☞ Refers to anyone who provides assistance to someone else who is, in some degree, incapacitated and needs help.
- ☞ “*Informal caregiver and family caregiver*” are terms that refer to unpaid individuals such as family members, friends, and neighbors who provide care.

The background is a textured, light beige color. In the top-left and top-right corners, there are decorative floral motifs. Each motif consists of a central flower-like shape with several pointed petals, surrounded by faint, concentric circular lines that create a ripple effect.

☞ “ Due to increased longevity and improvements in the health of our populations, it is more common for older individuals to be a caregiver...”



The Magnitude

- ❧ **52 million** informal and family caregivers provide care to someone aged 20+ years and above who is ill or disabled in the U.S.
- ❧ **34 million** adults (16%) of the population provide care to adults 50+ years
- ❧ **8.9 million** caregivers (20% of adult caregivers) care for someone **50+ years who have dementia**



The Magnitude (cont.)



❧ Unpaid family caregivers will likely continue to be the the largest source of long-term care services in the U.S., and are estimated to reach **37 million** caregivers by 2050, an increase of 85% from 2000.

❧ Health and Human Services Report, Report to Congress, 2003



Who are these informal caregivers?



- ❧ Gender: More women than men are caregivers. An estimated 59% to 75% of caregivers are female.
- ❧ Research suggests that the numbers of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors.



Who they are (cont.)



- ❧ While men are sharing in caregiving tasks more than in the past, women still shoulder the major burden of care.
- ❧ Some studies indicate that women caregivers handle the most difficult caregiving tasks (i.e., bathing, toileting, and dressing) when compared with their male counterparts who are more likely to help with finances, arrange care, and less burdensome tasks.



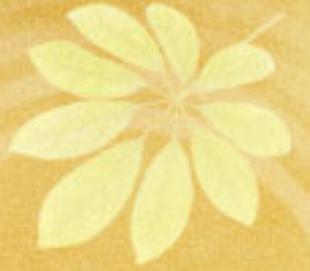
The Risks:

☞ A number of studies have found that female caregivers are more likely than males to suffer from anxiety, depression, and other symptoms associated with emotional stress due to caregiving.

☞ Yee & Shultz, 2000; Navaie-Waliser, Spriggs, and Feldman, 2002



Age of Caregivers



- ❧ The majority of caregivers are middle-aged (35-64 years old)

Age of caregivers (cont.)

- ❧ Many caregivers of older people are themselves elderly. Of those caring for someone aged 65+, the average age of caregivers is 63 years with one third of those caregivers in fair to poor health.
- ❧ Similarly, it has been shown that the number of hours dedicated to caregiving increases with the age of the caregiver.



Relationships between Caregivers and Care Recipients

- ❧ The person most likely to be providing care to an older person is an adult child
- ❧ As care recipients age, there is a much higher likelihood of receiving care from a spouse
- ❧ Some studies show that a significant percentage of caregivers (17%-24%) are caring for a friend or a neighbor as opposed to a family member



Employment Status



☞ Employed full-time	☞ 48%
☞ Employed part-time	☞ 11%
☞ Retired	☞ 16%
☞ Not employed	☞ 9%



Tasks of caregiving



- ❧ May include managing financial matters
- ❧ Providing transportation
- ❧ Advocacy with health care providers
- ❧ Understanding health insurance and coverage issues
- ❧ Tolerating the “medicalization” of the home
- ❧ Providing for daily care, including nursing, bathing, feeding

Impact of caregiving on caregiver's physical health

☞ Caregivers may have increased blood pressure and insulin levels, impaired immune systems, and be at risk for cardiovascular disease and other adverse health outcomes.

☞ Glaser & Glaser, 2003, Lee, Colditz, Berkman, & Kawachi, 2003

Impact of Caregiving on Caregiver's Physical Health (cont.)

- ❧ Elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age
- ❧ Many caregivers themselves are in poor health; one-third of of caregivers provide intensive care although they themselves are in “fair to poor” physical health.

Mental and Emotional Effects of Caregiving Experienced by Caregivers

- ❧ Psychological health appears to be the aspect most affected by caregiving:
 - ❧ Higher levels of depressive symptoms and mental health problems among caregivers vs. their non-caregiving peers
 - ❧ Depression is the most common psychological disorder, with 20% to 50% of caregivers reporting symptoms
 - ❧ Schultz, O'Brien, Bookwala, & Fleissner, 1995

Mental and Emotional Effects (cont.)

☞ While caregiving is stressful, studies show that there are beneficial effects, including feeling positive about helping, feeling appreciated, and feeling that their relationship with the recipient of care has improved.

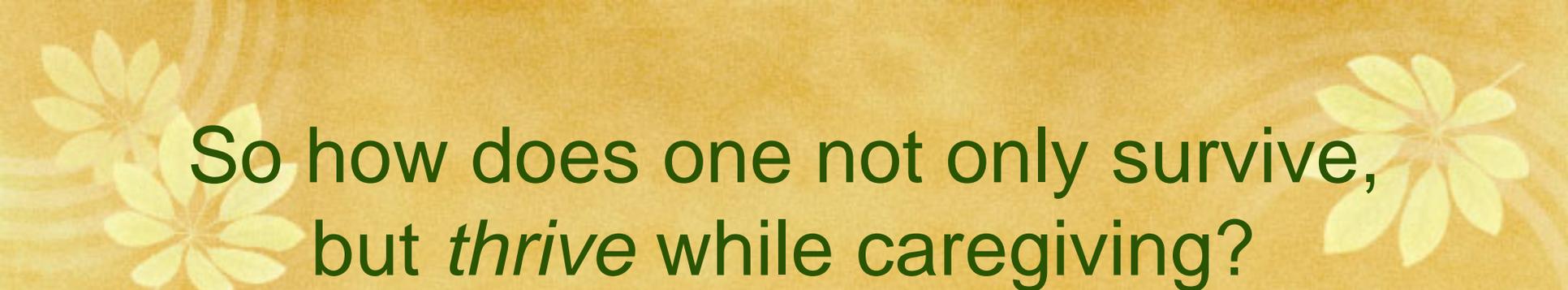
☞ Beach, Schulz, Williamson, Miller, Weiner, Lance, 2005



Fears among caregivers



- ❧ The future
- ❧ Progression of illness
- ❧ Death
- ❧ Death that doesn't come



So how does one not only survive,
but *thrive* while caregiving?

☞ Perhaps some of it lies in recognizing
the differences between stress,
depression, anxiety and grief and....

☞ *Knowing what to do about it!*

Common manifestations of stress

- ❧ Increasing symptoms of depressed mood
- ❧ More worry, “can’t relax”
- ❧ Feeling helpless
- ❧ Anger, frustration, short-tempered
- ❧ Loneliness, isolation
- ❧ Irritability
- ❧ Sleeping problems



Depression Symptoms



- ❧ Depressed/melancholy mood most of the day
- ❧ Loss of interest or pleasure nearly everyday
- ❧ Significant weight loss or gain
- ❧ Insomnia or sleeping too much
- ❧ Fatigue or loss of energy
- ❧ Increased restlessness
- ❧ Feeling guilty or worthless
- ❧ Decreased ability to think, concentrate
- ❧ Increased thoughts of suicide/death



Anxiety symptoms

- ❧ Feeling worried or “on edge” much of the time
- ❧ Heart palpitations
- ❧ Upset stomach, nausea, bowel issues
- ❧ Muscle tension
- ❧ Shortness of breath
- ❧ Cold or sweaty hands
- ❧ Difficulty concentrating
- ❧ Forgetfulness, overwhelmed



Self-care, health and respite

- ❧ Build in quality time for yourself
- ❧ Keep up with your own needs, hobbies and regular activities
- ❧ Exercise
- ❧ Eat a balanced diet, drink water
- ❧ Get enough rest
- ❧ Recognize when you are stressed



Self-care, health and respite

- ❧ Maintain a sense of humor!
- ❧ Get regular check ups!
- ❧ Think about your future
- ❧ Set limits and stick to them!



Seeking professional help



- ❧ When symptoms are impacting you on a daily basis
- ❧ When environmental interventions are not enough
- ❧ When your own physical health is being jeopardized
- ❧ Your quality of life is suffering day-to-day
- ❧ Other people are noticing a change in you

Powerful Tools for Caregivers

- ❧ Six week series that teaches caregivers in how to be effective in using community resources and managing their stress
- ❧ Some employers have developed caregiver family programs (Nike, Intel)



Interventions

- ❧ Family Education
- ❧ Resources
- ❧ Counseling
- ❧ Support Groups
- ❧ Family caregiver trainings/classes

The background is a textured, light beige color. In the top-left and top-right corners, there are decorative floral motifs. Each motif consists of a central flower-like shape with several pointed petals, surrounded by faint, concentric circular lines that suggest a ripple or a soft glow.

❧ Caregiver “overwhelm” can lead to
caregiver burnout



Ask your self these questions:

- ❧ Do I feel overwhelmed with the responsibilities and stresses of being a caregiver?
- ❧ Do I feel torn or conflicted between the roles of caregiver and that of spouse, parent, child, or friend?

Ask yourself these questions:

- ☞ Do I feel all my energy is focused on others?
- ☞ Do I wonder what happened to “me” time?
- ☞ Do I feel I have no time to take care of myself or do the things I enjoy?
- ☞ Am I feeling guilty for being angry, frustrated, and stressed?
- ☞ Do I feel alone in my situation?



Resilience

- ☞ We all have some innate resilience!
- ☞ We also can cultivate resilience by being exposed to difficulty.....
- ☞ Resilience means being able to rise above



Messages to live by



☞ You deserve to take care of yourself

☞ Taking care of yourself will enhance your ability to take care of those you love

10 Tips for Family Caregivers

- ❧ **Reward** yourself with breaks often
- ❧ **Watch out** for signs of depression and don't delay in getting professional help when you need it
- ❧ When people offer to help, **accept it** and suggest specific things they can do
- ❧ **Educate yourself** about your loved one's condition and how to communicate effectively with doctors



10 Tips (cont.)

☞ There is a difference between caring and doing. **Be open** to technologies and ideas that promote your loved one's independence



10 Tips (cont.)

- ☞ **Trust your instincts.** Most of the time they will lead you in the right direction.
- ☞ Caregivers often do a lot of lifting, pushing, and pulling. **Be good to your back.**
- ☞ Grieve for your losses, and then allow yourself to **dream new dreams.**



10 Tips (cont.)

- ❧ **Seek support** from other caregivers.
There is great strength in knowing you are not alone.

- ❧ **Stand up for your rights** as a caregiver and citizen.



Cultivate “mindfulness”



- ❧ “Mindfulness” simply stated, is being in the moment
- ❧ Spiritual/prayer practices
- ❧ At its foundation is an attitude of openness, acceptance and non-judgment
- ❧ Breathing, noticing something new



☞ Believe in yourself!

☞ Protect your health

☞ Reach out for help!



Resources

❧ Family Caregiver Alliance

❧ 800-445-8106

❧ www.caregiver.org

❧ National Family Caregiver's Association
(NFCA)

❧ www.caregiving.org

❧ www.strengthforcaring.com