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.
“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, to some degree, incapacitated and needs help.

- *Informal family caregiver* and *family caregiver* are terms that refer to unpaid individuals such as family members, friends, and neighbors who provide care.

- 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 US
- **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

- Gender: an estimated 59% to 75% of caregivers are female
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.

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

- Older spousal caregivers (aged 66-96) who experience caregiving related stress have a 63% higher mortality rate than non-caregivers of the same age.
Mental and emotional effects

Psychological health appears to be the aspect most highly 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, Bookwalls, & Fiessner, 1995
Fears among caregivers

- The future
- Progression of illness
- Death
- Death that doesn’t come
So…

- How does one grow into the caregiver role without losing one’s existing self-identity?
- How does one maintain dignity and hope?
- How does one not only survive but thrive in a caregiving role?
- How does one nurture “protective factors” and build resilience while caregiving?
Ask yourself.....

- Who were you before?
- Who are you now?
- Are there places where both intersect?
Mental and emotional effects

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
Interventions

- Family education
- Resources
- Counseling
- Support groups
- Family caregiver trainings/classes
Caregiver “overwhelm” can lead to caregiver burnout.
Ask yourself these questions:

• Do I feel overwhelmed with the responsibilities and stresses of being a caregiver?

• Do I feel torn or conflicted between my roles of caregiver and that of spouse, parent, child or friend?

• Do I feel that all of my energy is focused on others?
Ask yourself these questions:

- Do I wonder what happened to “me”? Do I feel I have no time to take care of myself or do things I enjoy?
- Am I feeling guilt for being angry, frustrated and stressed?
- Do I feel alone in my situation?
Caring for you

National Alliance for Caregiving shows the top four caregiver concerns are:

1. Keeping your loved one safe
2. Managing your own stress
3. Finding activities to do with your loved one
4. Taking time for yourself
Recognizing anxiety and depression

Symptoms of anxiety may include:
- Nervousness
- Tension
- Panicky feelings
- Confusion
- Fear
- Feeling something bad is going to happen
- Feelings of losing control
- Anger or irritation
- Physical symptoms
What you can do

- Identify the causes of anxiety
- Talk with someone who has been through a similar situation
- Use relaxation techniques
- Counseling
Recognizing depression

- Depression is more than periodic feelings of sadness.
- Depression may include appetite and sleep changes, feelings of hopelessness and helplessness, fatigue and difficulty concentrating.
- Alcohol abuse may be a sign of depression especially if it is recent or has worsened.
- If these feelings occur during most of the day on most days, and last more than three weeks, seek professional help.
- A combination of counseling and possibly medications can help.
Caring for you

• Forgive yourself for not being perfect.
• Acknowledge your right to feel emotionally off-balance.
• Determine your limits.
• Build in regular breaks from caregiving, and make them a priority.
• Be kind to yourself.
• Seek out joy in your relationship with the person with Parkinson’s.
• Develop a habit of participating in activities together outside cares.
• Try to forgive your loved one for past hurts.

  - National Parkinson Foundation, *Caring and Coping*
Self-assessment tool for Parkinson’s caregivers

- Support of friends
- Support of family
- Personal vocation
- Physical health
- Leisure and play time
- Spiritual life
- Sense of community
Trying to do it all…

• Can we? Yes, and no, depending on how one defines it.

• Doing any job well, including caregiving requires four things:
  – Recognizing you can’t do everything yourself— you work with others.
  – Taking daily breaks
  – Taking vacations to renew yourself
  – Being realistic about what you can do

- Powerful Tools for Caregivers: The Caregiver Helpbook
Cultivating resilience
Personal resilience

- **Resilience**: “an ability to recover from or adjust to misfortune or change”
  - Webster’s

- Steps to resiliency: **self-reflection, relationships, and action**

- Resilience can be developed, and is learned in response to being exposed to difficulty
Cultivating resilience

• Take time for yourself

• Utilize problem solving

• Manage self-care
Take time for yourself

• Set goals

• Make action plans
  – Decide what you can do
  – Make your plan behavior-specific
  – Determine your confidence level
  – Write down your action plan
Problem solving: a solution-seeking approach

- Clearly identify the problem
- List ideas to solve the problem
- Select one to try
- Assess the results
- Substitute another idea if the first one doesn’t work
- Utilize other resources if your solutions don’t work
- Accept that the problem may not be solvable now

- Powerful Tools for Caregiving: The Caregiver Helpbook
Managing self-care means:

• Take responsibility
• Focus on what we CAN do
• Communicate effectively with others
• Learn from our emotions
• Get help when needed
• Set goals and work toward them
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.
Wisdom from my friend who is a caregiver

Hilary’s pearls:
• Trust your instincts, and don’t let anyone talk you out of it!

• Think with your gut, and don’t let the docs get in your head (by telling you not to trust your instincts).

• Be flexible.

• Don’t necessarily go to someone else’s “dream doctor” - find the right fit for you and your loved one.
Hilary’s pearls continued

• Ask yourself, “what would my loved one want?”

• Do you know what that is?

• You are your loved one’s advocate and ears; and he/she may not always hear what you do.

• Make sure all of your legal affairs are in order, and all the documents are accessible (consider putting everything on Evernote, accessed through your phone).
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.

• There is a big difference between caring and doing. **Be open** to technologies and ideas that promote your loved one’s independence.
10 tips for family caregivers continued

• **Trust your instincts.** Most of the time they will lead you in the right direction.

• Caregivers often do a lot of lifting. **Be good to your back.**

• Grieve for your losses, and then allow yourself to **dream new dreams.**

• **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.

- Caregiver Action Network
Building resilience principles

• Connect to your purpose and meaning in life
• Use your unique strengths
• Maintain perspective
• Generate positive feelings
Building resilience principles continued

- Be realistically optimistic
- Persevere by being open minded and flexible
- Reach out to others

- Seven Principles for Building Personal Resilience, Warner (2011)
Other thoughts…

• Re-frame negative thoughts

• Examine self-talk

• Recognize barriers to self-care

• Reframe stress:
  – Can I change this?
  – If not, can I ignore it or let go?
  – Can I change my perception of it?
Hope and help

- A sense of hope is “knowing that your present moment has meaning.”
  - Robert Randall

- “We need not walk alone…we reach out to each other with love and understanding and with hope. We come together from all walks of life, from many different circumstances, we need walk alone.”
  - Credo from Compassionate Friends
Resources

• National Parkinson Foundation: 800-4PD-INFO (473-4636)
  – www.caremap.parkinson.org (CareMAP)
  – www.parkinson.org
• Family Caregiver Alliance: 800-445-8106, www.caregiver.org
• Caregiver Action Network (National Family Caregivers Association): www.caregiveraction.org
• National Alliance for Caregiving: www.caregiving.org
• Strength for Caring: www.strengthforcaring.com
My Dad: wonderful human being and person with Parkinson’s