



Practicing Self-Care Then, Now, and Tomorrow


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Today's Talk

- A whirlwind history of family caregiving and self-care
- 6 keys to caregiver self-care
- Overcoming "support hesitancy"
- The future



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- *Who are you caring for—parent, spouse, friend, other?*
 - *What is their diagnosis?*
 - *How many years have you been a family caregiver?*

- *On a 1 to 10 scale, in which 1 is very low and 10 is very high, how stressful has your caregiving experience been?*
- *What are your favorite ways of taking care of yourself?*







- *“At the time [1977], professionals didn’t always ‘get’ the need for programs to support [family caregivers]. Further, for caregiving families, exposing these personal, private issues to public scrutiny was new and uncomfortable. Because there was such reluctance to talk about the emotional, financial, and physical challenges of care—or because their concerns were dismissed by the very people they looked to for help—families and caregivers often lived in isolation and suffered in silence.”—Family Caregiver Alliance*

• AUG • 67



From Wife of Alzheimer's Patient

- *"I don't think anyone can understand the intense, crushing isolation and loneliness of caregiving unless they have 'walked a mile in our shoes.' I miss the intimacy we've had for more than 50 years, and I'm not talking about physical intimacy, although I miss that, too. I miss having someone to talk to or share a chuckle or one of our little 'inside' jokes. It's all gone! I'm not ready to ditch my marriage vows and dash out and have an affair, but I long to have a companion again--even someone to just stand and hold me while I cry the tears I've had to squelch and swallow for so long."*

- **Schulz (JAMA, 1999):** dementia caregiving among most highly stress family caregivers is associated with insomnia, depression, musculoskeletal problems, increased mortality
- Led to creation of National Family Caregivers Support Program (2000) to support family caregivers of older adults to live in their own homes in their communities

- *Anyone else remembers these days?*

Family Caregiving Today

- 53 M Americans engage in some form of caregiving activity in a year (NAC/AARP, 2020)
- Prevalence: 21.3% (18.2% in 2015)



- 60% women/40% men
- ¼ Millennials; ¼ Gen-Xers
- Average family caregiver: A 49-year-old woman still working at least part-time and caring for children—"sandwich generation"





- NAC/AARP 2020: 21% of caregivers said their health was fair or poor (17% in 2015; 12% in US pop in 2020)
- **Most stressed caregivers:**
- Spouses, military, dementia



○ *Any surprises here?*

Keys to Caregiver Self-Care

- Believe in the value of **caring for yourself**
- Accept negative and positive **feelings**
- Define **commitments** realistically
- Selectively separate **past**/present
- Find **positive** meanings in the sacrifices that you are making
- Utilize **support**

- *Believe in the value of caring for yourself*

Marathon Metaphor

Caregiving as marathon, not sprint:



- Learn the up-hills and down-hills of the course
- Maintain sustainable pace
- Take any and all replenishment
- Run alongside others

- Protected time
- Respite
- Physical exercise
- Spiritual practices
- Mindfulness/relaxation exercises



Mindfulness

- Daily reflection—journaling
- Meditation
- Present engagement; staying in the moment through caregiving tasks
- Positive self-talk
- Gaining larger perspective of limits of time → gratitude

- *Accept negative and positive feelings*

Normalizing Ambivalence


- *“Is it okay if I don’t always enjoy being a caregiver?”*
- Many caregivers have mixed feelings about their caregiving tasks
- They feel guilty about their negative feelings
- They then try to compensate for their negative feelings by working even harder

- It is normal and expectable to have negative feelings
- Hating caregiving tasks is not hating care recipient
- Give yourself permission to set limits on the caregiving tasks you hate

- *Define commitments realistically*

Defining Commitments


- *"I feel I have to do this. But what's the right way to do it? How much should I do?"*
- Take stock of individual and family development, resources
- Choose consciously to define commitments and limitations/necessary balance



“Everyone has limits about what they are willing and able to do. What part of caregiving will be especially hard for you? What are your limits?”

- Delegating isn't shirking duties
- Accepting compromise; “good enough” caregiver

- *Find positive meanings in the sacrifices that you are making*

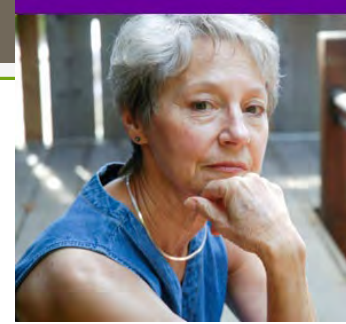


- *“What’s the purpose of this caregiving? Why am I making all of these sacrifices?”*

- Lack of purpose leads to greater likelihood of resentment and burnout

- *“Why do I do what I do for my loved one?”*
- *What are the values underlying my choice to give care?*

Karen



- *"Shortly after I was pregnant, I left my husband. And then after the child was born, I decided I was going to go back with him. And my parents knew it wasn't going to work. And my mother kept saying, 'You'll go back and have another baby.' And my father said to me, 'You can always come home. I don't care if you have 10 babies. You can always come home.' He left that door open for me. And I did just that. I went back and had another baby and came back with two babies. And I'll never forget that. I always knew I could go home."*

Prospective Retrospection

- Aka pre-hindsight
- **“How do you think you will look back at this time in your life 5 years from now?”**
- “What do you think will be important to you in the future about the choices you are making now?”

- *Utilize all available support as early and often as you can*

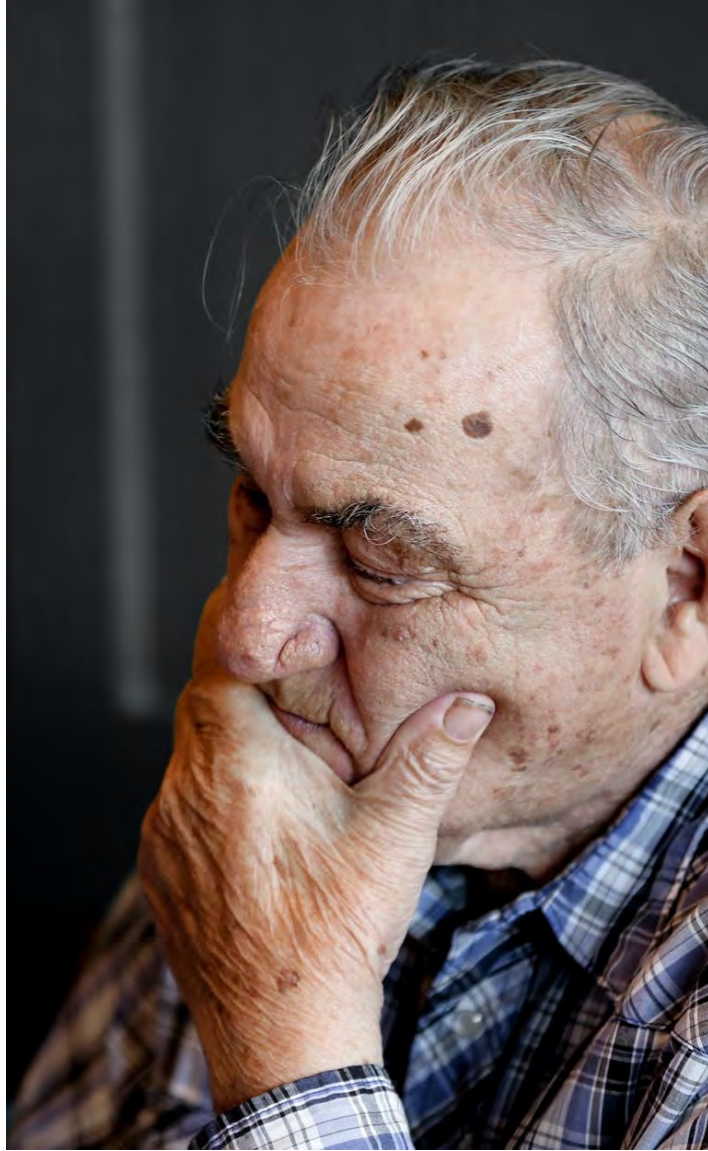
Types of Support

- In home: home modifications, home health aides, home health, digital platforms
- Out of home: adult day care programs, respite, rehab (PT/OT)
- Informational: books, websites, apps, AAAs, disease-specific organizations, health plans, care management
- Emotional: family, friends, neighbors, faith community, in-person and virtual support groups, mental health professionals

- *But some family members experience “support hesitancy”*



"I'm no family caregiver. I'm just her daughter doing what I'm suppose to do."



"Our family takes care of its own. Besides, no one can take care of her as well as I can"

No Support or Self-Care

- ◉ Accepting help almost feels shameful, disempowering
- ◉ Tantamount to shirking their duties
- ◉ Afraid of others' judgements
- ◉ Afraid of their own judgements

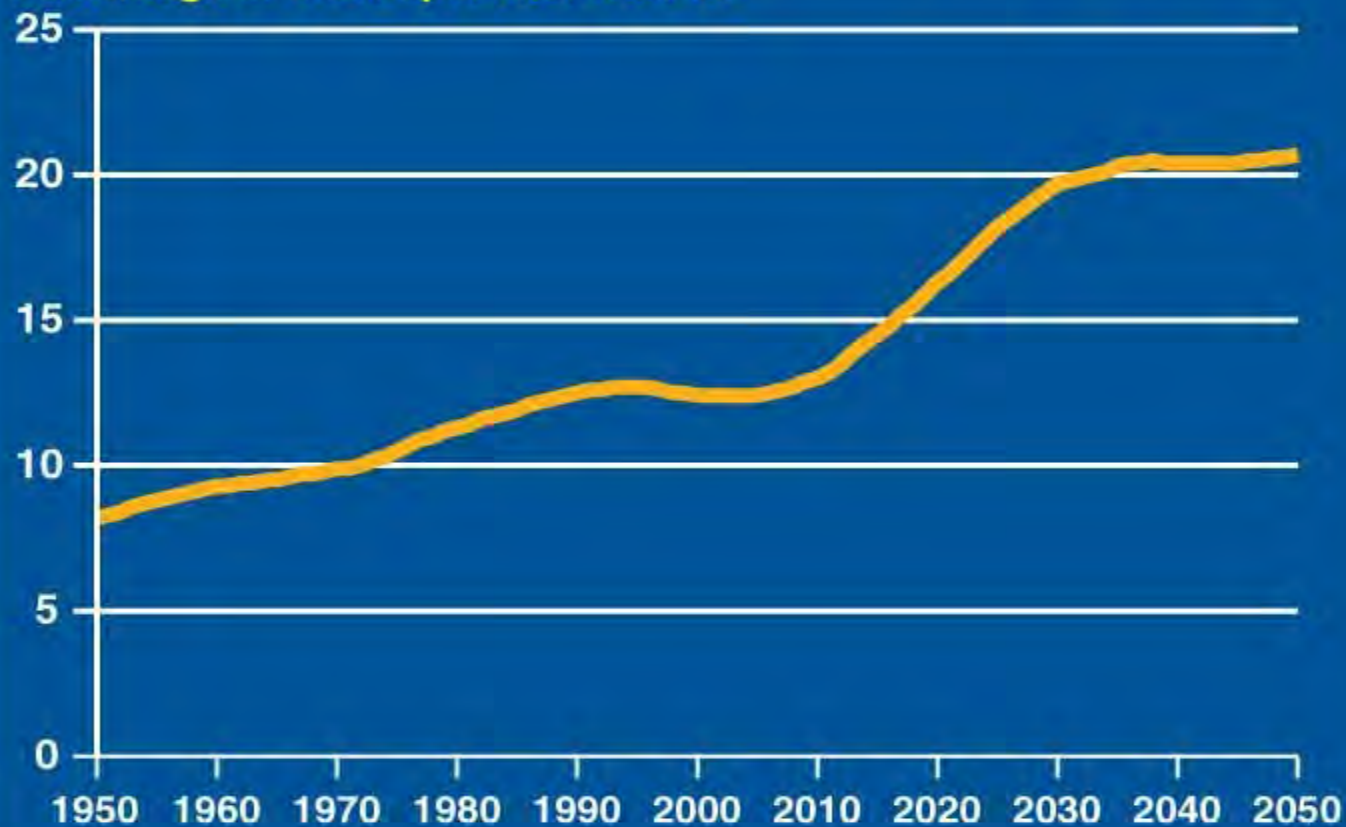
Marathon Metaphor



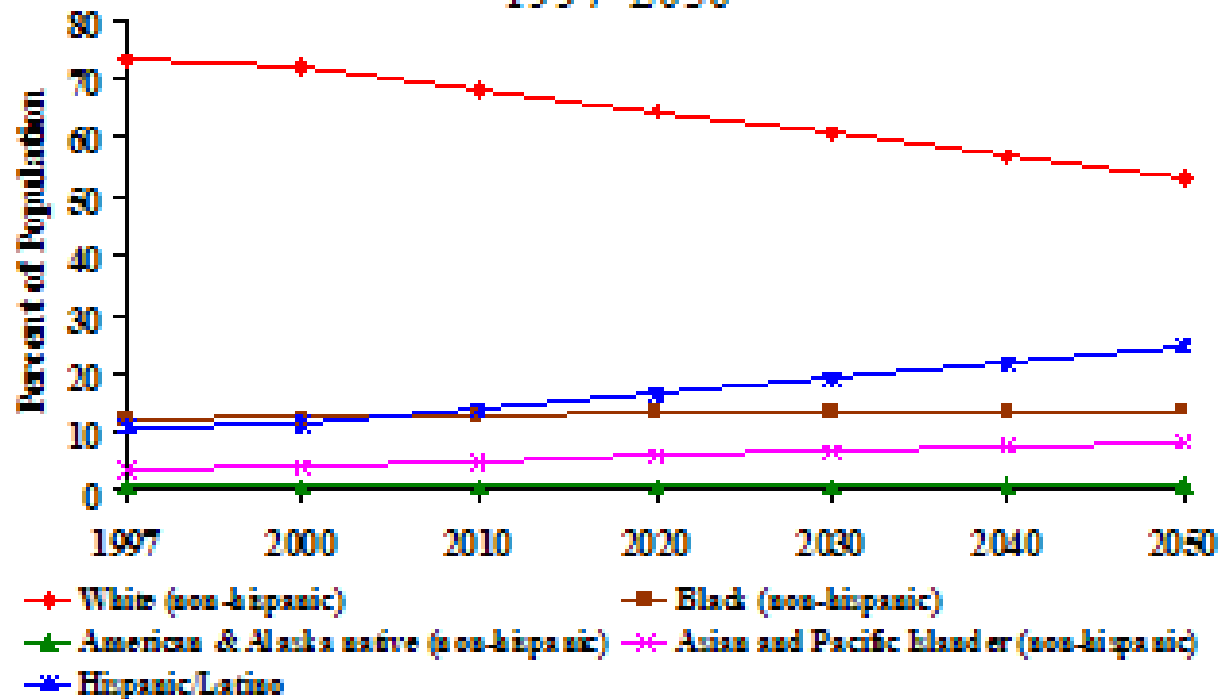
- *Do you already use any of these self-care strategies?*
- *Are there strategies here you'd like to try?*

Growth in Population Age 65 & Over

Percentage of U.S. Population Over 65



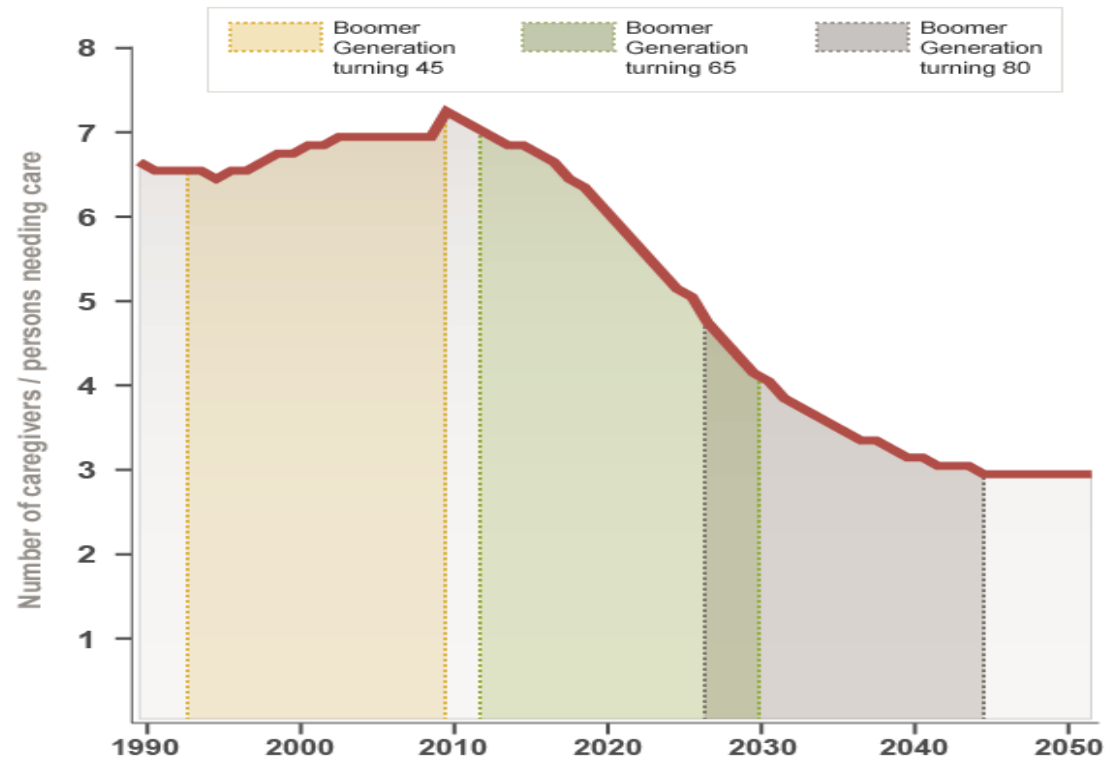
Race/ Ethnic Composition of the Resident Population of the United States: 1997-2050



Source: U.S. Census Bureau

caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio



In **2010**, the caregiver support ratio was **more than 7 potential caregivers** for every person in the high-risk years of 80-plus.



In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/ppi

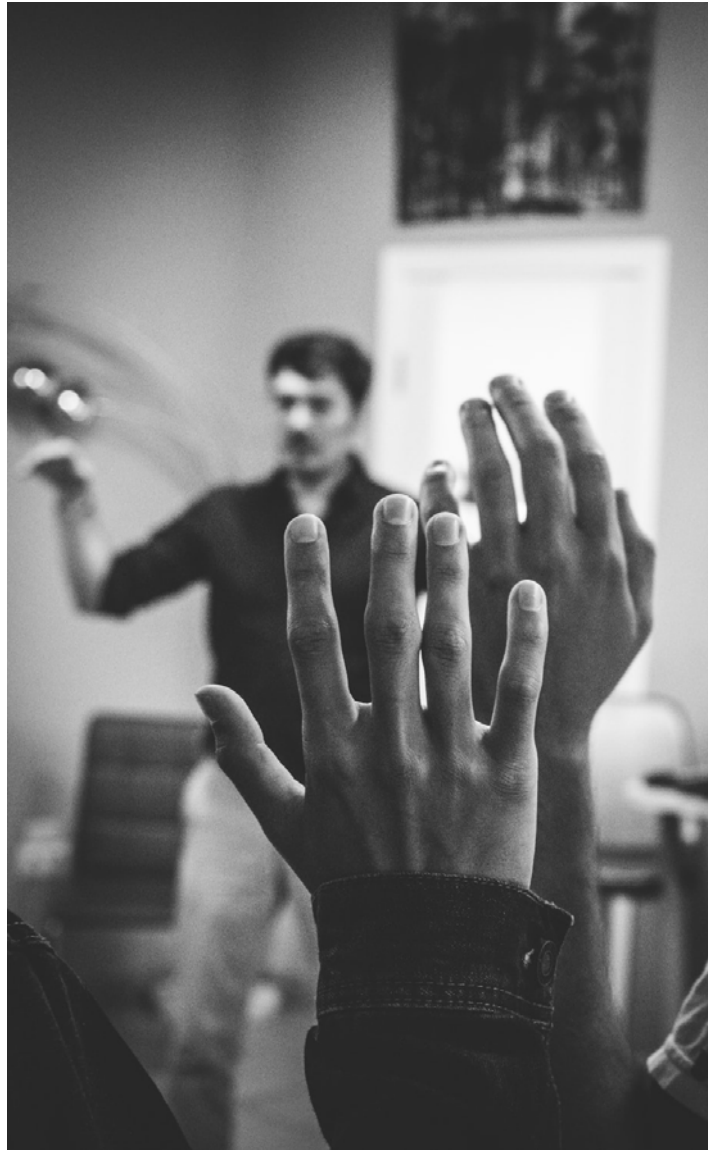
My Wild-Eyed Predictions

- ◉ Less trust in institutional care
- ◉ More home-based care
- ◉ Greater need for AAAs for information, guidance and care management
- ◉ More reliance on others to provide hands-on supports
- ◉ Greater use of technologies—digital communication and care management platforms, remote monitors, robots



But Self-Care is Still Optional...

Caregivers will still need to find ways to feel comfortable with accepting help and taking time for themselves.



Questions or
Other Thoughts?

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