



Be Pro-Active!

***The Challenges of
Family
Caregiving***

Paula Wolfson, LCSW, Manager Avenidas Care Partners

- Elder Care Consultations and Assessments
- Caregiver Group Support
- Call Paula for information at 650 289 5438

Family Caregiving Burden or Blessing?

- Family caregivers are the backbone of all elder care in America. The older family “CG” is 65 years+, the majority are female: a spouse, sibling, adult child, legal guardian or a legal decision-maker (DPOA.)
- “CGs” provide billions of dollars worth of custodial hands-on care, assisting a loved one with activities of daily living (ADLs) while also managing complex stressful legal, financial and health care decision-making, including end of life treatment options.

Data from Alzheimer's Impact Fact Sheet March 2018 (alzimpact.org)

- 65% family caregivers are women caring for a love one with dementia.
- 26% are 65 plus years.
- In 2017: 16.1 million family members, friends provided 18.4 billion hours of unpaid care to people with dementia.
- 86% provide care for 1 year
- 50% provide care for 4 plus years.

Center for Disease Control 2015-2016 Caregiver Data

- The caregiver burden is associated with financial challenges combined with two plus more years of caring for a loved one at home who has significant cognitive impairment and requires assistance with two or more ADLS.
 - CGs often present to their physicians with elevated levels of depression and anxiety: increased use of psychoactive medications.
 - Physical health compromised: increased report of heart, respiratory, auto-immune disorders.
 - Increased risk of early death.

“2015-2016 Behavioral Risk Factor Data collected from 38 states, DC, Puerto Rico. CDC”

Questions For Family Caregivers

- **Medical and health care advocacy:** is the family caregiver medically literate: do they have medical informed consent, understand skilled care and non-skilled care resources, insurance coverage, ER admission process, hospital discharge process, Medicare claims, grievance and appeals protocols, end of life care treatment options?
- **Legal and financial matters:** how well organized is the family and care recipient on having all legal documents in order? Is everyone in the family on the same page regarding care recipient's elder estate, financial management, housing and end of life treatment requests?
- **Family dynamics and mental health history:** is there unresolved family conflict and tension impacting your ability to be the caregiver? How will you solve these?
- **Self-care, your boundaries and respite needs:** Caregiving is a marathon not a sprint. You need to take care of yourself to go the distance. Find time for respite. Set boundaries.

Legal Documents for Proactive Planning

- Advanced Directive, Ethical Wills
- Informed Consent
- Durable Powers of Attorney
- Will and Trusts
- POLST
- Medical records
- Financial Beneficiary Statements
- Mortgages, Property holdings.
- **Hand out.**

Medical Crisis: transitions to higher levels of care

- Transitions: onset illness, events crisis driven. ER to ICU to Medical Unit to Rehab to Assisted or Memory Care, to Hospice.
- Prolonged years of repeated transitions from inpatient to community care to home.
- Managing costs of care: skilled vrs. non-skilled care. Finding Payor Resources: Long Term Care Insurance, Veteran's Benefits.
- End of life care treatment options. Compassionate care choices.

Emotional Work Inherent Within Caregiving

Regulating Emotions: Trigger Points and Emotional Contagion

- Caregivers ride an emotional roller coaster.
- Emotional Regulation: requires we know our triggers and control our impulses and reactive behaviors so that we can act responsibly.
- Emotional Contagion: a process when our feelings are fueled by others, systems stressors and we spiral out of control.
- Compassion fatigue: we take on the suffering of others to such an extent that our own energy is depleted: we can no longer function safely as the caregiver.

Cultivate Empathy

- Empathy is “the intelligence within our emotions.”
- Empathy helps us translate experiences into compassionate responses, often to resolve or reframe conflict.
- We need to feel empathic to develop resilience: the ability to bounce back, keep moving forward, regain our balance, stay centered, productive.
- Self-care, forgiveness, compassion, empathy, resilience.

Emotions As Messengers: You control them. Do not let them control you.

- **Anger/Fear** tells you when a boundary has been crossed, you experienced an injustice, a violation. Anger helps us set guidelines and recognize that we need to set limits to protect ourselves and loved ones.
- **Sadness/Grief** help us mourn and let go, process a loss, connect with others, take time out, renew and move forward.
- **Happiness** is a feeling of joy, affirmation, connection, hope and purpose. Happiness keeps us future forward. And feeling affirmed.

Community Resources: Don't Go It Alone!

- Adult Day Health Programs
- Assisted Living and Memory Care
- Caregiver On -Line Educational Resources
- Caregiver Support Groups
- Case Managers
- Elder Estate Attorneys
- Home Care Agencies
- Hospice
- Money Managers
- Senior Placement
- Senior Movers

New resource for that second opinion!

- Dr. Mehrdad Ayati
- Geriatric Medicine
- 851 Fremont Avenue, Suite 103
- Los Altos, CA 94024
- Tel: 650-808 – 0180
- FAX 650-666-8215
- *“We are not a substitute for your primary care provider. We collaborate with your providers and help manage older adult patients. We accept insurance. We have on board both a neuropsychologist and a geriatric psychiatrist.” Dr. Mehrdad Ayati, Director*

Caregiver Resources

- Avenidas: www.avenidas.org 650 289 5400 Main number
- Avenidas Information and Assistance 650 289 5433
- Avenidas Care Partners: 650-289 5438
- Avenidas Door to Door Transportation: 650 289 5411
- Alzheimer's Association: www.alz.org
- Family Caregiver Alliance: www.caregiver.org

Quote from Oprah: “What I Know For Sure!”

- “Ask yourself if the people in your life give you energy and encourage your personal growth or block that growth with dysfunctional and outdated scripts.
- If they do not fully support you, say good-bye.
- Put a stop to stagnant patterns that no longer serve you.”

References

- **Center for Disease Control, 2015-2016 Behavioral Risk Factor Surveillance System (BRFSS) Data.**
- ***“The Language of Emotions: What Your Feelings Are Trying to Tell You,”* Karla McLaren, M.Ed., Sounds True, Boulder Colorado, 2017.**
- ***“The Five Invitations, Discovering What Death Can Teach Us About Living Fully,”* Frank Ostaseski, Flatiron Books, March 14, 2017.**



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