

2019 AVENIDAS CARE FORUM CAREGIVER TOOL KIT
SESSION 4 - THE EMOTIONAL WORK INHERENT WITHIN CAREGIVING
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www.avenidas.org

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ELDER CARE CONSULTS, CAREGIVER SUPPORT GROUPS

WELCOME CAREGIVERS!

The Avenidas Care Forum is a 7- month lecture series designed to provide family caregivers with critical information, resources and access to experts in the fields of geriatric medicine, psychology and social work. Today, we are on our fourth lecture “The Emotional Work Inherent Within Caregiving.” This presentation will review common caregiver stress and trigger points, compassion fatigue, strategies for stress management, emotional regulation, setting boundaries and sustaining a viable self-care plan.

SECTION 1: IS CAREGIVING RISKY BUSINESS?

- **COMPASSION**: the desire to alleviate and take on the suffering of others. This is potentially risky business if the caregiver is overwhelmed, without support or respite, exhausted and depleted of one’s emotional energy.
- **SIGNS OF COMPASSION FATIGUE**: Caregivers develop compassion fatigue due to lack of self-care, unresolved conflict, continual crisis, constant change, loss, lack of respite, poor boundaries, enmeshed relationships and lack of professional support. Emotional and mental stagnation, frustration, apathy, decreased social interactions with others. Reduced sense of personal accomplishment. Depersonalization and disconnects in our thinking and behaviors.

CENTER FOR DISEASE CONTROL BEHAVIORAL RISK STUDIES FINDINGS 2016

- Older family caregivers (CG) are considered an “at risk” sub-group of elder Americans due to prolonged years of caregiving for a loved one experiencing continuous physical and cognitive decline. Stressors include family role reversals, financial hardship, complex health, legal and financial decision-making regarding quality of life issues and treatment options
- **FINDINGS**
- Increased self-report of caregiver social isolation, lack of sleep, chronic fatigue, poor self-care.
- Increased self-report of caregiver depression, anxiety, complicated grief: increased use of psychoactive medications.
- Increased rates of caregivers diagnosed with high blood pressure, reduced immune function increased risk of coronary heart disease (CHD) for women.

SECTION 2: SELF-CARE PLAN STRATEGIES

A. UNDERSTAND YOUR STRESSORS AND TRIGGER POINTS

CAREGIVER TRANSITIONS, TRIGGERS: ADJUSTMENT CHALLENGES

- **Initial Stage of Caregiving:** your life begins to change, less time, money for self, travel, leisure activities disappear. You may need to quit work. Family relationships change.
- **Loved one has sensory loss** (hearing, vision, taste), mobility issues, becomes incontinent.
- **Loved one has increased cognitive and physical decline** which changes their personality and your relationship with them *You experience loss of familiar companionship, loss of intimacy. CR is completely dependent on you for their safety and comfort.*
- **Family roles change, conflict over tasks and responsibilities, conflict over decision-making, conflict over budget, goals of care and treatment. Everything feels conflicted all the time.**
 - **CR frequently falls at home.** Home needs modifications to enhance CR safety.
 - Home care, managing work force in home, strangers in the house.
 - Cultural communications clashes with home care providers.
 - *Navigating complex legal, medical and financial systems and policies.*
 - **Navigating CR need for higher levels of care** as their cognitive and functional abilities change: frequent trips to ER, hospital, skilled nursing facilities, assisted and memory care relocation. Do not understand co-pays and medical bills.
 - *Discharge planning sessions and hand-offs between providers.*
 - *Care recipient resists help, becomes agitated, paranoid, hallucinates, wanders.*
- **Designating legal decision-makers, managing elder care estate plans, Wills, Trust, Advanced Directives, POLSTS.**
 - **Financial stressors** - maintaining budget, high costs of custodial care, arranging for fiduciary services, selling family home to pay for assisted and or memory care.
 - **End of life care treatment options**, palliative and hospice care, death and dying process, making funeral and memorial service plans, meeting with elder estate attorney, navigating Wills, family conversations: grieving process.
 - Family, siblings, children, former spouses, friends are critical of you as the caregiver.

A. TECHNIQUES AND STRATEGIES FOR COPING WITH STRESSORS

MIND OVER MOOD: change how you feel by changing how you think.

Track dysfunctional patterns of thought which influence moods and behaviors: these are described as “assumptive” or “hot” thoughts: evolve from emotional reactivity to triggers, not evidence based. Seek actual causes for the event and moderate your responses. Ask questions, investigate, gather facts, data, take a pause before responding verbally or taking any action.

Goal - reduce reactive thinking and behaviors: maximize reasonable responses to triggers, reduce drama, stay calm, renew or sustain emotional energy.

- **Assumptive or hot thoughts** include the following patterns of thinking:
- **Going global:** making generalized statements: “You are completely unreliable about his medical care. It was your turn to take him to the doctor!”
- **Alternative response:** “I was hoping you were going to take him to the doctor. Why were you not available? I thought it was your turn.”
- **Jumping to conclusions:** “You took my money!!!”

- **Alternative Response:** “Has anyone seen my wallet and my cash.?”
- **Discounting the positive:** “Oh, his sister always sends flowers: so, she does not have to visit him at the memory care place.”
- **Alternative:** “I think his sister might be heart broken he has dementia. How can we help her? He misses seeing her.”
- **Using “Should” rather than “I” statements.** “You should call more often!”
- **Alternative:** “I miss you, please call us more often, I need support.”
- **Personalizing events as if everything is your fault:** “I should not have said that.”
- **Alternative:** “May I help you? Are you upset?”
- **Shaming and blaming others:** “His sister is clueless about dementia caregiving.”
- **Alternative:** “I will call his sister and offer suggestions how to plan activities for her visits with Don.”

EMPATHY IS AN EMOTIONAL SKILL

Empathy is an “emotional” skill, forms the foundation for positive-regard, patience, open mindedness, kind-hearted relationships, forgiveness.

Author and researcher Karla McClaren, M.Ed states empathy is composed several aspects which impact our behaviors and thoughts.

- **Emotional awareness:** before empathy kicks in you need to sense that a feeling / emotion is occurring and or a response is expected of you. Empathy relies on one’s ability to detect, understand and share emotions. Empathy is an emotional skill.
- **Empathic accuracy:** the ability to accurately understand your feelings and others so that you can make appropriate responses. This is always a challenge as cultural norms vary regarding discussions of death, aging, illness, treatment, sex, abuse, etc. Some cultures avoid intimate discussion to “save face”, topics taboo, inappropriate, vulgar, insulting.
- **Emotional contagion and regulation:** Necessary to have self-awareness and insight, so that in the presence of strong and powerful emotions you can take control rather than be overpowered by strong feelings, especially if they are dangerous to your safety or that of someone else. We might think of this as “impulse control.”
- **Perspective taking:** Put yourself in the other persons’ “shoes.” Understand others’ wants, needs, capacity for coping. Requires open-mind, open hearted approaches and humility.
- **Perceptive engagement:** Allows you to gauge complex interactions, situations, and respond respectfully to your own and the other person’s needs. “Sometimes the most empathic action may be to do nothing at all, just listen, give people their privacy, space.”

EMOTIONS AS MESSENGERS

USE THEM WISELY; DO NOT LET THEM USE YOU!

Use your emotional intelligence: what message is conveyed when you feel an intense emotion? Hint: if feeling angry you do not have to respond as such. Pause.

- **Anger:** arises when a boundary has been crossed. Anger helps you understand your values, beliefs and allows helps you set personal guidelines. Anger can also help you set healthy detachment, avoid enmeshment, protect yourself and others. Anger body talk: shortness of breath, knot in the throat, complexion changes, excessive alcohol and drug consumption, increased smoking, lack of patience, desire to strike out. May need to count to 10, walk away, seek support.
- **Guilt** and shame arise to help us try not hurt, embarrass, dehumanize self and one another.

- **Fear** orients us to surroundings, situations and others who present danger, high risks, possible hazards. Fear grounds us in a present moment of crisis and change. Helps us take decisive action.
- **Anxiety** helps us identify unresolved feelings about past events, concern for future and worry about present tasks. Anxiety may cause us to spiral into depression if not addressed properly. Anxiety side effects: muscles ache, head-ache, feel jumpy, cannot be still, talk too much and say nothing-imagine rocking in a chair fast and going nowhere.
- **Panic** arises when you feel a threat to your survival. Panic side effects: Chest pains, pressure, sweat, dizzy, panic attack may feel like a heart attack.
- **Anticipatory Grief:** informs us loss and change taking place; if used wisely these feelings help us pro-actively plan and seek help as needed.
- **Sadness** helps you release that which is no longer, mourn, honor and let go, move forward.
- **Grief** acknowledges when you have lost a loved one: a person, a pet, a prized possession (wedding ring), a time in your life (high school) and or an experience that you cannot get back (your youth). And to take time, reflect, go through a grieving process so you can renew your life and energy.
- **Happiness** (joy, hope, love), keep you connected to others, community, feel affirmed, have purpose, and invested in the present and the future. Allows for play, relaxation, open-hearted connections, renewal of hope, feelings of contentment, life satisfaction.

BOUNDARIES & RESPITE

- Preserve sense of self, values, integrity, self-respect. Protect personal time, resources.
- Setting a firm boundary re: use of your time, money, emotional energy. By saying no to certain demands from others you are saying yes to self-care. This is not saying “I don’t care about you.” Instead one is declaring, “I need to make myself the priority in this moment.”
- Our boundaries help sustain emotional energy. Help us sustain a practice of taking respite.
- Sustaining a safe, personal boundary is very much like a consistent “declutter” practice: declutter your life of situations, relationships which drain and deplete your spirit. And time.
- *“Ask yourself if the people in your life give you energy and encourage your personal growth or block that growth with dysfunctional dynamics and outdated scripts. If they do not fully support you, say good-bye. Put a stop to stagnant patterns that no longer serve you.”*
“What I Know For Sure” by Oprah Winfrey.

THRESHOLDS

- Mark transitions with sacred personal time, rituals, create your own pathways forward: helps you renew your energy: have time alone or with others, meditate, journaling, lighting candles, praying, chanting, walks outside, being in nature.

RESILIENCE

- Resilience-is one’s ability or capacity to overcome stressful situations and bounce back from crisis and conflict without lasting emotional difficulties. Those with resilience find purpose and meaning in life: experience adversity as an opportunity for personal growth.
- Characteristics of those with resilience include having perspective, optimism.
- Resilient people manage self-care and practice being mindful of their intentions.

E. HIGH RISK BEHAVIORS WHEN TO SEEK PROFESSIONAL SUPPORT

- **Compassion Fatigue**: Tells us we are almost depleted of energy to function well and to think clearly. Emotional outbursts, frustration, anger, dark moods, fatigued.
- **Compassion- Fatigue Body Talk**: aches, tension, over- sleep, over- eat, or self-neglect.
- **Complicated Grief**: Lasts many months into a year, several components. Disbelief in the death of the loved one. Intense sorrow, bitterness, anger. Blaming oneself for the death. Avoiding others. Life feels meaningless. Loss of identity and purpose. Wishing to die.
- **Complicated Grief Body Talk**: Emotional numbness. Loss of appetite, oversleeping, isolation, crying. Mood is intensely sad. Cannot move forward on one's own. Requires medical and mental health support, intervention.
- **Suicidal ideation**: arises when something difficult in your life (bullying, financial stress, interpersonal strife, depression) needs to end but NOT your physical life. The question is what idea or behavior needs to end or be transformed?
- If in crisis call suicide hot line 1 800 273 8255. Go to nearest emergency room. Share feelings with supportive friend who will take you to your health providers, urgent care.
- **Addictive behaviors**: substance and drug abuse, self-harm.

REPORTING ELDER ABUSE

- Elder abuse includes emotional, physical, financial and or neglect, self-neglect resulting in “failure to thrive”.
- Call Adult Protective Services to report a suspicion of elder abuse and neglect.
- You only need to have a suspicion or a concern, not proof.
- APS staff will evaluate your call and send out investigators.
- APS office is county based.
- APS Santa Clara County: 800 414 2002, San Mateo - 800-675 8437.

COMMUNITY RESOURCES

- National Alliance Mental Health-Support, Education, Advocacy, Referrals for Therapists
- Santa Clara County - 408 453 0400.
- Check your health plans for access to mental health support: psychiatrists, psychologists, social workers, palliative care and hospice teams, health care navigators.
- Private Pay therapists are listed online by certification, area of expertise. Sample: Google Search: “Psychologist specializing in grief, loss and or depression among older adults.”
- Linda Nastari, LCSW, 408-358 5414-San Jose office
- Nina Poletica, MFT, 650-269 1695-Palo Alto office
- Mental Health Clinics
- Stanford Outpatient Psychiatry
- KARA – Palo Alto, Grief, Loss-650- 321 5271

CAREGIVER SUPPORT GROUPS

- Alzheimer's Association- Google alz.org - Caregiver support groups
- Avenidas www.avenidas.org | Caregiver Support Groups (Call Paula for an intake interview at 650-289 5438).
- Monday Caregiver Group (Location: Palo Alto Sunrise Assisted Care Community on Sheridan Street) - Time 11:30 AM – 1 PM.

- Wednesday Caregiver Group - Avenidas, 450 Byrant Street, Palo Alto, 11:30 AM – 1 PM
- Rose Kleiner Center Caregiver Support Group - Friday at Noon, 270 Escuela Ave, Mt. View

REFERENCE MATERIALS

ARTICLES

Family Caregiver Alliance-<https://www.caregiver.org>

- “Emotional Side of Caregiving,” Donna Schempp, LCSW, 2014
- “Dementia, Caregiving and Controlling Frustration-The Stresses of Caregiving.”
- “Caring for Someone with Incontinence: Emotional and Social Issues”

American Cancer Society - www.cancer.org

- “Seeking Help and Support - Grief and Loss”

Greater Good, Berkeley Publication

- “What is Compassion?” <https://greatergood.berkeley.edu/topic/compassion/definition>

The American Institute of Stress - www.stress.org

- “What is Compassion Fatigue?” - American Psychological Association
- “Controlling Your Anger Before It Controls You” - <https://www.apa.org/topics/anger/control>

BOOKS

- “*The Art of Empathy*” Karla McLaren
- “*Mind over Mood -Change How You Feel by Changing the Way You Think*” Dennis Greenberger, PhD, Christine A. Padesky, PhD
- “*The Four Agreements*” Don Miguel Ruiz
- “*Caregivers Path to Compassionate Decision-Making*” Viki Kind, MA
- “*What I Know For Sure*” Oprah Winfrey
- “*The Four Agreements*” Don Miguel Ruiz
- “*The Giving Tree*” Shel Silverstein

Section 4 – GUIDELINES FOR CAREGIVER GROUP DISCUSSIONS

Reflection Questions: Options to help with your group discussion.

List your 5 top priorities for creating a self-care plan: discuss reasons why these are important and your list of action items.

- **What situations tend to overwhelm you?**
- **What are your top 5 Caregiver stressors or trigger points?**
- **What happens when you are triggered and what do you do about it?**
- **Do you have difficulties setting boundaries and saying no to others?**

SAMPLE SELF CARE PLAN

- **Personal Support Team-Relatives, neighbors: speak to a friend each day**
- **Professional Support Team-Physician, Social Worker, Attorney, Financial Planners: ask for help when needed**
- **Time Management for Respite: Take a vacation, time off each day.**
- **Set a Daily Intention**
- **Go Outside Each Day, Need Sunshine**
- **Identify caregiver trigger points, coping strategies**
- **Track assumptive and hot thoughts: find alternative responses, practice, role play.**
- **Acknowledge accomplishments**
- **Develop Thresholds**
- **Set Boundaries: protect your time, energy, resources**
- **Declutter: let go of people, objects, commitments which do not enhance your well-being, but drain your energy.**
- **Join caregiver support group**
- **Seek professional mental health support for high risk behaviors: complicated grief, suicidal ideation, compassion fatigue, elder abuse and neglect.**

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