Essential Caregivers: 360º Activism

Balancing advocacy roles with being one's own champion.

Kara Barton,
MSW, LCSW, Clinical Instructor,
Keck School of Medicine

Dr. Monica Zell,
Clinical Assistant Professor of Medicine,
Keck School of Medicine

Type “**ME**” into chat

...if you ARE **essential** to your care recipient’s well-being, but if sometimes it feels as if no one is giving you credit for your caregiving expertise

and…
type "**FOR SURE**"
in the chat

…if caring for someone else, sometimes, feels as if it comes at the expense of caring for yourself

Today's All About MORE Balance...

Family Caregiver Experts & Authors

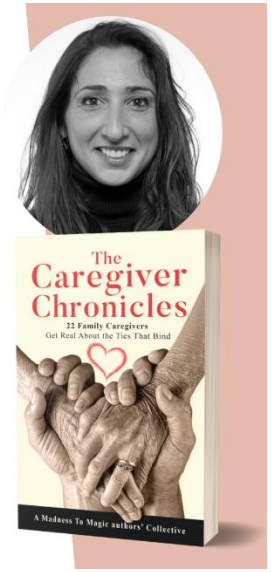
Mary

Susan

Karen

Out of everything bad something good can come."

Mary Barbato
Chapter 15:
The Space Between



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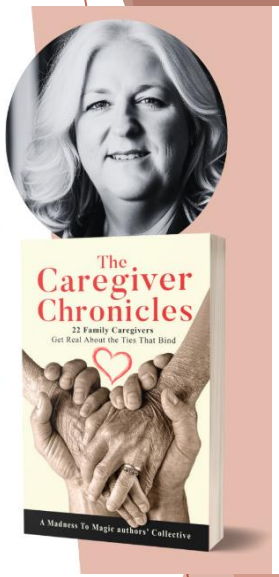

I am an Essential Support Person - if only to keep track of my mom's panties"

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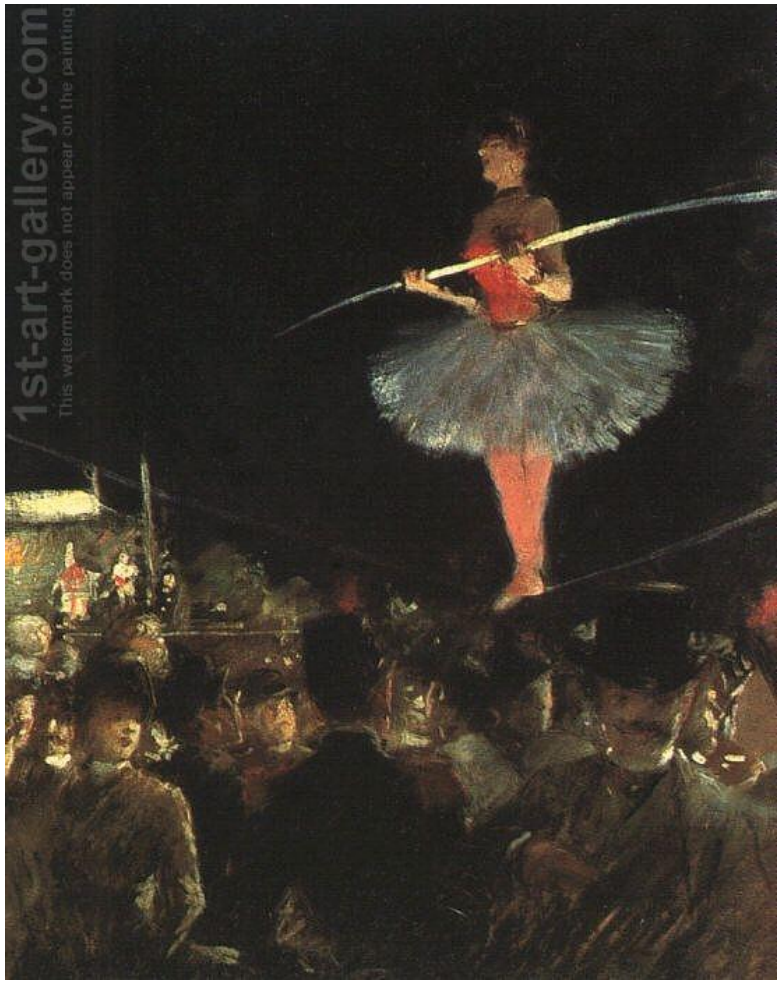
Chapter 13:
Through a Daughter's Eyes: Navigating the System

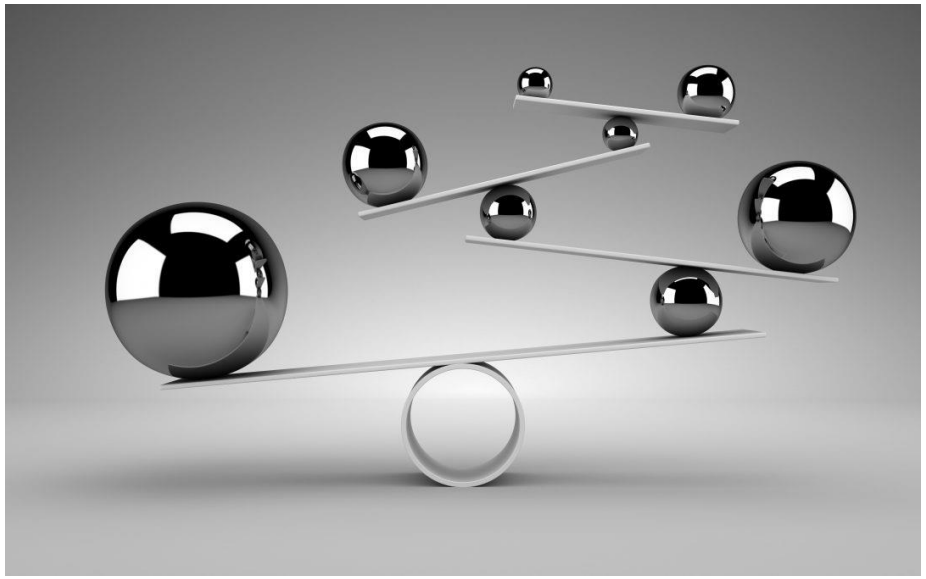
Life: A Balancing Act

November 13, 2024

Kara Barton, LCSW

Micro Balancing





Between selfish and selflessness

SELF-PRESERVATION

Aging and Illness

Part of being human

Changes that are involuntary

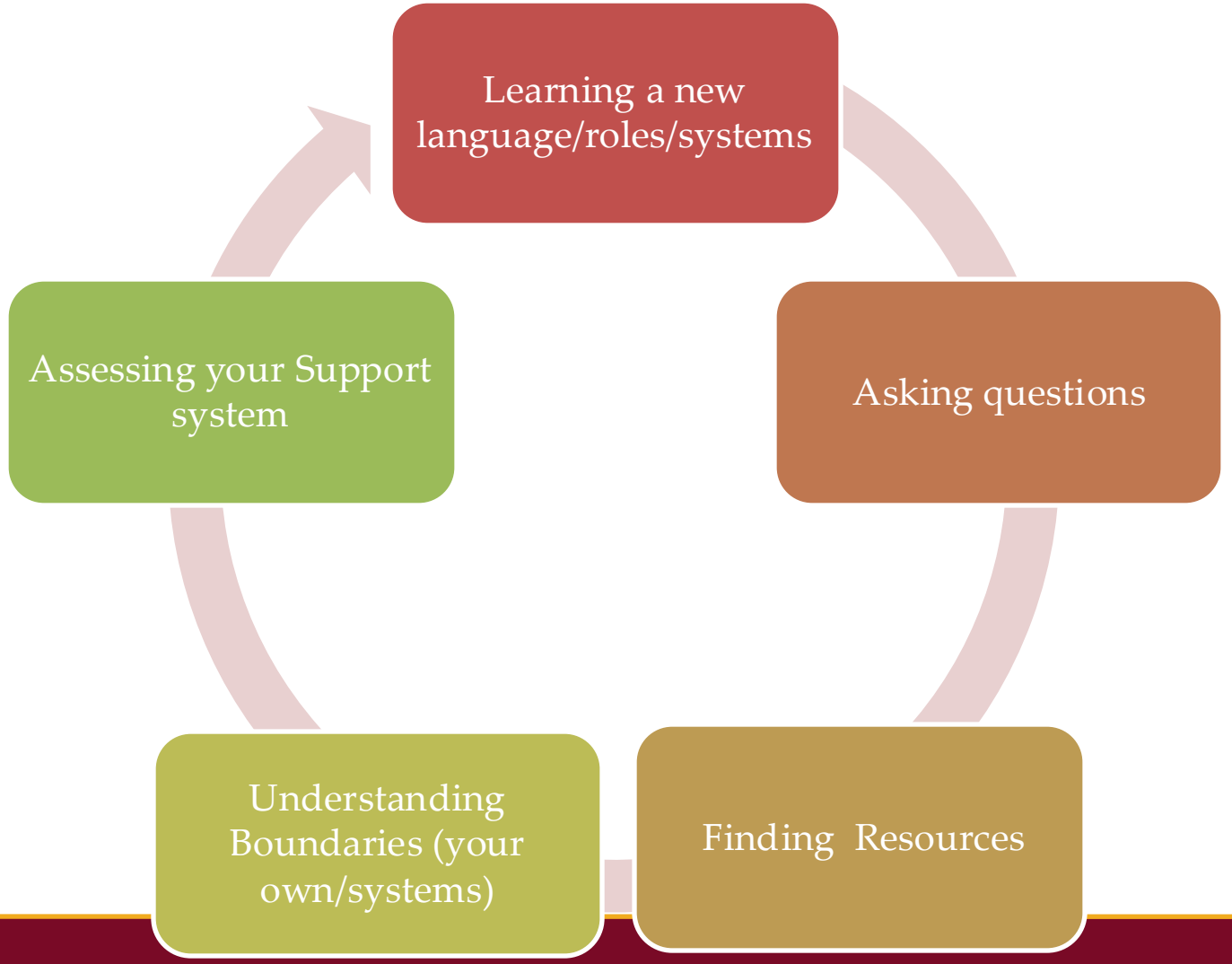
Challenge to sense of self

New needs and responsibilities

Changes in roles and expectations (self/others)

Plan to avert crisis

Caregiving: New Territory



Caregivers are ESSENTIAL

You are one of the Experts

You hold important parts of the whole

You are a witness to the issues your care recipient is experiencing

You are part of the network supporting the care recipient

Without YOU, the whole system could collapse

Question to our Family Caregiver Authors:

How do you feel hearing this?

What's been your experience?

Discernment

	Urgent	Not Urgent
Important	I (MANAGE) • Crisis • Medical Emergencies • Pressing Problems • Deadline-driven Projects • Last-minute Preparations for Scheduled Activities	II (FOCUS) • Preparation/Planning • Prevention • Values Clarification • Exercise • Relationship Building • True Recreation/Relaxation
	Quadrant of Necessity	Quadrant of Quality & Personal Leadership
Not Important	III (AVOID) • Interruptions, Some Calls • Some Mail & Reports • Some Meetings • Many "Pressing" Matters • Many Popular Activities	IV (AVOID) • Trivia, Busywork • Junk Mail • Some Phone Messages/Email • Time Wasters • Escape Activities • Viewing Mindless TV Shows
	Quadrant of Deception	Quadrant of Waste

Resources

- LA Caregiver Resource Center
- Center for Health Care Rights
- Counseling
- Meditation
- Social Support
- Time Management
- Discernment: Urgent/Important Quadrant

What's ONE THING so far that's hit home for you? Tell us in the chat...

A Holistic Approach to Caregiving
...through The Lens of A Palliative Care Physician

Dr. Monica Zell

More on Palliative Care vs. Hospice in an upcoming series…

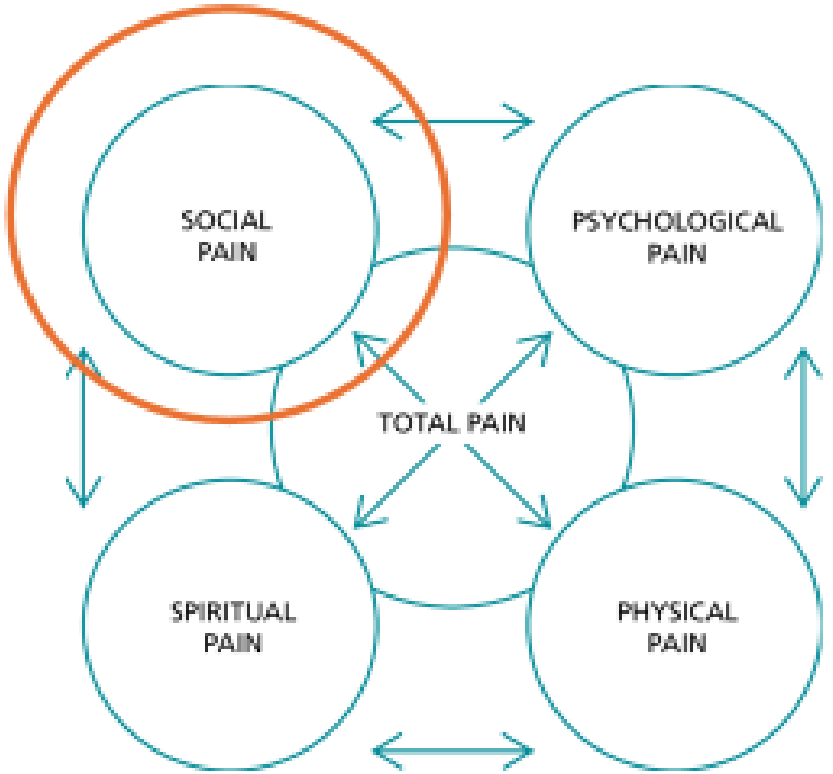
Palliative care = Supportive care

- Palliative care is not one thing:
  - HOSPITAL vs. CLINIC (outpatient) vs. HOME vs. FACILITY
  - Sometimes it is available **earlier in chronic illness course** vs. **towards end of life only**
  - Differences are based on geographic and provider availability, insurance coverage, variable provider knowledge about the potential benefits of involving palliative care earlier

As a Palliative Care physician…

- I have the privilege to walk alongside my patients ***and*** their essential caregivers through the most challenging journeys

- The concept of "total pain" guides my approach to holistic care of the patient/family/caregiver unit



As a Palliative Care physician…

- **Value** the family/caregiver's vital input and daily experience
- Work with family/caregivers to **strategize together** how to best support the patient and how to best support the family/caregiver
- Empower family/caregivers to **promote sustainability** and **resiliency**
- Explore what family/caregivers need from their providers and serve as a **sounding board** and an **advocate**

"We have two ears and one mouth so that we can listen twice as much as we speak."

Epictetus, Greek Philosopher
~ 100 AD

As a Palliative Care physician…

I try to assess and meet the ***variable needs*** of patients and their caregivers

Sometimes that looks like…

- Helping with **medication/symptom management**
- **Strategizing about action plans and resources** to "make it work" in the here and now
- Sharing **anticipatory guidance** about what the future may hold and things to consider along the way
- Providing **therapeutic support** in adjusting to uncertainty, lack of control, changing roles, grief over the loss of "normalcy"

Challenges/barriers in the system and with providers

- Our medical system is complex and overwhelming and far from perfect
- Providers have it rough, too

What can you do to care for yourself and advocate for your loved one?

- Ask about available resources – Palliative Care? Social work? Case management? Placement specialists?
- Come prepared to provider visits – write a list of updates/questions/needs
- Find care elsewhere if you do not feel providers are meeting your needs
- Seek out your own support – mental health, solicit help from community/family
- Remember that perfect is the enemy of good

“We do not have to become heroes overnight. Just a step at a time, meeting each thing that comes up, seeing it is not as dreadful as it appeared, discovering we have the strength to stare it down.”
- Eleanor Roosevelt

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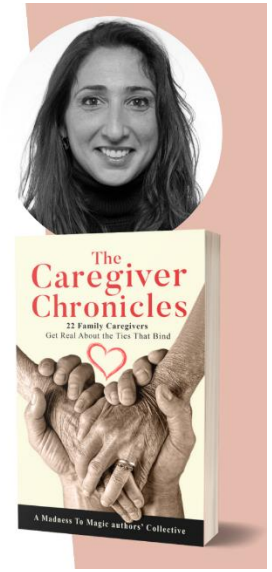

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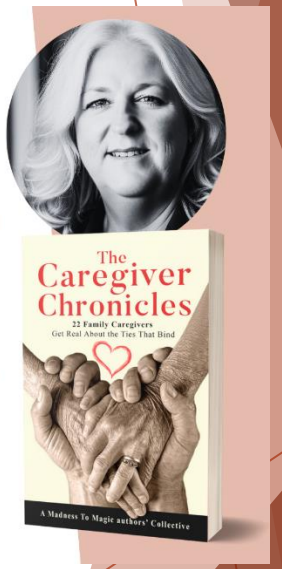

QUESTIONS?