Caregiver Connections
An Educational Webinar Series With The Experts
The presentation will begin shortly.
Thank you for your patience!
dukefamilysupport.org
919-660-7510

---

Through the Caregiver Journey:
Finding Purpose in the Pain

JENNA B. RENFROE, PH.D., ABPP
BOARD CERTIFIED NEUROPSYCHOLOGIST
OWNER, TAILORED BRAIN HEALTH

---

Caregiver burnout

- Caregiver burnout is real
- Significant relationship between the level of burden and:
  - the lack of free time
  - caregiver’s gender (higher in women – also significantly more women caregivers overall)
  - the number of hours devoted to day care
  - the number of years of patient care,
  - the degree of a caregiver’s self-esteem
  - the severity of the patient’s disease.

Caregiver burden, anxiety and depression were also related to neuropsychiatric symptoms in the patient – especially in pt’s with higher depression, anxiety, and apathy

- Burnout and depression is higher when the caregiver is a spouse (Grief)
- A metaanalysis of coping in caregivers showed a positive relationship between caregiver mental health and problem focused coping strategies, acceptance, and social-emotional support coping strategies.

- Poor outcomes were associated with wishful thinking, denial, and avoidance coping strategies.

Pudelewicz et al., 2019   Lou et al., 2015, Gilhooley et al., 2016
Outline

1. Caregiver Burden
2. Origins of Finding Meaning in Suffering
3. Post Traumatic Growth
4. “The 5 S's” = Strategies for Coping through the Caregiver Journey
   1. STOP
   2. SOOTHE
   3. STAND
   4. SEEK
   5. SAVOR

Slide 5

Growth emerges from pain and suffering

- Siddhartha emerged from pain, Sidschartha contemplating his own suffering
- “No mud, no lotus”

Slide 6

Growth emerges from pain and suffering

- Viktor Frankl, Jewish psychiatrist, WWII
- Those who lasted the longest in concentration camps were not the strongest or the fittest but those who were connected to a greater purpose in life.
- He channeled his values and natural talents to help his fellow prisoners and emerged to write his ideas.

“When we are no longer able to change a situation—
we are challenged to change ourselves.”

—Viktor E. Frankl
Slide 7

In this world you will have trouble. But take heart! I have overcome the world.

- John 16:33

Growth emerges from pain and suffering

Slide 8

POST TRAUMATIC GROWTH

#1) Increased appreciation for life
#2) More meaningful interpersonal relationships and greater sense of compassion for one another
#3) Increased sense of personal strength
#4) Changed priorities in life
#5) Richer existential and spiritual life.

Slide 9

Post Traumatic Growth

The MORE stressful the event is, the more likely posttraumatic growth is to occur.

Preexisting personal traits make people more prone to posttraumatic growth:

- Resilience/hardiness
- Extraversion
- Optimism

PTG is a process... a journey.
Model of the post traumatic growth process

- Comprehensive model of PTG (Tedeschi and Calhoun, 2004)

Five Steps – or the Five “S”s

- It’s a Journey
- STOP
- SOOTHE
- STAND
- SEEK
- SAVOR

STOP

When you are feeling overwhelmed, anxious, or burnt out:

S = Stop
T = Take A Breath
O = Observe, Explore with Kindness
P = Proceed
Slide 13

**STOP**

**Notice Your Struggle**

*One Must Imagine Sisyphus Happy*  
- Camus, Myth of Sisyphus

---

Slide 14

**The Reality Slap & The Reality Gap**

- **THE REALITY SLAP**: living for a loved one with dementia (no one expects that!)
- **THE REALITY GAP**: how you think about yourself and your life, how you expected your life to go or how it was going prior to the onset of the illness

---

Slide 15

**The Larger The Gap – The More Struggle**

- With a small gap, you may feel:
  - Anxiety
  - Frustration
  - Sadness

- With a massive gap, you may feel:
  - Anguish
  - Despair
  - Panic
  - Resentment
Whenever there is a gap between what we want or how we wish our life was, and how it actually is—the tendency is to struggle AGAINST THAT.
Slide 19

Suffering = Pain X Resistance

Slide 20

We Are So Busy Struggling, We Are Consumed

- Consequently, we miss out on LIFE.
- And the more we struggle, the more it takes us DOWN.
- What is the FIRST THING you have to do to prevent yourself from sinking?
- The very first thing we have to do to improve our coping as a caregiver is to let go of the struggle.

Slide 21

Let Go of the Struggle

- In order to move forward and live a rich and fulfilling life in spite of our difficult circumstances, the first step is letting go of the struggle against what is happening
- IMPORTANT TO KNOW: this is not a ONE-TIME event, it will be necessary to remind yourself to do this again and again.
Dropping Anchor

- Drop Your Anchor (Come into Your Body, The Present Moment.)

- Do this with me now...

Assume a firm but comfortable position.
- Plant your feet into the floor, sit upright in your chair.

Have a stretch.
- Notice any thoughts, sensations.

Identify 3 things you can see.
- Notice any thoughts, sensations.

Come back to the room and what you were doing.

Five Steps – or the Five “S”s

- STOP
- SOOTHE
- STAND
- SEEK
- SAVOR
Slide 25

**SOOTHE**

- Acknowledge your struggle... but let go of the struggle against it.
- Acknowledge your pain associated with this situation.
- Allow the pain.
- Accommodate your stress and your pain.
- Learn to be your own best friend.
- Sounds cheesy, but...

Slide 26

**Who Is the One Human Being In Your Life Who Can:**

- Always be there for you, in any moment, no matter what happens?
- Understand, validate and empathize with your pain better than anyone else on the planet?
- Truly know just how much you are suffering?

Slide 27

**You Are.**
Unfortunately, we often relate to ourselves in a highly critical manner:

- **Inner Critic**
- Trivializing/minimizing, critical, condescending, dismissive or unsupportive
- Counterproductive

Self-compassion involves three main components:

1. **Mindfulness** (as opposed to suppression or magnification/over-identification)
2. **Common Humanity** (as opposed to isolation) (the reality that everyone suffers)
3. **Self-kindness** (as opposed to self-judgment/criticism)

Some ways to do this:

- Ask yourself: What is showing up for me? What do I need in this moment?
- Ask yourself: What would I say to a friend or a loved one in the same situation?
- Offer yourself a self-compassion statement or mantra: e.g., "This is very painful right now. This is a moment of suffering. I offer myself warm and understanding to this moment. What is in this moment helpful?"

Self-compassion resources:

- Kristin Neff, Ph.D., is a leading researcher/teacher in this field
- Check out [www.self-compassion.org](http://www.self-compassion.org) for a list of tools, resources, including guided meditations.
Five Steps – or the Five “S”s

- STOP
- SOOTHE
- STAND
- SEEK
- SAVOR

STAND

A Roadmap for how you want to live

- STEP 1: Identify What Matters
- STEP 2: Live With Intention

STANDING = COMMITTED ACTION
Slide 34

- Our VALUES act as a COMPASS on the journey of life.
- They show us the way to pivot or move, and help to inspire and motivate us.

Slide 35

Do a little exercise...

- Imagine some time in the future, Looking Back...
- Imagine that you have handled this “challenge” in the best possible way, behaving like the person you really want to be, deep in your heart. From that perspective, answer these questions:
- What did you stand for in the face of this? For example, did you stand for courage, kindness, compassion, persistence, caring, supportiveness, love?
- How did you treat yourself as you dealt with this?
- How did you treat others that you care about?

Slide 36

The Choice Point

We are either making choices that move us TOWARDS the kind of person we want to be and what we want for our lives, or away.

When we are "HOOKED" (struggling/resisting), we can easily get pulled into doing AWAY MOVES, actions that move us away from what we want for our lives.

The goal is to develop coping skills to be less "HOOKED" by our circumstances/difficult thoughts and feelings, which will enable us to make more frequent TOWARDS MOVES.
To Make Towards Moves

- We have to use coping skills to address the difficult emotions such as anger, fear, grief, depression, grief.
- This might mean deep breathing, meditation, yoga, journaling, sharing your thoughts or writing lists of them and choosing the story, thinking it through, meeting with a mental health professional... etc.
- By properly addressing stress and underlying thoughts and emotions, we free up mental space to be able to make more conscious "towards moves" that are in alignment with our values.

Five Steps – or the Five “S”s

- STOP
- SOOTHE
- STAND
- SEEK
- SAVOR

SEEK

- "Seek and you shall find..."
- Continue to seek your purpose
- Search for the meaning in the storm you are going through
- Ask yourself the following questions:
  - How can I learn or grow from this experience?
  - What personal qualities can I develop during this time?
  - What practical skills might I learn or improve upon?
- Spiritual seeking (remember how this was linked to post-traumatic growth?)

This Photo by Unknown Author is licensed under CC BY-NC
Slide 40

Five Steps – or the Five “S”s

- STOP
- SOOTHE
- STAND
- SEEK
- SAVOR

---

Slide 41

Appreciate and Savor

- As you begin to live with intention and in the moment, savor the fruits of your labor.
- Soak in a sense of loving kindness towards yourself.
- Treasure the small, ordinary moments whenever you remember to do so.
- The more present we are, the more gratitude is born, and the greater our sense of privilege and fulfillment.

---

Slide 42

SAVOR

- CHOOSING TO BE PRESENT
- FINDING THE HIDDEN TREASURE
- STAYING GROUNDED
- DISCOVERING SMALL VICTORIES
- SHARING COMPASSION & CONNECTION
- FILLING YOUR SPIRIT
- FINDING PURPOSE IN THE PAIN

---
“There is as much life in a moment of pain as in a moment of joy.”
– Steven Hayes
Creator Of ACT

Slide 44

Thank you!

Dr. Jenna Renfroe

Slide 45

Tailored Brain Health

@tailoredbrainhealth
Phone: 336-542-1800
info@tailoredbrainhealth.com
www.tailoredbrainhealth.com
DUKE DEMENTIA FAMILY SUPPORT PROGRAM

Caregiver Connections
An Educational Webinar Series With The Experts

Thank you for joining us today!

dukefamilysupport.org
919-660-7510