

From Survive to Thrive: Tips for living well with a chronic illness

This webinar will start shortly

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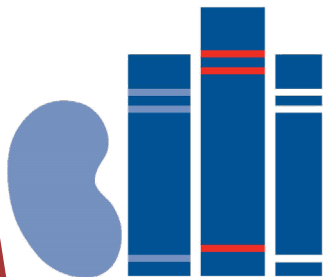
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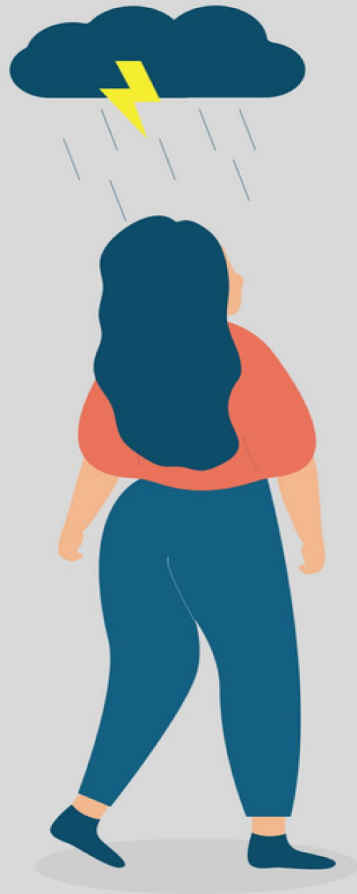
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Reminders

- All lines are muted
- Ask questions or make comments through the Chat Box
- Written questions will usually be answered at the end of the program
- You will receive the link to the **recording** and **slides** within a week
- Please complete the feedback form at the end of the program





2:00 pm EST



May 26, 2022

From Survive to Thrive: Tips for living well with a chronic illness

Mana K. Ali Carter, PhD

Rehabilitation Psychologist

Medstar National Rehabilitation Hospital

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Themes

Burnout

Grief

Coping with uncertainty

Balancing it all

Resilience

if you're reading this:

RELEASE YOUR SHOULDERS
away from your ears

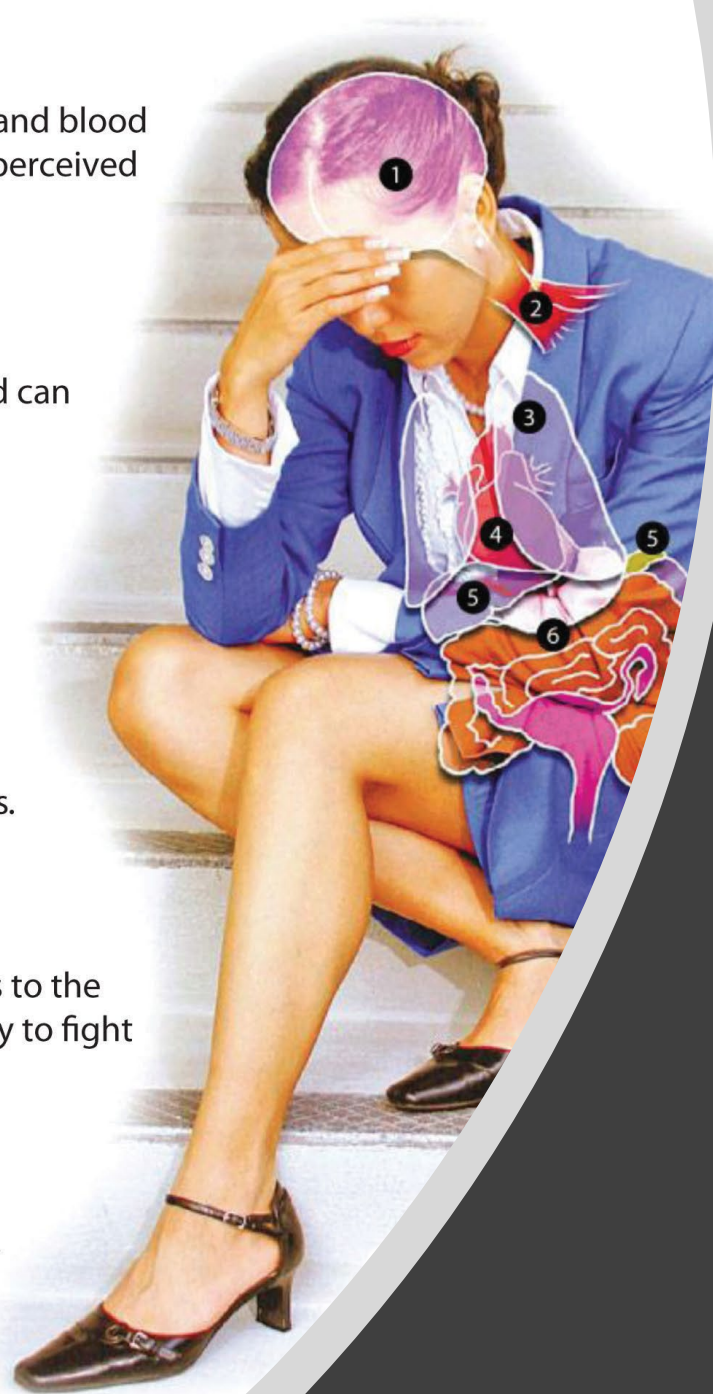
UNCLENCH YOUR JAW

DROP YOUR TONGUE FROM
the roof of your mouth



Adapted from: Watson, P., Gist, R., Taylor, V., Evlander, E., Leto, F., Martin, R., Vaught, D., Nash, W.P., Westphal, R., & Litz, B. (2013). Stress First Aid for Firefighters and Emergency Services Personnel. National Fallen Firefighters Foundation.

- 1 Nervous system.** The heart may beat faster, and blood pressure rises to ready the body to fight the perceived threat.
- 2 Musculoskeletal system.** Muscles tense and can trigger tension headaches.
- 3 Respiratory system.** Breathing quickens.
- 4 Cardiovascular system.** Heart rate increases.
- 5 Endocrine system.** Signals sent from glands to the body cause a release of cortisol into the body to fight the perceived threat.
- 6 Gastrointestinal system.** Eating habits may change, and the feeling of "butterflies" in your stomach may occur.



Stress Response



Prolonged Stress

Can result in physical and psychological conditions

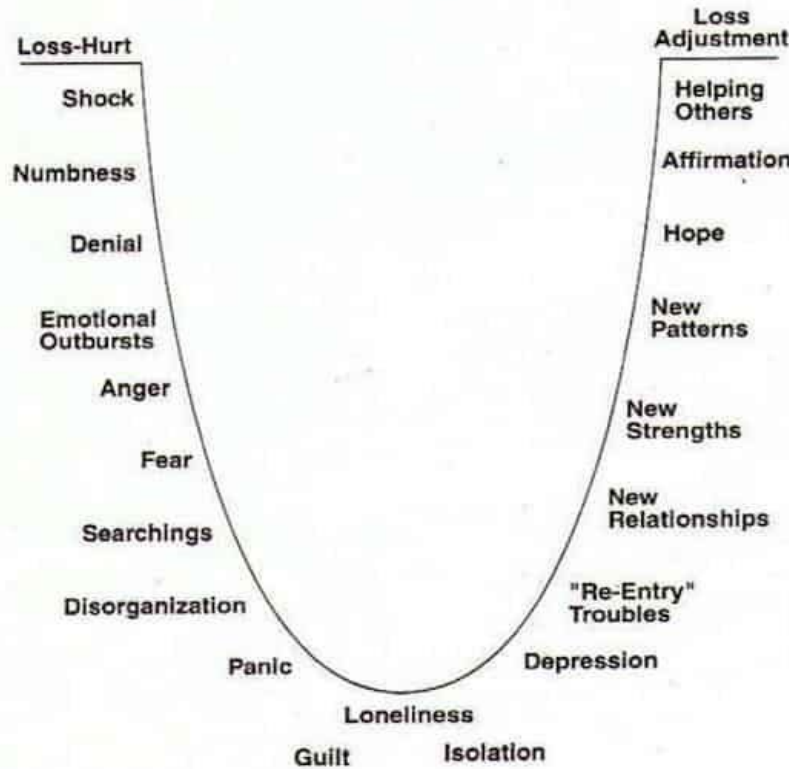
Can occur when situations are unpredictable and uncontrollable

Can create stress in other domains of life (e.g., relationships, work, health habits)

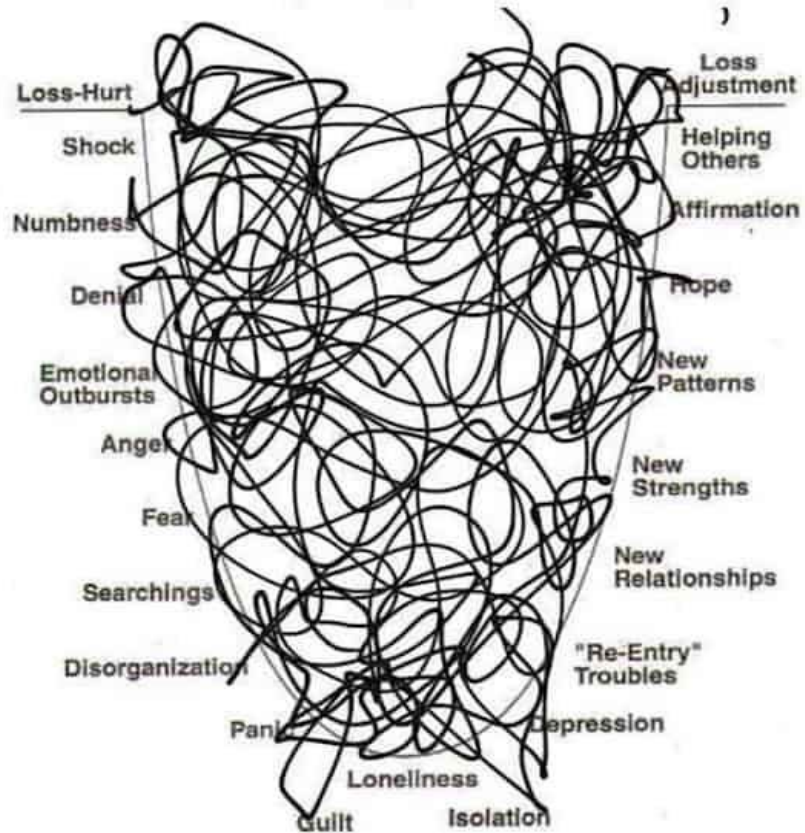
Can result from tasks that require high level of vigilance and decision making (e.g., medical treatments, dietary requirements, managing dialysis and medical appointments)

Grief and Anticipatory Grief

STAGES OF GRIEF



My experience

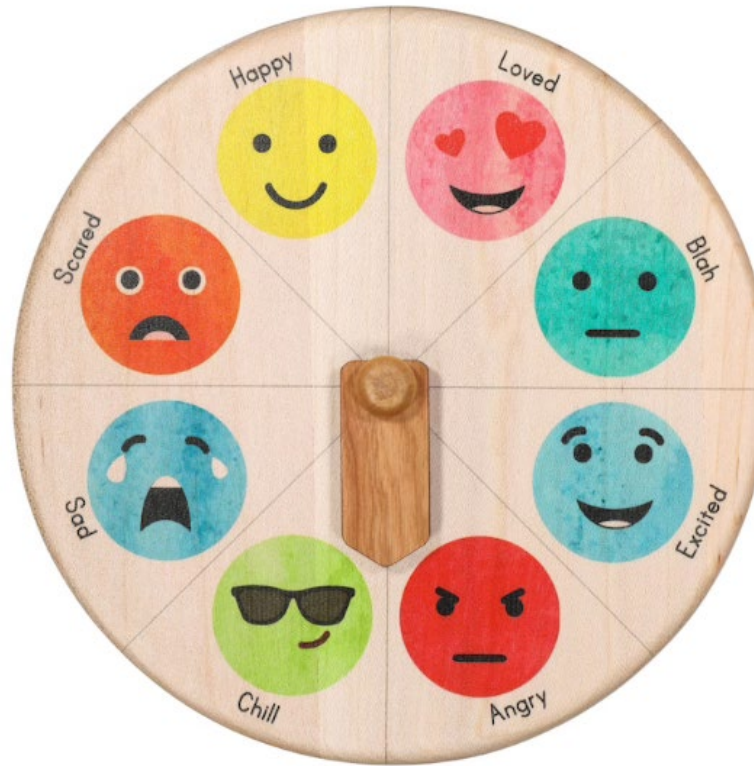




The Pandemic Added to the Pile

- Added responsibilities (e.g., grocery shopping, disinfecting)
- Caution fatigue
- Changing dynamics with providers due to teletherapy
- Limited opportunities for personal well-being and social isolation
- Changing support (e.g., health aides, new caregiver roles for loved ones)

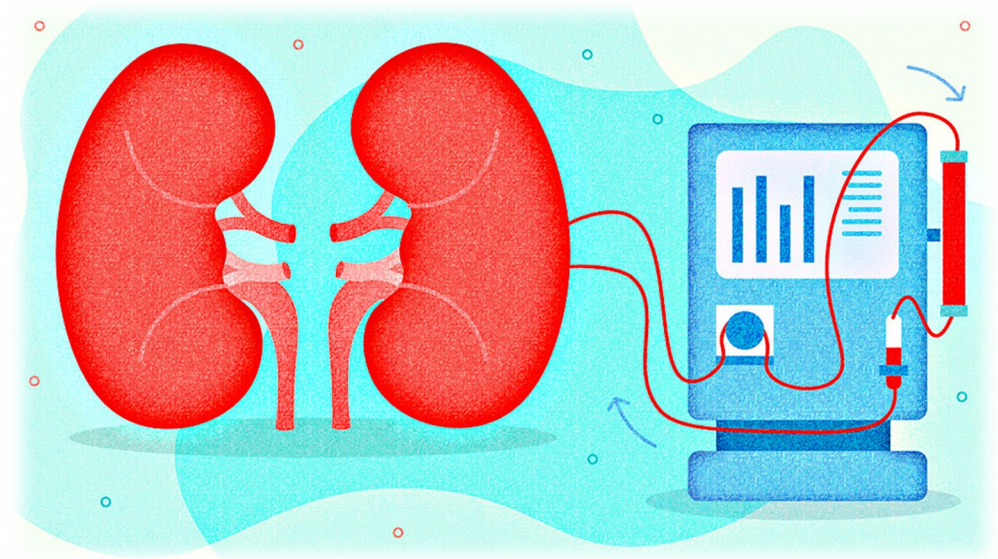
Emotional Responses to Kidney Disease



- Mixed emotions
- CKD: 25% depression and 20% anxiety symptoms
- Peritoneal dialysis report poorer physical health yet higher satisfaction with care vs. community-based hemodialysis
- About 35% of individuals on dialysis report depression compared with about 13% of those not on dialysis
- Quality of life improves 6 and 12 weeks after starting dialysis

Stress with Kidney Disease

- Complications of renal replacement therapies (e.g., tired, dry skin, itching, numbness/tingling, pain)
- Decreased interest in pleasurable and meaningful activities
- Inability to work and change in life plans
- Feeling “like a burden”



Factors Associated with Distress

Females report
higher symptoms

Family,
connectedness
social support

Quality of care
(e.g., availability
of education,
resources)

Sleep disorders

Spirituality

Exercise

Diagnosed at
stage III of CKD
or above

Reported Caregiver Stress

- Duration and amount of care provided
- Duration and frequency of dialysis, and treatment modality
 - Mixed results, though frequency of dialysis and caregiver stress have been found
 - Higher in caregivers of those receiving hemodialysis compared with caregivers of those receiving peritoneal dialysis, renal transplant or not yet receiving dialysis
 - Lower in caregivers of those had a kidney transplant history
- Quality of life decreases at the start of loved ones' treatment but returns after 12 weeks



Positive Effects of Caregiving

- Feel needed
- Provides meaning
- New skills
- Strengthened relationships with others
- Feelings of accomplishment and self-efficacy
- Some evidence that helping others can lower mortality by 5 years



Factors Associated with Caregiver Stress

Socioeconomic status, lower more affected

Prior health status

Older age more affected

Females more affected

Marital status, single more affected

Availability of support (e.g., resources, social, dialysis nurses)

Care recipient's behavior, cognitive, and functional abilities

Relationship between caregiver and care recipient, spousal relationships more affected

Perception of care recipient's suffering

Spirituality

Recognizing Distress

- Those with kidney disease
 - don't disclose to nursing staff
 - feel unprepared for emotional distress
- Only 56% of caregivers aware of their tendency toward depression



Burnout Signs: What are yours?

- **Emotional:** worry, fear, irritability, sadness, depression, anger, mood swings, guilt, helplessness, hopelessness
- **Cognitive:** difficulty concentrating, trouble remembering, feeling confused, feeling stuck
- **Physical:** back pain, muscle tension, headache, changes in appetite, sleep disturbance, fatigue
- **Behavioral:** increased substance use, increased pacing, snapping at loved ones, withdrawing, poor self-care, giving up, limited meaningful activity participation



From Surviving To
Thriving...

Imagine your Experience

Happy

Sad

Frustrated

Tired

Thriving

Feeling “negative” emotions and resilience can exist at the same time!

Resilience

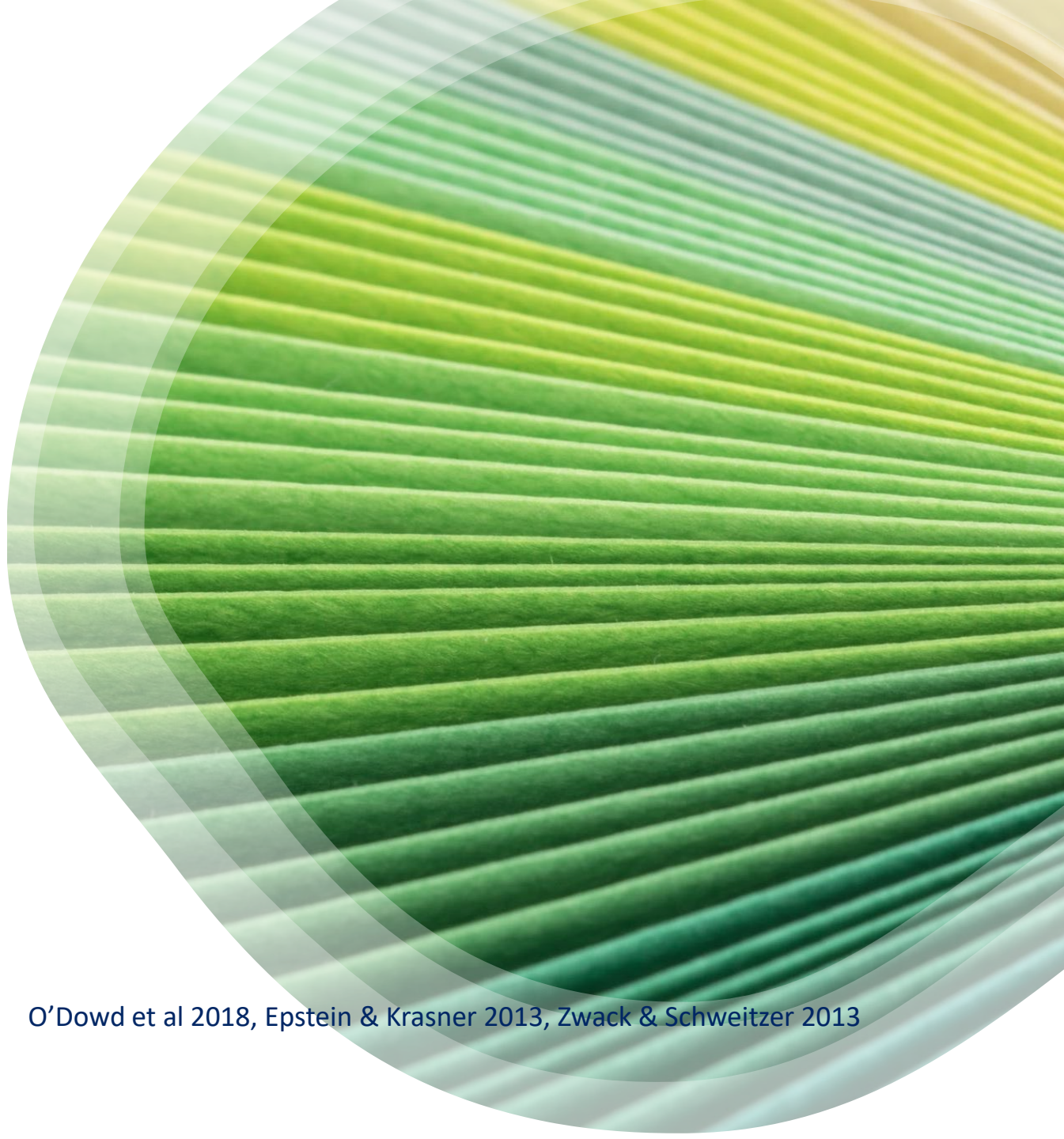
Central element of well-being

Ability to respond to stress in an adaptive way

Bounce back and grow from challenges

Resilience can be developed

- Self awareness and self-monitoring
- Self-regulation and coping



Factors that Promote Resilience





Practical Tips

Ask questions and for adapted information

Ask for help

Never worry alone

Support groups, information, and other resources

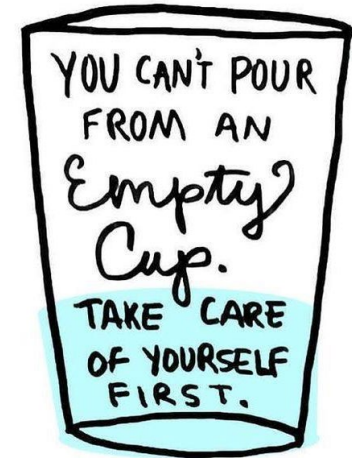
- National Kidney Foundation
- Dialysis Patient Citizens

“Self-care is not
self-indulgence, it is
self-preservation.”

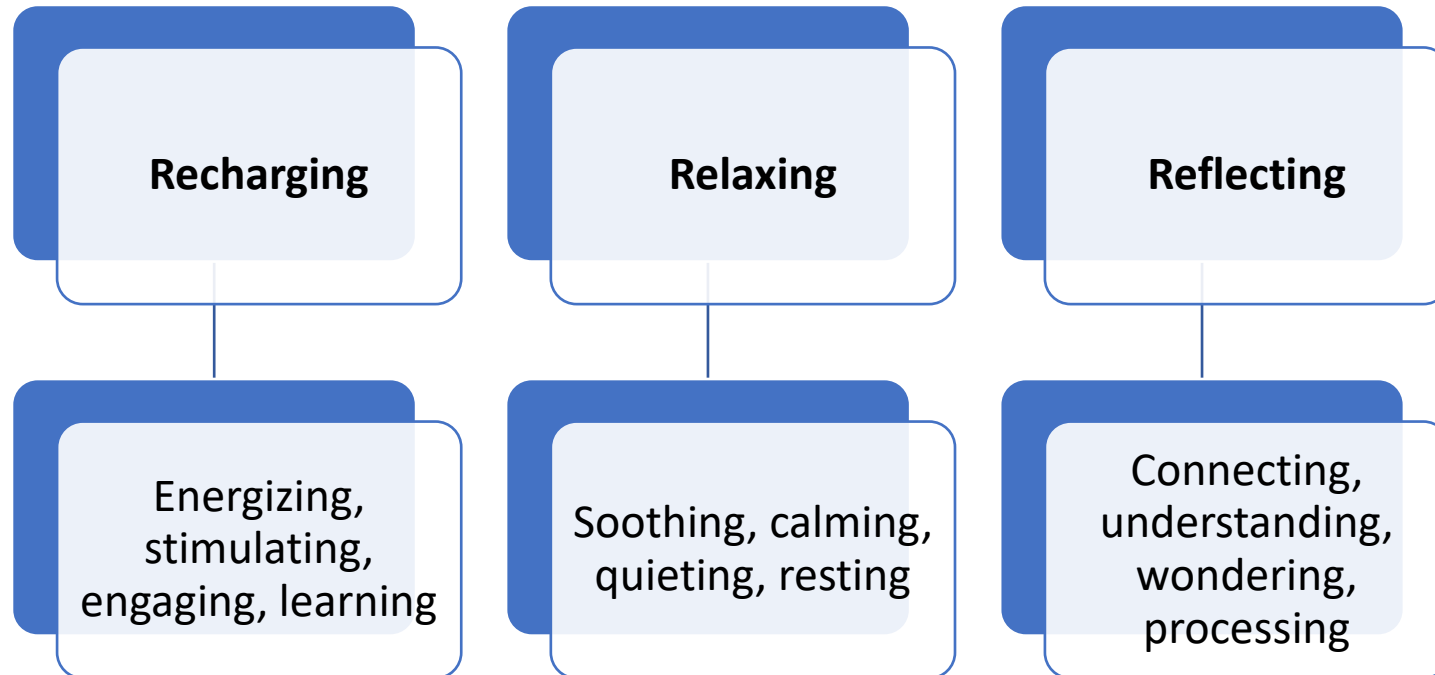
AUDRE LORDE
feminist and civil rights leader



THE Healthy



What kind of self-care do you need?





Put your ideas in the chat!

Balancing Life: *Values, Purpose and Meaning*

- Looking forward
- Looking back
- Setting intention for each day

Jar



Rocks



Pebbles



Sand



Time

Life

Priorities

Importance

Urgencies

Small Tasks

Distraction

Leisure

Manage Expectations

- Stress management vs. stress elimination
- Living with uncertainty vs. eliminating uncertainty





Cultivate Awe

Look for beauty everywhere and in everything

Be amazed by an invention or innovation

Notice something tiny and something huge

Look at the sky

Go for a walk/wheel and see something new

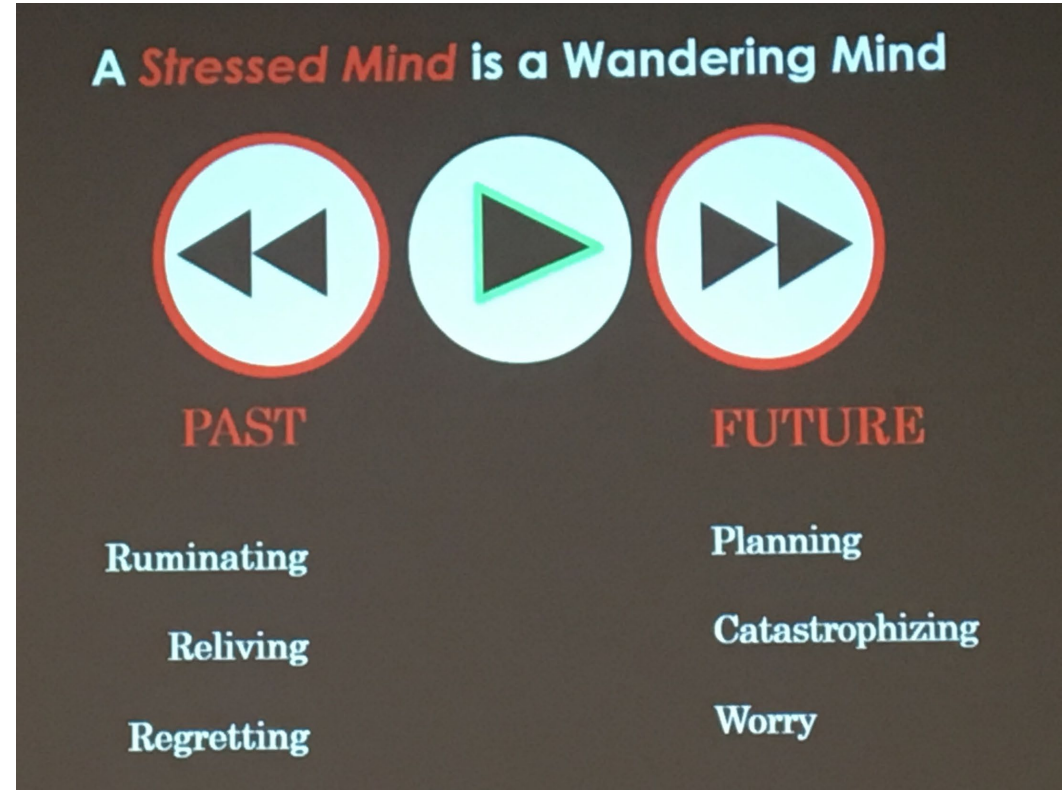
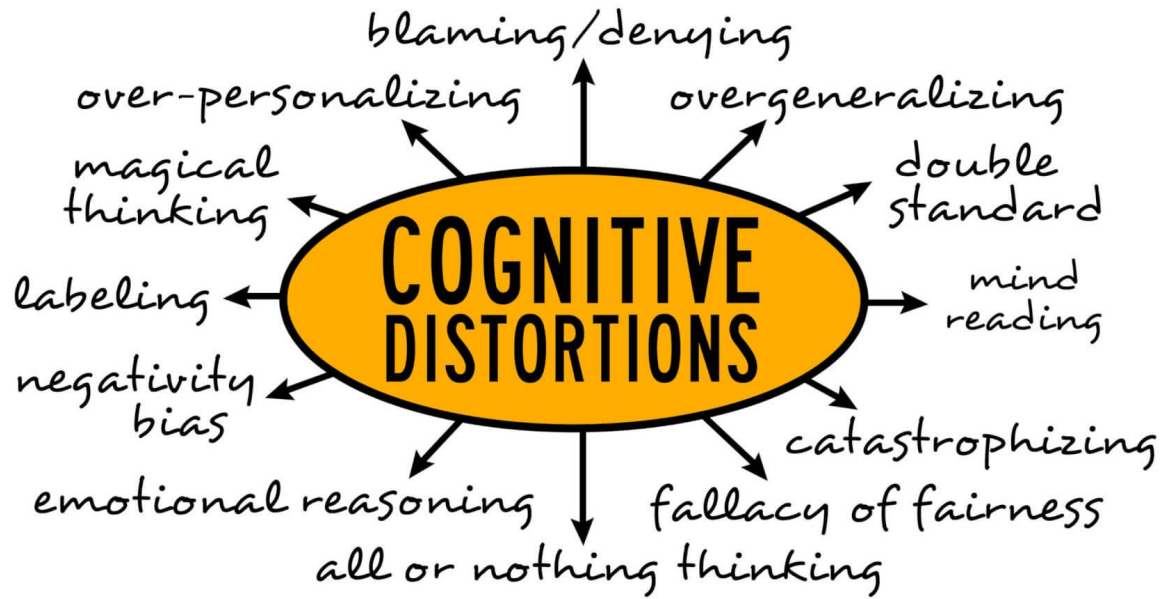
<https://www.window-swap.com/Window>



3 good
things

Gratitude

- Three Good Things/Blessings
(by Martin Seligman)
- Each day:
 - Think of three good things that happened or three blessings.
 - Write them down.
 - Reflect on why they happened.



Avoid Stinkin' Thinkin'

- Thoughts are not truth
- Watch out for a wandering mind
- Be an observer of your thoughts
 - "I notice I am having the thought...."

Question you Thoughts

- I've lost everything!

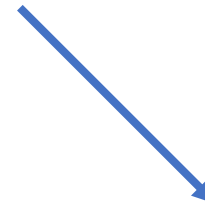
- I've lost everything?

Reasons why I think this?



Employment
Independence....

Reasons why this is NOT true?



Family/friends
My body is working is
hard
I've gained gratitude...

I've lost [somethings]; I've found [somethings]

Self-Compassion



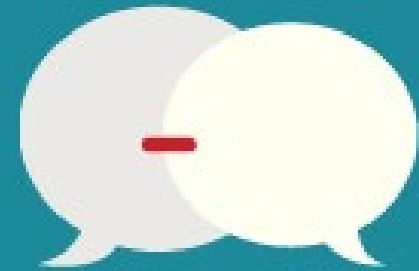
Mindfulness

Self-compassion involves recognising when we're stressed or struggling without being judgmental or over-reacting.



Self-Kindness

Being supportive and understanding towards ourselves when we're having a hard time, rather than being harshly self-critical.



Connectedness

Remembering that everyone makes mistakes and experiences difficulties at times. We are not alone!

Thank you!

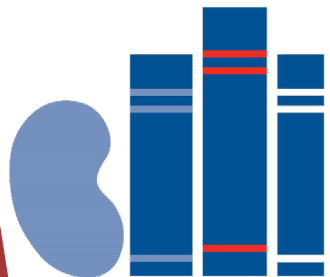




Questions?



Please use the Chat Box
Email Dr. Mana K. Ali Carter
Mana.K.Carter@medstar.net



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