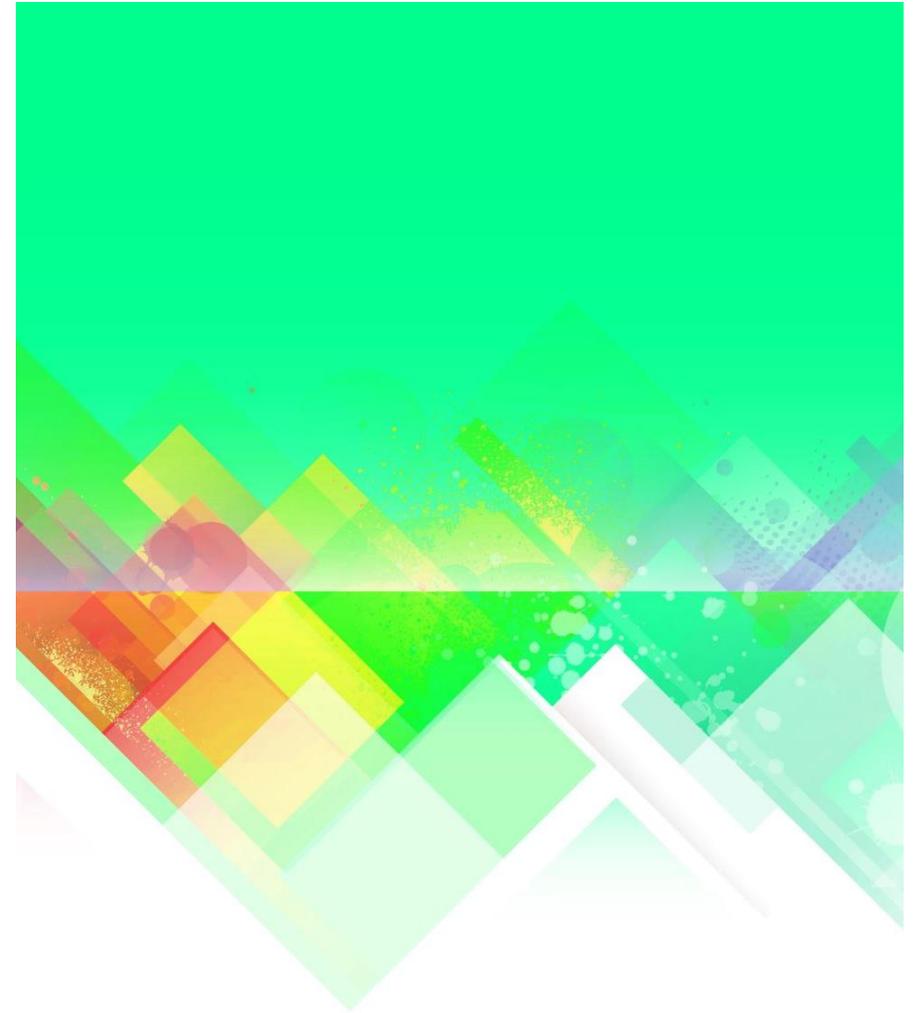


The Zebra is Gray: Living and Thriving with Rare and Chronic Medical Illness

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Gaucher Community Alliance
Patient and Family Conference
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Agenda

Trauma and Chronic Medical Illness

Trauma and Stress

What Can We Do: Strategies

Trauma and Chronic Medical Illness

The Trauma of Being Sick

- Physical effects of diagnosis
 - E.g., Pain/Chronic Pain, insomnia, GI sx, brain fog, fatigue
- Physical effects of medications
 - E.g., energy changes, weight changes, fatigue, other medical issues, feeling “not like self”
- Emotional effects of illness
 - E.g., Depression, anxiety, panic
- Stress 2/2 interaction with healthcare system
 - E.g., Minimizing of patient experience, not accessing adequate care, gaslighting
 - Start with believing patients*

What is Trauma?

Which one(s) describe your experience?

A deeply distressing or disturbing experience

A serious injury or shock to the body, as from violence or an accident

An emotional wound or shock that creates substantial, lasting damage to the psychological development of a person

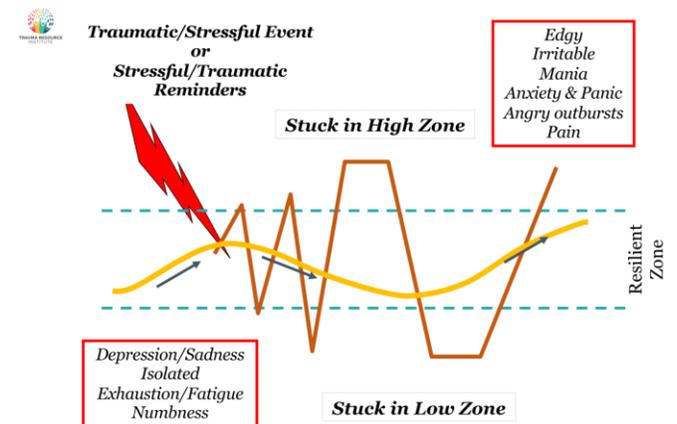
Individual may be a witness or a victim

How we **experience** an event v. the event itself (Mead, 2018)

Results from an event, series of events, or set of circumstances experienced by an individual as physically or emotionally harmful or threatening, and that has lasting and adverse effects on the individual's functioning and physical, social, emotional or spiritual well-being. **In sum, trauma is the sum of the event, the experience, and the effect.** (SAHMSA)

Important Trauma Concepts

- Homeostasis
- Fight, flight, freeze, fawn
- Hyperarousal v numbness/depression (mouse in the maze)
 - Miller-Karas, Trauma First Aide
 - Both responses are about trying to restore safety/homeostasis
 - Neurons that fire together, wire together
 - Emotions are data
 - Epigenetics, neuroplasticity



Common symptoms following trauma exposure

Table CORE - 1 Common Signs & Symptoms Following Exposure to Trauma

Physical	Cognitive/Mental	Emotional	Behavioral
<ul style="list-style-type: none"> • Chills • Difficulty breathing • Dizziness • Elevated blood pressure • Fainting • Fatigue • Grinding teeth • Headaches • Muscle tremors • Nausea • Pain • Profuse sweating • Rapid heart rate • Twitches • Weakness 	<ul style="list-style-type: none"> • Blaming someone • Change in alertness • Confusion • Hyper-vigilance • Increased or decreased awareness of surroundings • Intrusive images • Memory problems • Nightmares • Poor abstract thinking • Poor attention • Poor concentration • Poor decision-making • Poor problem solving 	<ul style="list-style-type: none"> • Agitation • Anxiety • Apprehension • Denial • Depression • Emotional shock • Fear • Feeling overwhelmed • Grief • Guilt • Inappropriate emotional response • Irritability • Loss of emotional control 	<ul style="list-style-type: none"> • Increased alcohol consumption • Antisocial acts • Change in activity • Change in communication • Change in sexual functioning • Change in speech pattern • Emotional outbursts • Inability to rest • Change in appetite • Pacing • Startle reflex intensified • Suspiciousness • Social withdrawal

Acute stress v. post-traumatic stress

Acute Stress Disorder (ASD)

- Stress occurs within 1 month of initial trauma
- Duration: 2 days to 1 month
- Symptoms include:
 - 1 reexperiencing sx
 - Marked avoidance
 - Marked anxiety
 - Evidence of significant impairment
- ASD considered a predictor of PTSD, although not a precursor (APA, 1994)

Post-Traumatic Stress Disorder (PTSD)

- Stress can occur from 1 month to several years after initial trauma
- Duration: from 1 month
- Symptom types include:
 - Intrusion
 - Avoidance
 - Cognitive & mood changes
 - Arousal & reactivity changes

Case example: post-traumatic stress and cancer (Jane)

- Jane was diagnosed with metastatic breast cancer at age 64. She had previously been treated for BC 3 years prior. She was referred to a health psychologist for symptoms of depression and anxiety. Upon evaluation, she endorsed experiencing significant anxiety intrusive memories of her previous experiences when entering the hospital for chemotherapy. Because of this, she would arrive late for her appointments or sometimes cancel or reschedule at the last minute. She declined information for a support group because "other people's stories make me anxious." She further identified persistent decreased mood, motivation, difficulties with sleep and concentration, and hyper-awareness of somatic sensations.

Trauma and Stress

How Does Stress Impact Our Bodies?

- Inflammation
 - Increases cortisol
 - suppresses non-essential functions eg immune response, digestion
 - Increases glucose production (boosts energy to large muscles)
 - Decreases insulin
 - Narrows arteries (raises blood pressure, harder to pump blood to extremities in order to protect core organs)
 - Increases adrenaline (to increase heart and respiratory rate, send more oxygen to large muscles)
 - Decreases lymphocytes (white blood cells that fight infection/part of immune system)
 - Increases pro-inflammatory cytokines (become upregulated/part of normal response when stress is chronic)-creates regular low-levels of inflammation in body (depression, fatigue, decreased enjoyment)

How Does Stress Impact Our Bodies?

- Neurotransmitters = chemicals that carry messages from nerve cells to other cells, usually to increase or decrease certain actions
- Increased cortisol can deplete
 - Serotonin: affects mood, learning, appetite, sleep, impulse control
 - Dopamine: affects energy, motivation
- Epinephrine: affects heartrate, breathing, energy
- Adrenaline: heartrate, blood flow, heightened awareness

NEUROTRANSMITTERS

ADRENALINE fight or flight produced in stressful situations. Increases heart rate and blood flow, leading to physical boost and heightened awareness.	GABA calming Calms firing nerves in the central nervous system. High levels improve focus, low levels cause anxiety. Also contributes to motor control and vision.
NORADRENALINE concentration affects attention and responding actions in the brain. Contracts blood vessels, increasing blood flow.	ACETYLCHOLINE learning Involved in thought, learning and memory. Activates muscle action in the body. Also associated with attention and awakening.
DOPAMINE pleasure feelings of pleasure, also addiction, movement and motivation. People repeat behaviors that lead to dopamine release.	GLUTAMATE memory Most common neurotransmitter. Involved in learning and memory, regulates development and creation of nerve contacts.
SEROTONIN mood contributes to well-being and happiness. Helps sleep cycle and digestive system regulation. Affected by exercise and light exposure.	ENDORPHINS euphoria Released during exercise, excitement and sex, producing well-being and euphoria, reducing pain

How Does Stress Impact Our Bodies?

- Sleep Stages/alpha waves
- Neuroplasticity
- PNI

- Distress v Eustress

What Can We Do: **Strategies**

What Can We Do to Minimize the impact of Stress on Our Bodies?

- Sleep
- Breathe
- PMR
- Ground
- Mindfulness
- Visualization
- *Diet/Movement (not today)*

What Can We Do: Sleep

- Strategies:
 - Sleep hygiene
 - Sleep quotient

What Can We Do: Breathe

- Strategies:
 - Mindful breathing
 - Diaphragmatic
 - 4 square

What Can We Do: Muscle Relaxation

- Strategies:
 - Progressive muscle relaxation
 - Shortcuts
 - Paradoxical technique

What Can We Do: Grounding

- How does grounding sleep improve stress indicators?
- Strategies:
 - 5 senses exercise

What Can We Do: Mindfulness

- Mindfulness: success = process, not outcome (ie increased awareness of monkey mind, not mythical calm state)
- Strategies:
 - Breathing
 - Walking*
 - Eating - raisin/Hershey kisses*

What Can We Do: Visualization

- Strategies:
 - My river visualization

Why Do These Strategies Work?

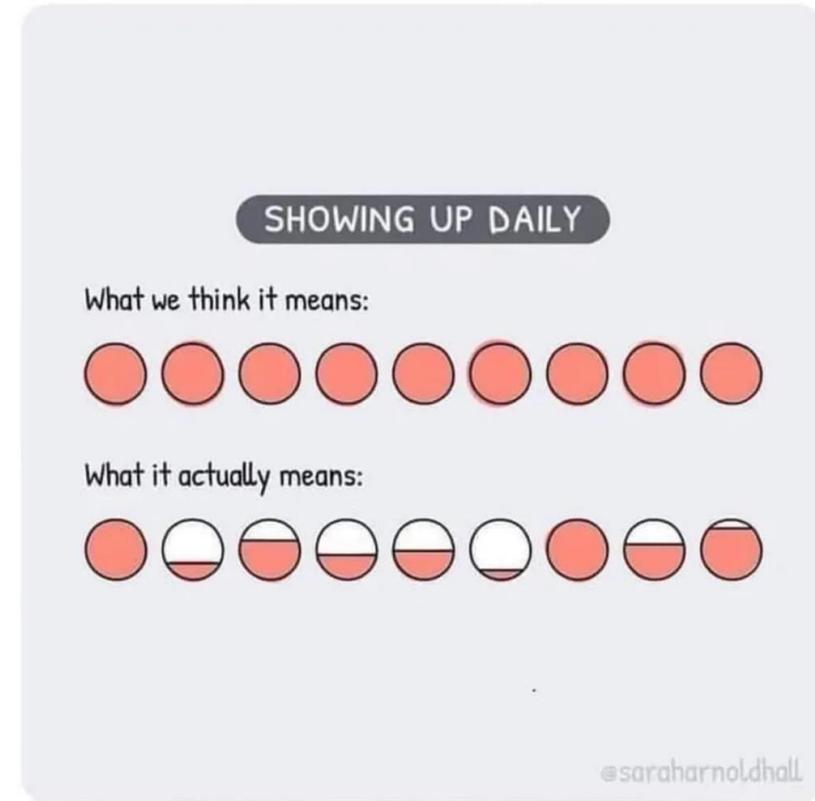
- Present moment
- Being in body in positive ways
- Disconnect from thoughts/emotions and focus on physical ways to reduce stress
- Address the chemical contributors to stress
- Move away from instinct to “fix” feelings or thoughts focusing elsewhere

Resilience and self-care are skills

Types of
Self-Care:
It's Not Just
Bubble Baths



“Successful coping is not something that can be achieved outright, once and for all. Patients and families, and, what is more, practitioners, too, struggle to cope on a daily basis. We cope well on Tuesday, badly on Wednesday morning, better Wednesday afternoon, better still on Thursday, worse again Friday morning, and so on...To meet one day with defeat, the next with hope, the great adversity of chronic illness with its many losses and threats surely is a moral lesson that can keep even the most indocile of us from despair.” (Kleinman)





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