


NOFASD Australia Presents:

Managing the Toll of Caregiver Trauma and Building Resiliency in Families of Children with FASD

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WHO ARE WE?

- Mother
- Father
- Parent
- Special-Needs Parent
- Advocate
- Caregiver



When you are in the middle of a story it isn't a story at all, but only a confusion; a dark roaring, a blindness, a wreckage of shattered glass and splintered wood; like a house in a whirlwind, or else a boat crushed by the icebergs or swept over the rapids, and all aboard powerless to stop it. It's only afterwards that it becomes anything like a story at all. When you are telling it, to yourself or to someone else.

- Margaret Atwood, *Alias Grace*



Points for Discussion

- Relational stress in marriages, partnerships, and family systems
- Compassion fatigue and burnout
- Disenfranchised grief
- Core values and our emotional response
- Building resiliency

Relational Stress

- When the relationship between the person and their environment (or other people in their environment) is appraised by the person as exceeding his or her resources and endangering his or her well-being. (Lazarus et al 1984).
- Our bodies and minds automatically react to stressful situations, preparing us for a "flight or fight" response.
- Extreme and/or prolonged stress can lead to our autonomic nervous system or "internal balance" being unable to return to its normal resting state (recover) which can lead to physical illness and mental illness. The maladaptive ways our bodies respond can, over time, become automatic.
- Symptoms include: isolation, intolerance, lashing out, nagging, lack of intimacy, distrust, assaultive behavior, feeling resentful, irritability, agitation

Compassion Fatigue

- Result of an ongoing and snowballing process that occurs in a demanding relationship with a needy individual.
- Leads to profound shifts in the way we view the world and loved ones
- Characterized by emotional depletion
- May result in becoming increasingly cynical, fighting with partners more often, losing patience with kids more easily
- Research has shown that when someone is suffering from compassion fatigue, they work harder and harder with diminishing results

Caregiver Burnout

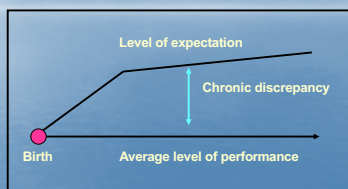


- the demoralization,
- disillusionment,
- cynicism,
- and physical, mental and emotional exhaustion
- that occurs frequently among individuals who are responsible for the constant care of another individual.

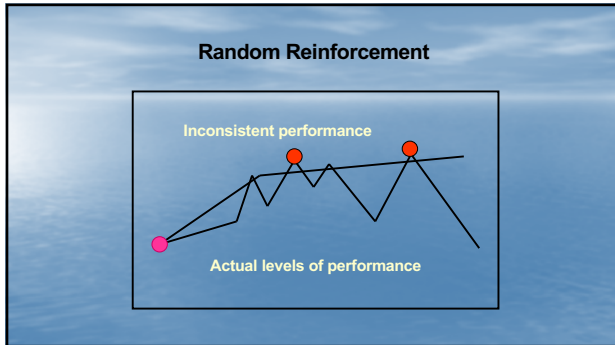
The Body Keeps Score: Our Cortisol Levels

- Cortisol: our body's alarm system (fuels "fight or flight" response), primary stress hormone
- Works with our brain to control mood, motivation, fear
- Keeps inflammation down
- Regulates your blood pressure
- Increases your blood sugar (glucose)
- Controls your sleep/wake cycle
- Boosts energy so you can handle stress and restores balance afterward
- Constant stress = "alarm button" staying on, then overtime, turns off

Development of Burnout



Visual based on Freudenberger



- ### Characteristics of Compassion Fatigue & Burnout
- Develops over time
 - Chronic discomfort, anger, fear
 - Denial, avoidance
 - Physical complaints
 - Withdraw from families/friends
 - Changes in appetite and/or weight
 - Excessive use of alcohol or other substances
 - Slowly become more exhausted to the point of being chronically tired
 - Increased frustration, decreased flexibility
 - Diminished self-esteem
 - Depressed, isolated
 - Loss of interest in enjoyable activities
 - Change in sleep patterns
 - Feeling irritable, helpless, hopeless
- Source: Freudenberger, Burnout

- ### Grief
- Loss – of “what could be”
 - Longing – yearning for meaning, understanding, what will not be
 - Feeling Lost – attempting to reorient ourselves to our physical, emotional, and social worlds
- Brene Brown, “Rising Strong”

Disenfranchised Grief

Loss that is not socially sanctioned, openly acknowledged, or recognized by others, and is not publicly mourned.

Grief Manifestations

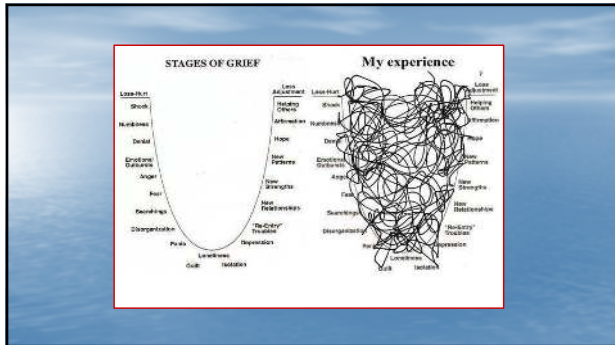
- Physical (ex: feeling tension in the body, headaches, fatigued, heaviness in body, feeling ill, experiencing prolonged or frequent illness)
- Emotional (ex: depression, anxiety, tearful, angry, easily provoked, jealousy, PTSD symptoms)
- Cognitive (ex: "foggy", impulsive or reckless in reactions to situations or relationships)
- Behavioral (ex: shutting down, isolating, withdrawing, irritable, lashing out, yelling)
- Spiritual (ex: losing faith in God/Higher Power/Greater Good, hopeless)

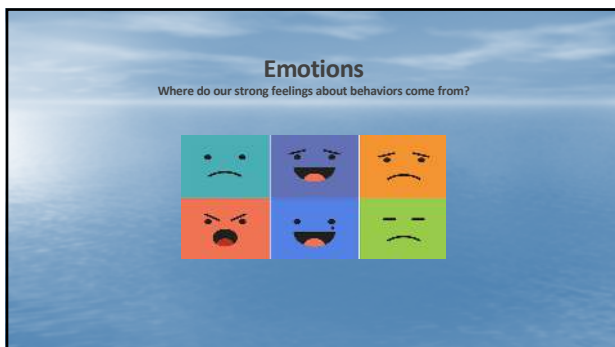
Stages of Grief

- Denial
- Anger
- Bargaining
- Depression
- Acceptance



- Stages are part of the framework that make up our learning to live with what was lost.
- They are tools to help us frame and identify what we may be feeling.
- They are not stops on some linear timeline.





Age-Based Expectations	
"Act your age" at 6	"Act your age" at 16
<ul style="list-style-type: none"> • Tie your shoes • Play nicely with others (share, take turns) • Learn numbers, letters, start to read • Sit still and listen for 20 minutes • Follow 3-step directions 	<ul style="list-style-type: none"> • Drive • Be <i>responsible</i> (part-time job, manage money, manage schedule/time) • Social life • Independent • Planning for the future

Age-Based Expectations & Dysmaturity


"Act your age" at 6 ➡ 3	"Act your age" at 16 ➡ 8
<ul style="list-style-type: none"> • Tie your shoes • Play nicely with others (share, take turns) • Learn numbers, letters, start to read • Sit still and listen for 20 minutes • Follow 3-step directions 	<ul style="list-style-type: none"> • Drive • Be <i>responsible</i> (part-time job, manage money, manage schedule/time) • Social life • Independent • Planning for the future

Engaging with Emotion & Getting Curious

Curiosity is the death of shame and criticism.

*The aspects of recognizing
we're feeling something is to
disengage from tough
emotions, they don't go
away. Instead they own us,
they define us.*

-Brenda Brown



Recognizing Emotions

Thoughts – Actions – Behaviors

- Body/physical responses (stomach in knots, heart racing, easily tearful)
- Behavior Signals (yelling at our spouse “for no reason”, wanting to punch a wall, wanting to hide/retreat)
- Compulsive Behaviors (eating compulsively, drinking excessively, excessive online shopping)
- Action needed: connecting thoughts, actions, behaviors & addressing all three equally

Depression and anxiety are two of the body’s first reactions to stockpiles of hurt.

Numbing Emotional Pain

• Alcohol	• Perfectionism
• Drugs	• Internet
• Compulsive Shopping or Spending Money	• Food
• Point of Views	• Staying Busy
• The Glass Being Half Empty	• Loyalty to Suffering
	• Always Needing to Be Right

"We can't selectively numb emotions – when we numb the dark, we also numb the light." - Brene Brown

Resilient

Spring back; rebounding

Returning to the original form or position after being bent, compressed, or stretched

Recovering readily from illness, depression, adversity, or the like; buoyant

Resilience

- Is not a fixed characteristic
- Becomes stronger with lifelong practice (we have to work regularly at building it)
- Is not about pushing through or soldiering on
- It represents our ability to meet the challenges we encounter each day, trusting that we have the resources (both internal and external) to weather those challenges with the least amount of negative consequence to our physical, emotional, spiritual selves.
- It means that we can hold space for whatever our experiences might be, regardless of what they look like from the outside.
- It is about recognizing when we are dysregulated, overwhelmed & honoring the appropriateness of that response.
- It's being aware of our own nervous systems, patterns of arousal, so that we can maintain our regulation which in and of itself helps our children regulate











Steps to Wellness

- Take stock: what's on your plate?
- Re-evaluate priorities and expectations
- Delegate – learn to ask for help (be proactive, be open & honest, who is one person who you've thought of asking for help at some point, but never reached out?)
- Find support (individual therapist, marital therapist, online or in-person support groups)



Steps to Wellness

- Commit to finding balance - baby steps are still steps forward!
- Look after the basic 3: eating, sleeping, exercise/movement
- Slow down to observe and gain perspective
- If possible, seek out respite
- Have a concrete plan on how to reduce stress and build resiliency (share it with others for accountability)
- Stop neglecting what you know keeps you well



Thank you!

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