A photograph of a woman with long brown hair, wearing a red scarf and a dark jacket, kissing a young boy on the cheek. The boy is wearing a tan jacket and has his eyes closed. The background is blurred, showing another person in a dark jacket. The image is framed by a white border and set against a light brown background.

Parents of Children with Medical Complexity and
Traumatic Stress: Improving Care for Patients and
Families

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Justine Dellaria, LICSW

Introductions





Children with Complex Medical Needs

- Statistics
- Medically fragile
- High risk
- Heavy utilizers
- Their parents are an under-studied demographic

Children with Complex Medical Conditions: an Under-Recognized Driver of the Pediatric Cost Crisis
Current Treatment Options Pediatrics (2016) 2:289-295



*Children with Medical Complexity:
An Emerging Population for
Clinical and Research Initiatives
(2011)*

Caregivers often experience:

- enhanced stress
- poor health
- marital discord
- financial consequences

PEDIATRICS Volume 127, Number 3,
March 2011

Research on Family Health and Children and Youth with Special Health Care Needs (2022)

- Physical health is worse; poor sleep; stress leads to neuroendocrine dysfunction, elevated systemic inflammation and poor immune response
- Depression, anxiety, stress
- Medical trauma and post traumatic stress disorder
- Literature is **limited** and there are **gaps** in it. “Paucity of literature about the causes and implementation of programs that address these family needs.”
“Poor understanding of factors impacting mental health.”



Mental Health and Wellbeing of Caregivers of Children with Medically Complex Conditions During COVID-19

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Background

- Care for children with medically complex conditions creates multiple demands on caregivers, exacerbated during a pandemic.
- Previous research has highlighted the chronic stress experience of caregivers with resultant calls to raise awareness about the issue.
- Several reports have described caregiver burden during the pandemic. Few studies, however, have focused on the mental health and wellbeing of caregivers of children with medically complex conditions.
- Recent consolidation of two Mass General Hospital for Children (MGHfC) programs for children with medically complex conditions has led to a new integrated Courageous Kids (CK) program.
- This new program afforded an opportunity to survey parents of program children.

Objective

- To assess mental health and wellbeing among caregivers of children in the CK program during COVID-19.

Design/Methods

- We conducted an online cross-sectional survey of caregivers of patients in the CK program from April 2020 to April 2021 (n=65).
- We assessed caregiver mental health and wellbeing using the Short Form Health Survey (SF-20) and Impact on Family Scale (IOF).

Results

Table 1
Demographics of Caregivers of Courageous Kids Patients

	Frequency	Percentage (%)
Age (mean: 38.9 years)		
Sex		
Male	4	6.2
Female	60	92.3
Other	1	1.5
Race		
American Indian or Alaska Native	1	1.6
Asian	2	3.1
Black, not Hispanic	7	10.9
Hispanic	14	21.9
White, not Hispanic	33	51.6
Other	7	10.9
Education		
Partial High school	1	1.6
High School Graduate or GED	7	10.9
Partial College or Associates Degree	16	25.0
College or Technical Degree	21	32.8
Master's or Doctoral Degree	16	24.4
Prefer not to answer	3	4.7
Insurance		
Public only	26	43.3
Private/Commercial only	11	18.3
Both Public & Private	23	38.3
Total Household Income		
\$0 to \$24 999	13	20.0
\$25 000 to 49 999	7	10.8
\$50 000 to 99 999	14	21.5
\$100 000 and greater	24	36.9
Prefer not to answer	7	10.8

Table 2
Short Form Health Survey (Health of Caregiver)

	Score	Reference Mean (SD)
Physical Functioning	81.6	78.5 (30.8)
Role Functioning	85.1	77.5 (38.3)
Social Functioning	69.5	87.2 (23.6)
Mental Health	57.1	72.6 (20.2)
Current Health Perceptions	64.7	63.0 (26.8)
Pain	40.0	31.4 (27.7)

Table 3

Impact on Family Scale

	Score	Reference Mean (SD)
Total Impact on Family	64.9	59.0 (9.5)
Financial Burden	15.6	10.4 (2.2)
Familial/Social Impact	23.0	22.1 (4.9)
Personal Strain	20.8	16.6 (3.5)
Mastery	5.5	10.0 (2.0)

- Average caregiver SF-20 mental health score was 57.1 (reference mean = 72.6 ± 20.2).
- Physical and role functioning scores were 81.6 (reference mean = 78.5 ± 30.8) and 85.1 (reference mean = 77.5 ± 38.3) respectively.
- Social functioning score was 69.5 (reference mean = 87.2 ± 23.6).
- Total impact on family score was 64.9 (reference mean = 59.0 ± 9.5).
- Financial burden and personal strain scores were 15.6 (reference mean = 10.4 ± 2.2) and 20.8 (reference mean = 16.6 ± 3.5) respectively.

Conclusion

- Caregivers of children with medically complex conditions report lower mental health scores and higher family burden scores as well as more financial burden and personal strain than normative samples.
- Further studies will examine key demographic differences in these scores.
- Timely and appropriate interventions might improve the mental health and wellbeing of caregivers of children with medically complex conditions.

Journal of American Medical Association Study 2021

Mothers and fathers of children with illness each had 61% and 55% higher overall rates of healthcare encounters, diagnoses, and prescriptions compared with parents of control children

- *JAMA Network Open*. 2021;4(12):e2137250. doi:10.1001/jamanetworkopen.2021.37250
(Reprinted)



Parents Self-Report

Negative effects in physical health, family life, marriage, social life, finances, education, and career;

Greater symptoms of post traumatic distress, greater emotional distress, higher levels of anxiety, fewer healthy behaviors, sleep disturbances, lower quality of life

JAMA Network Open 2021;4(12):e2137250.doi:10.1001/jamanetworkopen.2021.37250

Allostatic Load

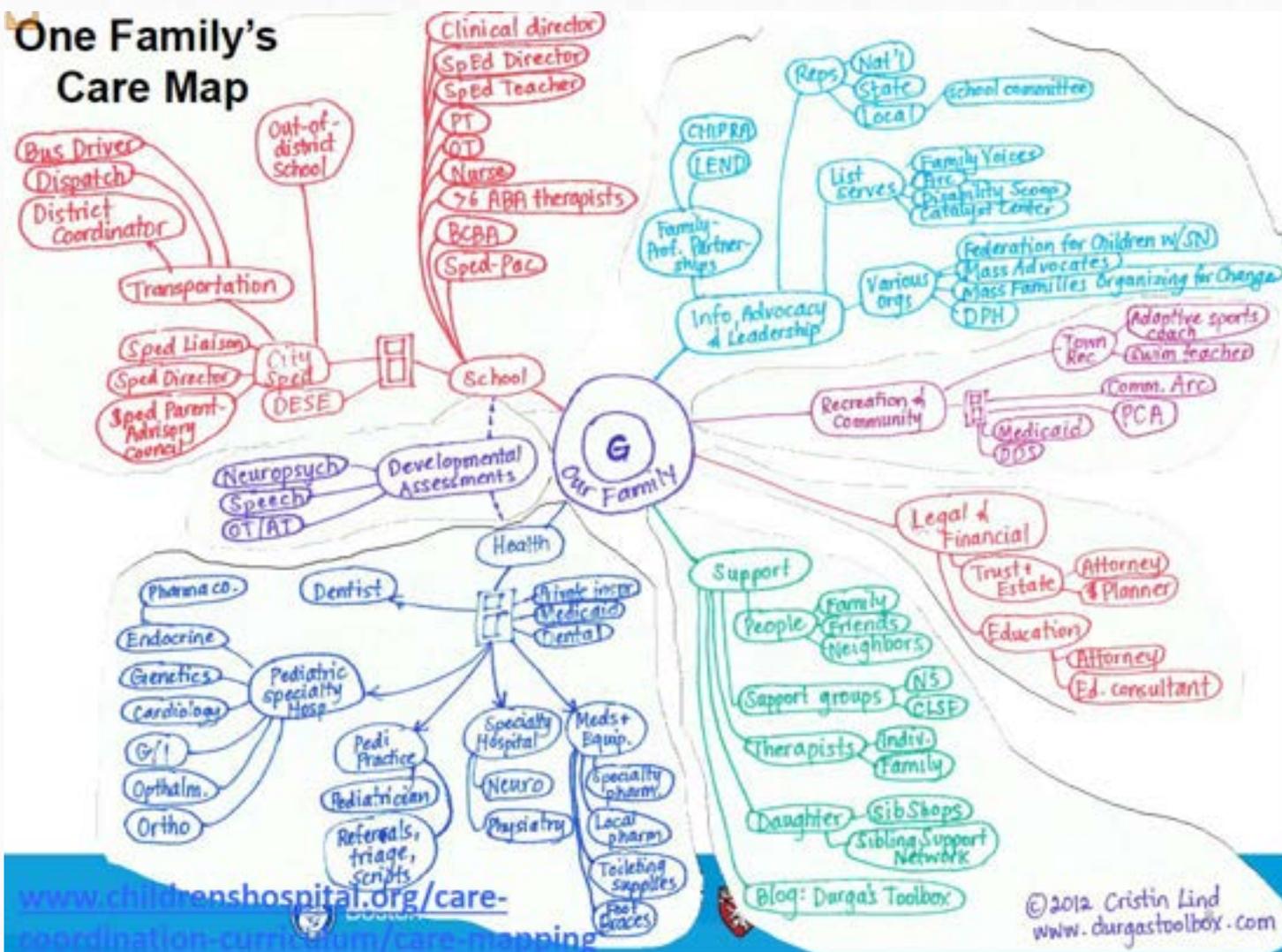
Allostatic load refers to the cumulative burden of chronic stress and life events. It involves the interaction of different physiological systems at varying degrees of activity. When environmental challenges exceed the individual ability to cope, then allostatic overload ensues. Allostatic load is identified by the use of biomarkers and clinical criteria

What We See

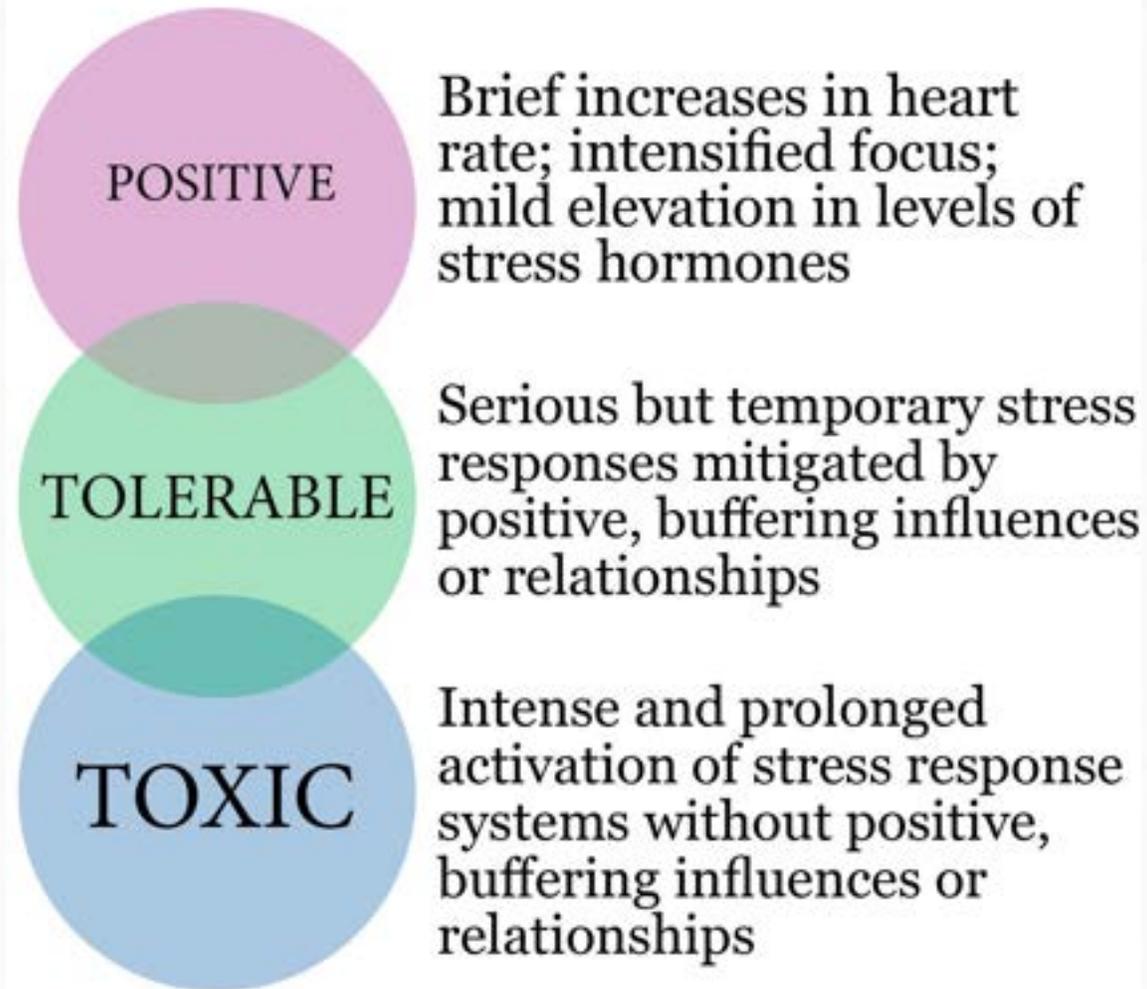
- Greater subspecialty care
- Coordination is a challenge – CCC, iCMP
 - Pediatric Palliative Care
 - Fragmentation
 - Complexity
- Parents are overwhelmed

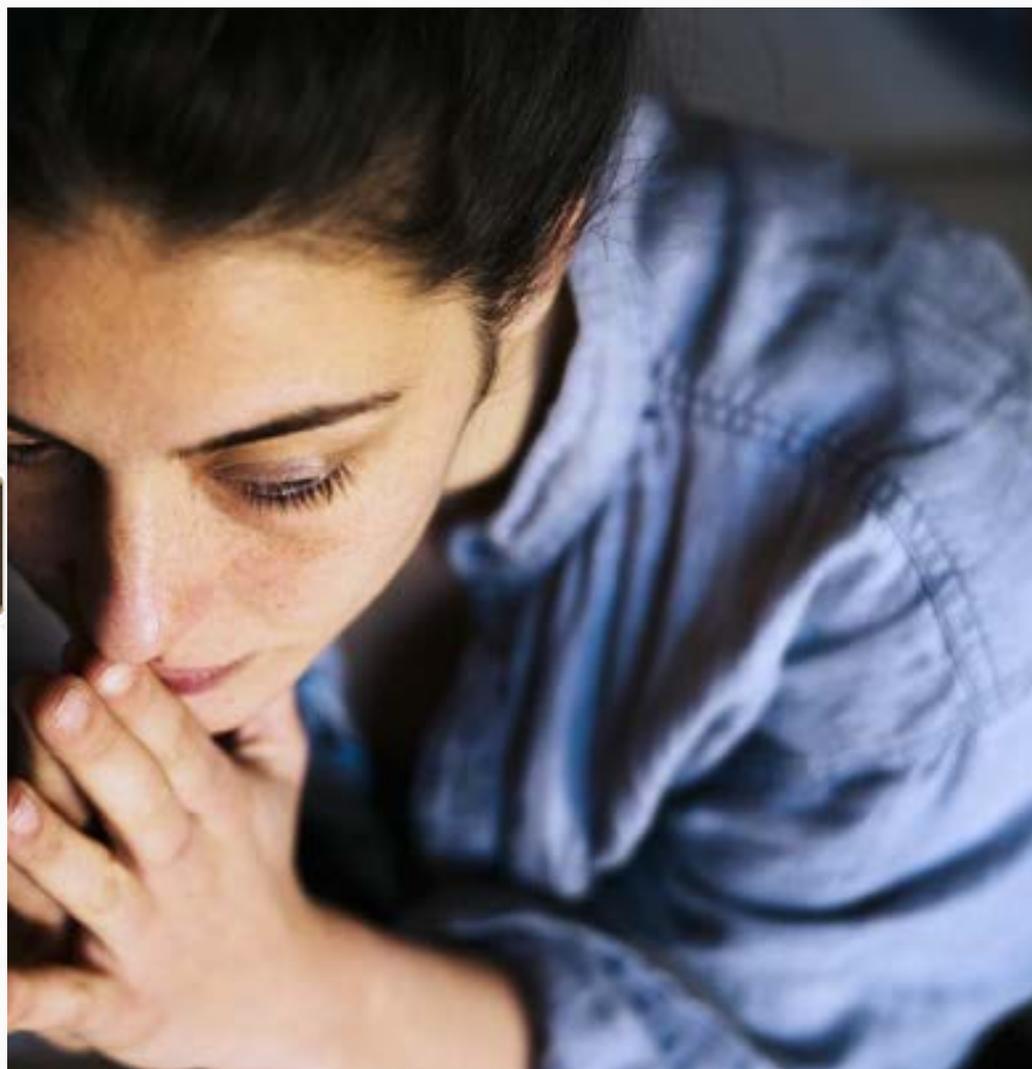


One Family's Care Map



DEGREES OF STRESS





BRAIN

Difficulty concentrating, anxiety, depression, irritability, mood, mind fog

CARDIOVASCULAR

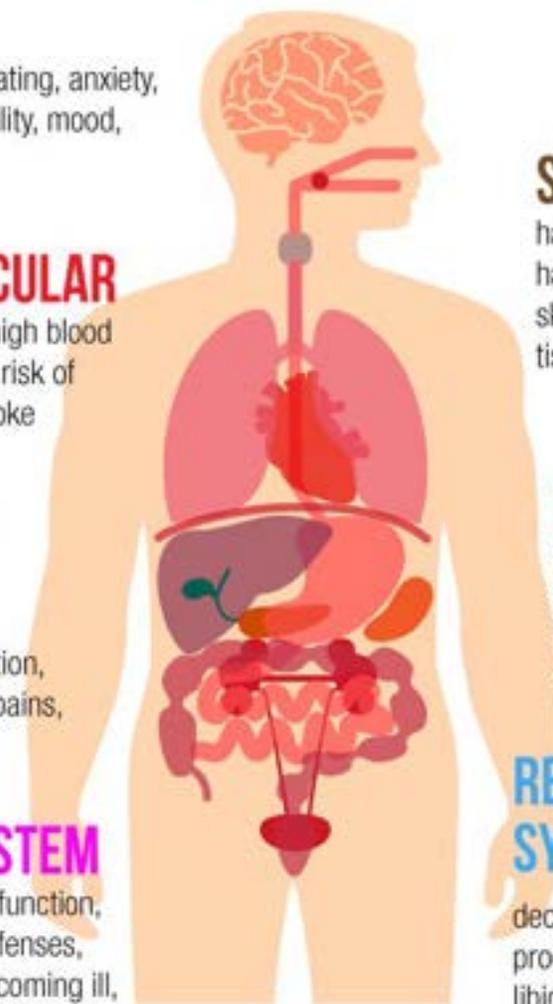
higher cholesterol, high blood pressure, increased risk of heart attack and stroke

JOINTS AND MUSCLES

increased inflammation, tension, aches and pains, muscle tightness

IMMUNE SYSTEM

decreased immune function, lowered immune defenses, increased risk of becoming ill, increase in recovery time



SKIN

hair loss, dull/brittle hair, brittle nails, dry skin, acne, delayed tissue repair

GUT

nutrient absorption, diarrhea, constipation, indigestion, bloating, pain and discomfort

REPRODUCTIVE SYSTEM

decreased hormone production, decrease in libido, increase in PMS symptoms



Anticipatory Grief



Similar feelings associated with grief

Every emotional is normative – can feel more like a rollercoaster

Find ways to take control

Spend quality time together, opportunities for engagement / memory making

Share your feelings, be honest

Make time for "normal" routine and activities

Continue to engage in self-care (physical and emotional)

Know when to get professional support

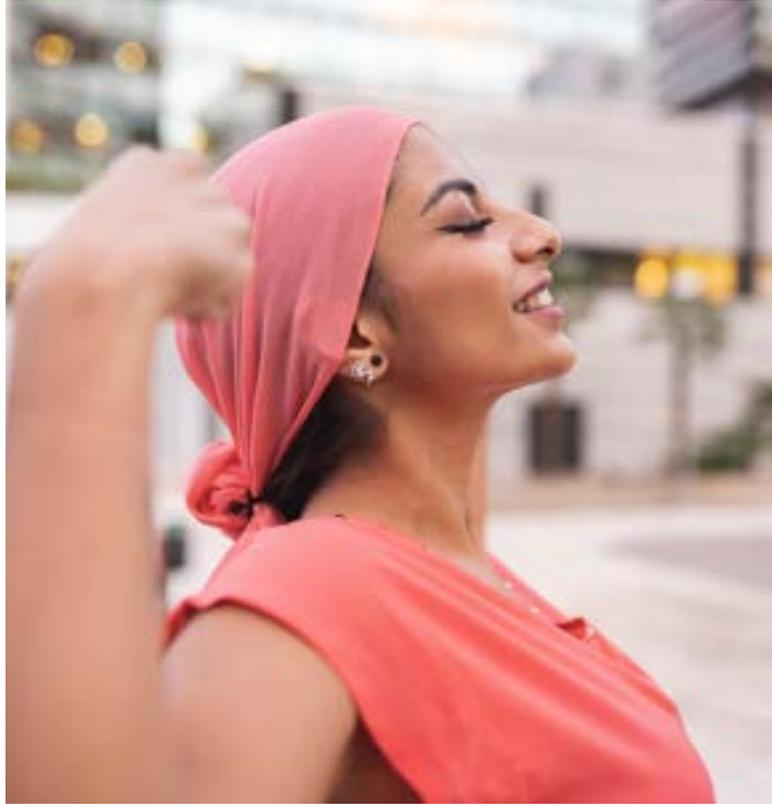
What do parents need?

- Recognition of trauma of the system
- Validation
- Self-compassion to combat guilt
- Basic physical help in the home
- Sibling support
- Sense of control AND adequate support
- Providers who are well-trained in communication
- Help with finances
- Grief work and end of life care
- Spiritual needs met
- Mental health needs met
- Opportunities for advocacy



Where are parents getting support?

- Informal supports
- Online supports
- Seeking individual supports – Therapy
 - Insurance/accessibility
- Self-help / Self-care

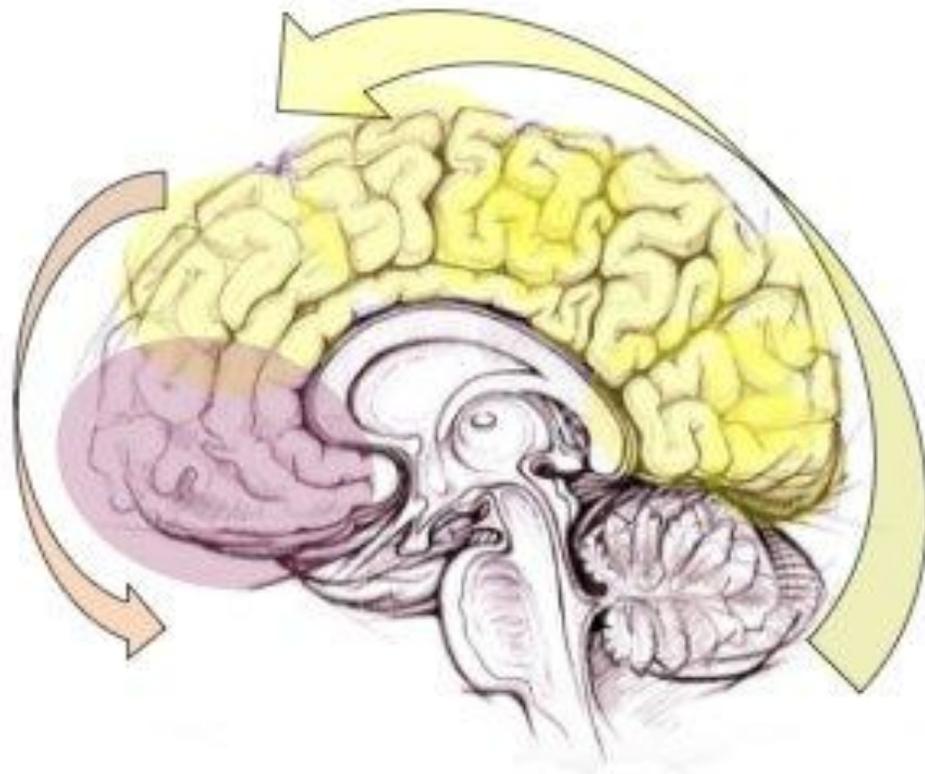


The Path to Wellness

Authentic and Sustainable Self Care Begins With You:

- Self compassion
- Purposeful engagement
- Connectedness
- Exchange information and feelings with people who can validate you.
- Clarify your personal boundaries. What works for you; what doesn't.
- How does your stress impact your mind? Your body?

Intentional
Directed
Aware
Slow
Mindful
Hungry



“Automatic”
Unnoticed
Routine
Fast
*Mind-less
Efficient

RESPONSIVE \longleftrightarrow REACTIVE

Mindfulness Meditation

A mental state that involves being fully focused on "the now" so you can acknowledge and accept your thoughts, feelings, and sensations without judgment. Mindfulness meditation is a mental training practice that teaches you to slow down racing thoughts, let go of negativity, and calm both your mind and body.

“Not only does this enrich the present moment activity/ experience you're engaging in, but it also allows you to be present in your time rather than going back into the past or into the future.”

- **Brushing your teeth:** Feel your feet on the floor, the brush in your hand, and your arm moving up and down.
- **Doing dishes:** Savor the feeling of the warm water on your hands, the look of the bubbles, and the sounds of the pans clunking on the bottom of the sink.
- **Doing laundry:** Pay attention to the smell of the clean clothes and feel of the fabric. Add a focus element and count your breaths as you fold laundry.
- **Driving:** Turn off the radio—or put on something soothing, like classical music—imagine your spine growing tall, find the half-way point between relaxing your hands and gripping the wheel too tightly, and whenever you notice your mind wandering, bring your attention back to where you and your car are in space.
- **Exercising:** Instead of watching television while on the treadmill, try focusing on your breathing and where your feet are in space as you move.
- **Getting kids ready for bed:** Get down to the same level as your kids, look in their eyes, listen more than you talk, and savor any snuggles. When you relax, they will too.

Writing Therapy

- Write a letter to your former or future self
 - What are you proud of?
 - What have you overcome?
 - What do you need to remember?
- 3 Soul Questions
 - What enlivens you?
 - What drains you?
 - What does your soul most long for?
- Write a letter to the person who has been most influential or supportive.
- What is some regret or resentment that needs to be rewritten?
- What are you grateful for? Things you appreciate?

Bessel Van Der Kolk

The Body Keeps the Score

- Aromatherapy
- Breathing techniques/guided imagery
- Massage
- Acupuncture/Tapping
- Storytelling/Poetry
- Yoga/Yoga therapy
- Dance/Movement
- Music Therapy
- Drama Therapy/role play
- Tai Chi
- Art
- Body Art

Guided Imagery





Final thoughts

- Despite gaps in the research, we see parents' trauma and stress
- Drawn from research of other populations
- Impact on the mind and body is real
- Self-care is important and a way to protect from the impact of toxic stress