

Patient, Sibling, and Parent Psychosocial Needs in Complex Care

Project ECHO – Core Competency

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Agenda

- Introductions
- Learning Objectives
- Adverse Childhood Experiences/Events
- Trauma-Informed Care
- Window of Tolerance
- Post-Traumatic Stress Disorder
- Psychosocial Needs in Complex Care
 - Child/Youth ("Patient")
 - Parent/Caregiver
 - Sibling
 - Family Unit
- Hospitalizations & the CMC Family
- Mindfulness Meditation: Self-Compassion
- Questions/Discussion



INCLUSIVE COSTUMES

Frozen, Batman and other popular adaptive character costumes and themed wheelchair covers for your kiddo.

Learning Objectives

- To introduce a trauma-informed framework to practice
- To develop a deeper understanding of the impact of living with a child with medical complexity on families
 - Parents/Caregivers
 - Patient/Child/Youth
 - Siblings
 - Family Unit
- To identify areas of need from a bio-psychosocial lens for families living with a child with medical complexity

Adverse Childhood Experiences

- Potentially traumatic events that occur in childhood
- Linked to chronic health problems, mental illness, and substance misuse in adulthood
- Impact brain development
- Common

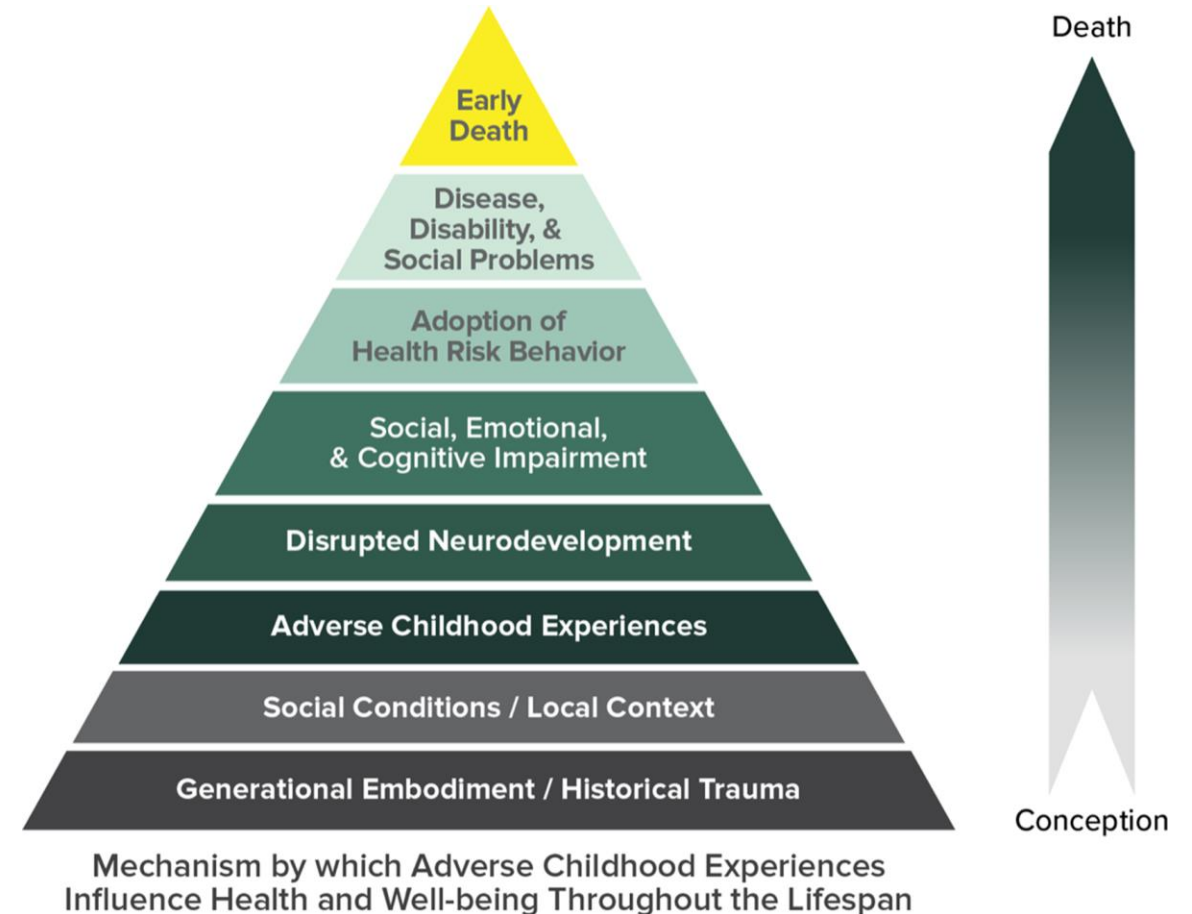
(Centers for Disease Control and Prevention, 2023)



Source: Cronholm, P.F., et al. (2015)

How Common are Adverse Childhood Events?

- ½ to 2/3 of Canadians experience an ACE prior to the age of 18 (1)
- 1 in 6 adults had four or more ACEs



(Giovanelli et al, 2019)

Trauma Informed Care

- Recognizes the pervasive nature of trauma
- Assumes an individual is more likely than not to have a history of trauma
- Promotes environments of healing and recovery to prevent re-traumatization
- Takes stance of "universal precaution"
- Creates policies and procedures to minimize barriers to services
- Integrates knowledge about trauma into staff training to prevent re-traumatization



(CPI, 2021)

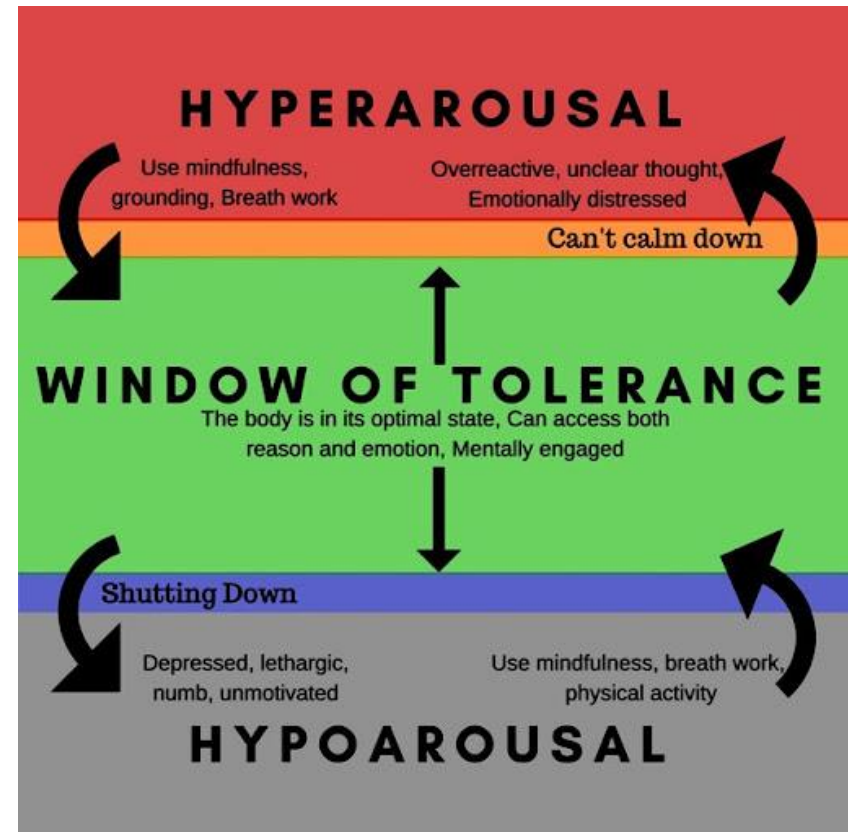
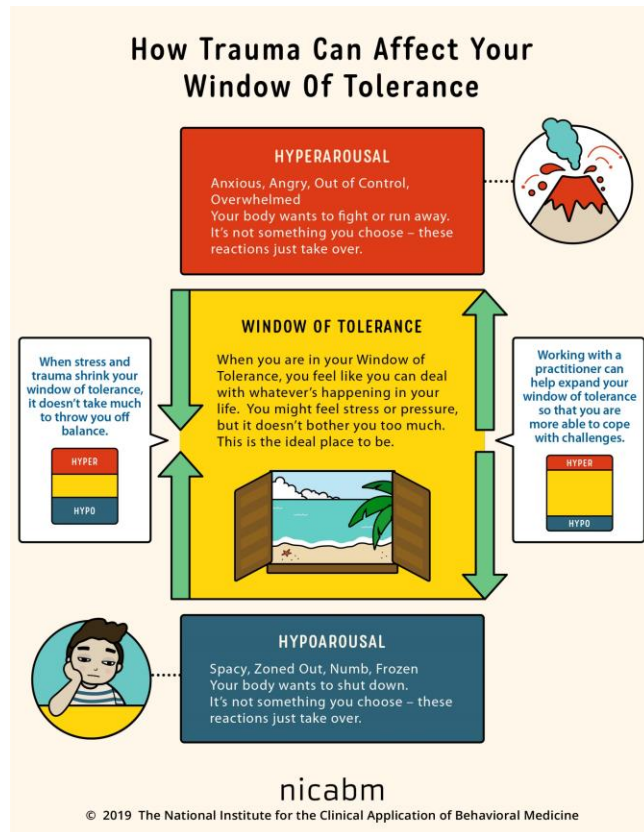
Principles of Trauma Informed Care

- Safety – physical and emotional safety enhanced with welcoming common areas; privacy respected
- Choice – clear and appropriate message about rights and responsibilities
- Collaboration – treatment decisions are created by the service recipient and provider
- Trustworthiness – interpersonal boundaries, task clarity, consistency
- Empowerment – skill building with each contact



Don't suffer alone
the definition of trauma is an
overwhelming event experienced
alone

Window of Tolerance





Post-Traumatic Stress Disorder

- Traumatic Experience
- Post-Traumatic Stress Disorder
- Ongoing fear of (past) threat in the here and now
- Building Block Effect
 - The more event types, the greater the likelihood of PTSD
 - Every time you add a traumatic event, the hot memory grows (fear network expands)
 - "What fires together wires together"

Post-Traumatic Stress Disorder (PTSD)

"Exposure to actual or threatened death, serious injury or sexual violation."

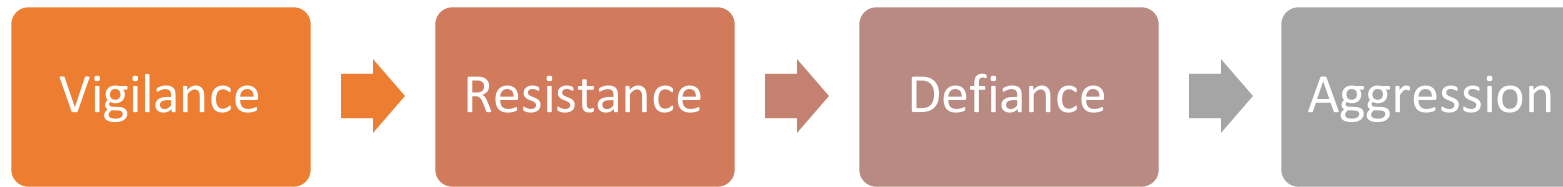
Exposure results from one or more of the following:

- 1) individual directly experiences the traumatic event
- 2) witnesses the traumatic event in person
- 3) learns the traumatic event occurred to a close family member or close friend
- 4) experiences repeated or extreme exposure to aversive details of the traumatic event"

(American Psychiatric Association, 2023)

Adaptive Responses

Hyperarousal Continuum



Dissociative Continuum

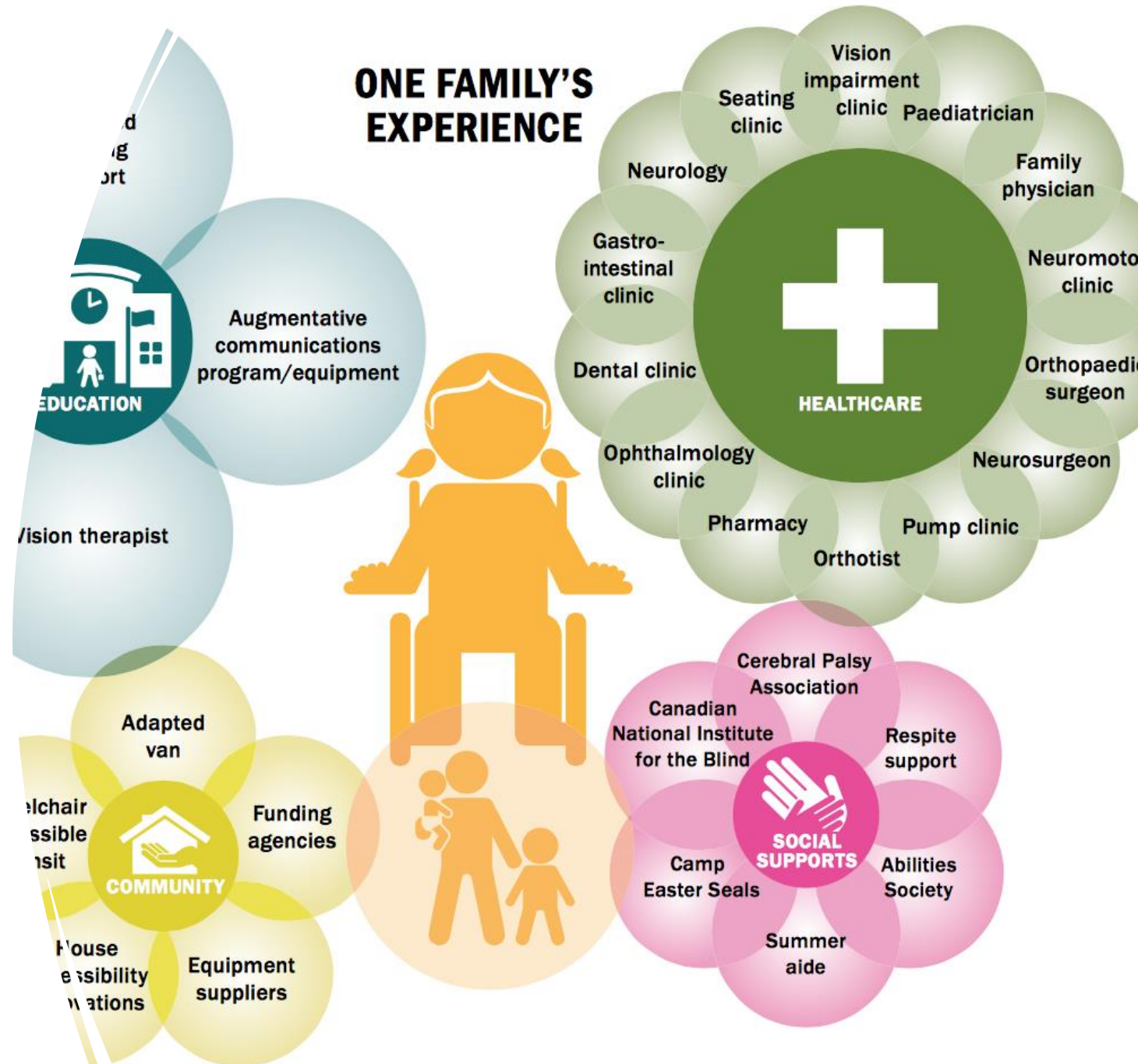


(Perry, 1995)

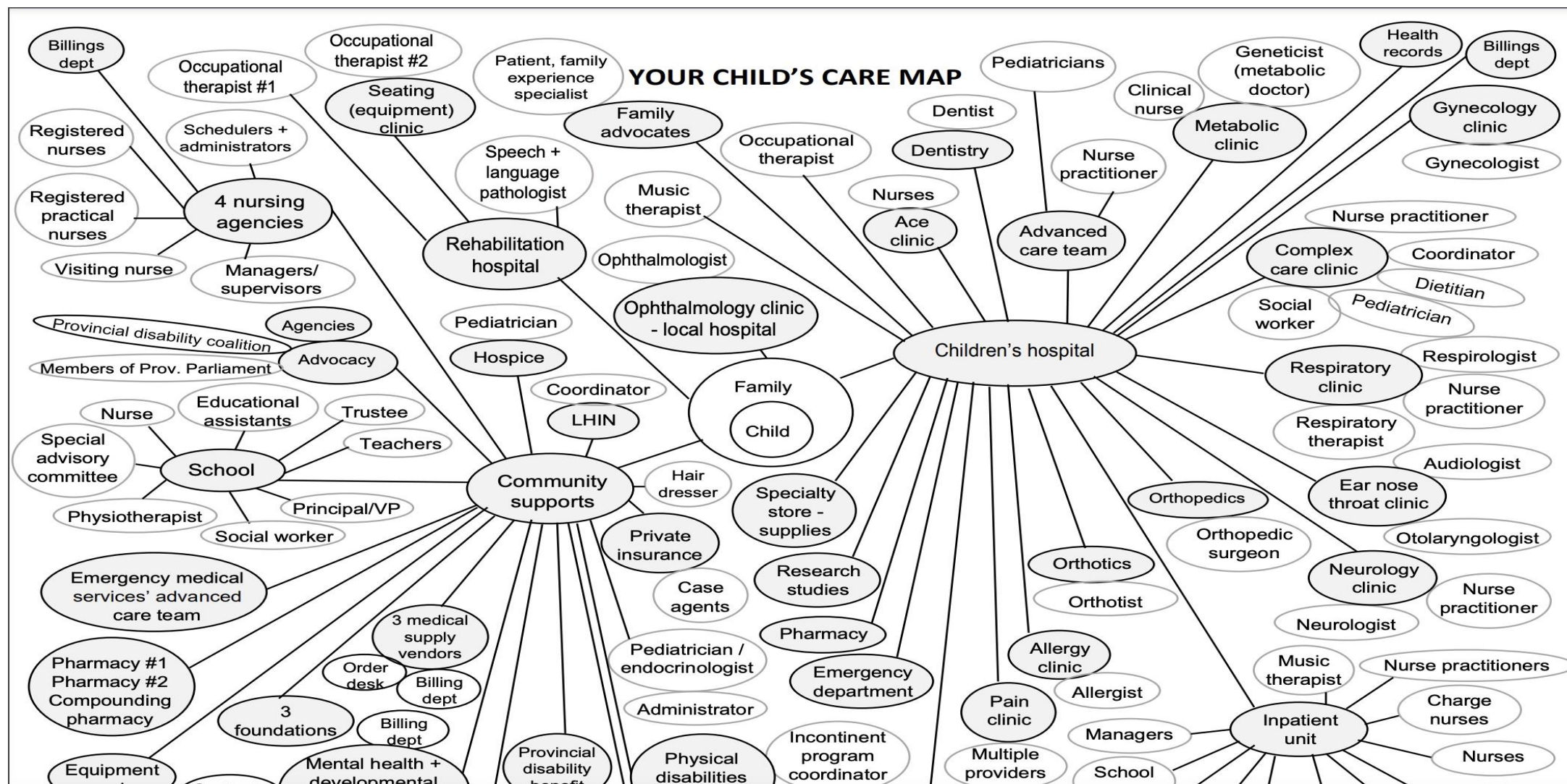
Adaptive Responses

Time	Future	Days/Hours	Hours/Mins.	Mins./Secs.	No Time
Brain	Neocortex	Subcortex	Limbic	Midbrain	Brain Stem
State	Calm	Arousal	Alarm	Fear	Terror

The Family of CMC



One Care Map



Parent/Caregiver



Impact

- Relationships
 - Family
 - Friends
 - Community
 - School
- Sense of Self/Identity
- Financial
- Safety
- Mental Health
- Religion/Spirituality
- Ability
- Independence
- Control
- Loss of future
- “Normalcy”
- Logistics
- Hopes and wishes
- Support Network



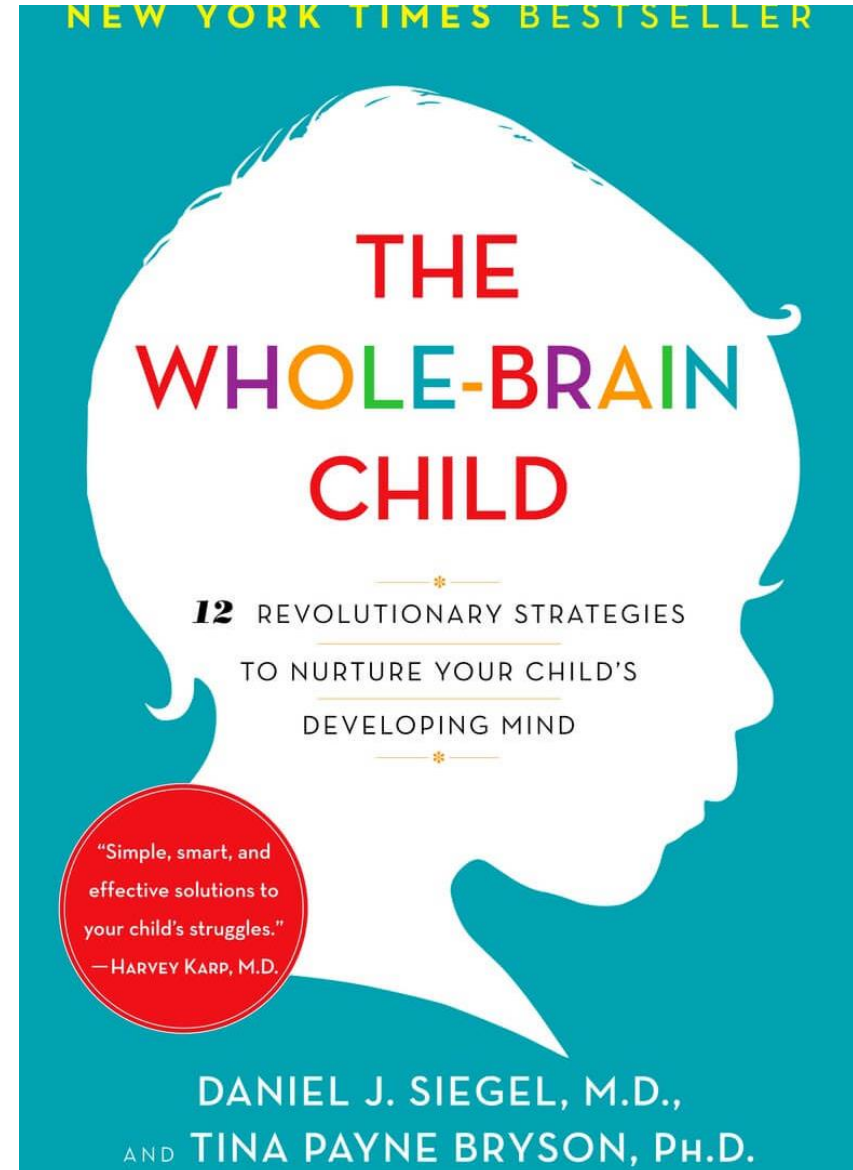
Parenting Themes: Newborn/Toddler

- Language/Cares
- Grief
- Mental Health (Post Partum – Depression, Anxiety, Psychosis)
- Loss of Idealized Child or Birth Experience
 - Not a Social Media Moment
- Pregnancy History
- Toddler's behaviour and medical trauma
- Navigating development



Parenting Themes: School Age

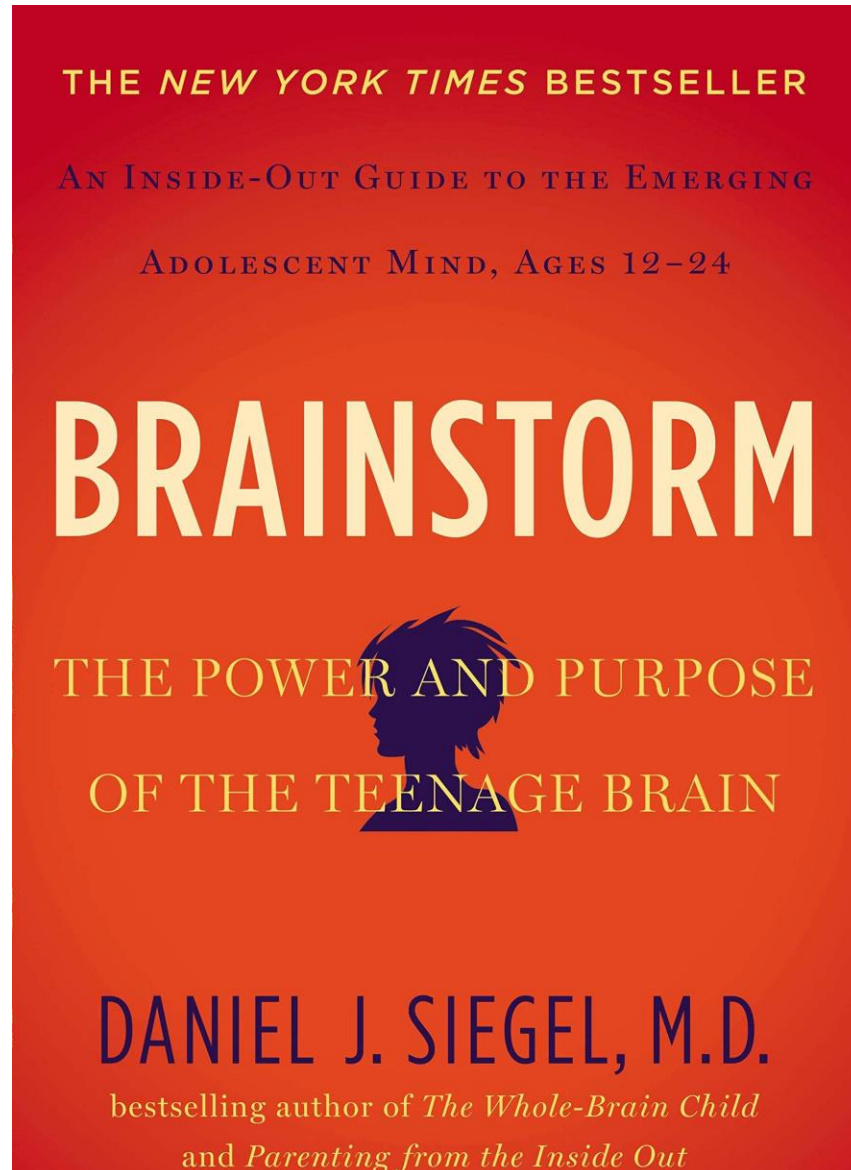
- Transfer of Services
- New Team
- Managing
- More Care Providers
- Stress
- Grief
- Competing Parenting Needs
- Multifactorial Treatment Adherence
- Medical Trauma
- Kids starting to ask more questions and opinions about care



Parenting Themes: School Age & Youth

- Illness Narrative (Identity)
- Feel Unwell
- Fair World Belief Challenged
- Body Integrity
- Opportunity for Normative Experiences & Inclusion
- Education & Friendships
- How to Parent this Child?
- Protection
- Financial
- Parent Sense of Self





Parenting Themes:

Adolescence

- Transition
- Independence
 - Knowing their Care
 - Relationship & Interface with Health Care and Health Advocacy
- “Normative Goals”
 - Dating & Personal Relationships
 - Post Secondary & Work Experience
 - Developmental Disability
- Grief & Loss for Parent
 - Teams
 - Future Thinking
- Push & Pull

Parent/Caregiver Challenges

- Losing & Starting Over
- Triggering Initial Trauma
- Future
- Relationships
- Fragmentation of Care
- Grief
- Trauma
- Family: Parent, "Patient"/Client, Sibling



Couple Relationship

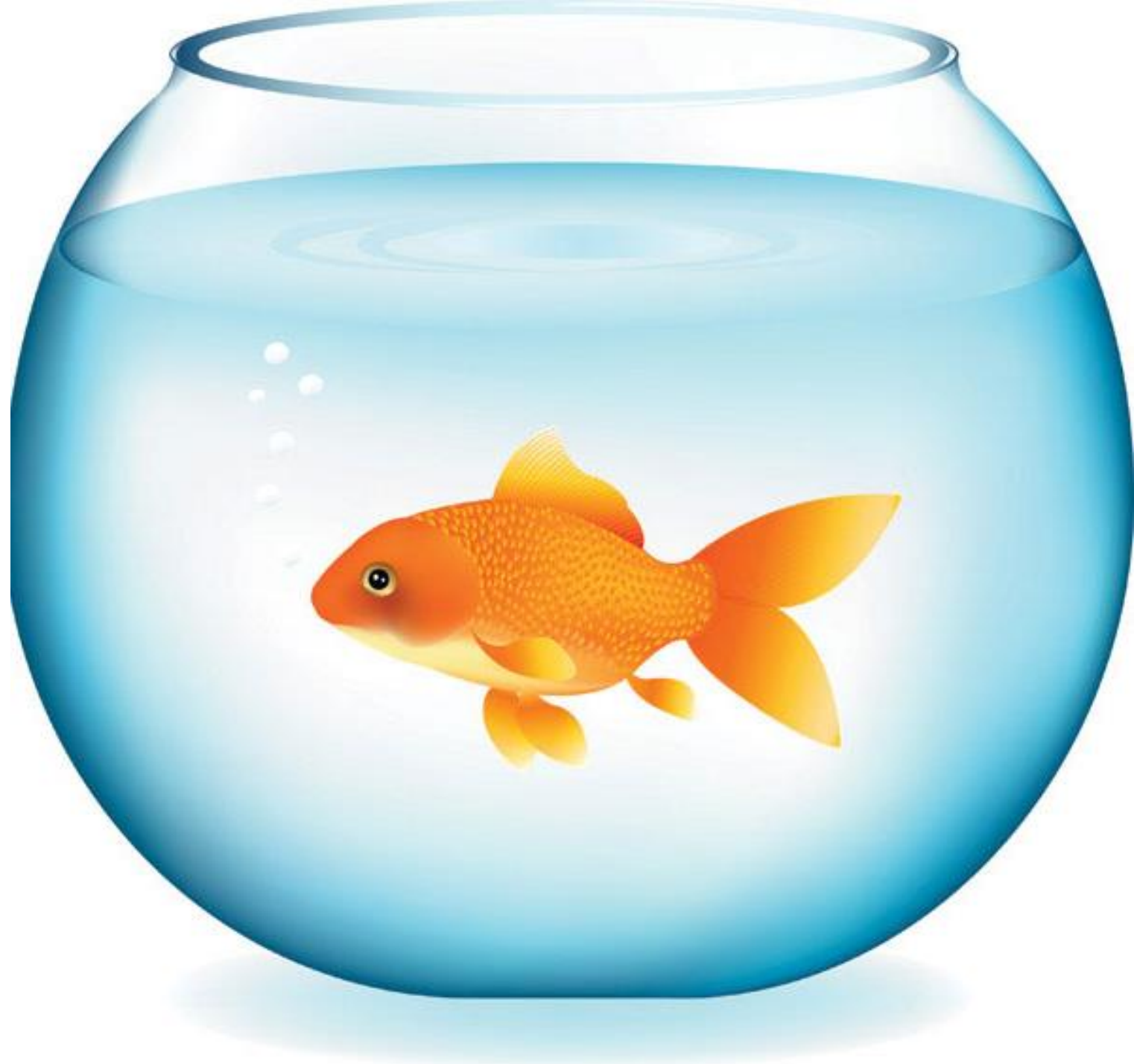
- Pre-existing Couple Stressors and Dynamics
- Parenting & Familial Norms
- Coping as Couple (or Co-Parents) and as an Individual



What do parents of CMC manage?

- Sleep deprivation
- Witnessing acute, life-threatening events
- Providing care to own child
- System stressors (paperwork; navigation)
- Home supports under stress (groceries, laundry, ordering supplies)
- Family/friends do not understand
- Loss of predictability
- Loss of previous social, emotional, and recreational opportunities
- Isolation
- Distance from home
- Financial strain
- Stress
- Life in survival mode – impacts relationships, health and mental health
- Vicarious traumatization (code blue; code white)
- Medical fragility – hospitalizations +++++

Child/Youth
("patient")

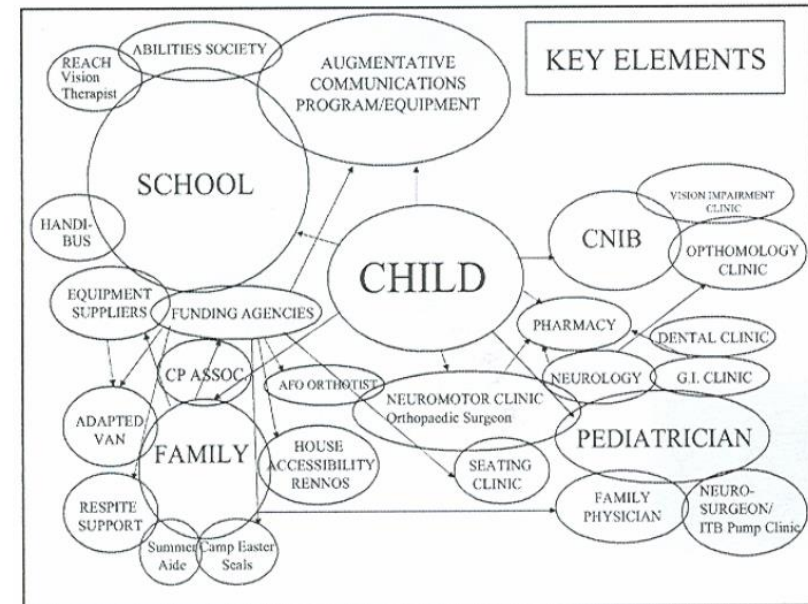


Pediatric Traumatic Stress

Children and youth may experience psychological and physiological responses to:

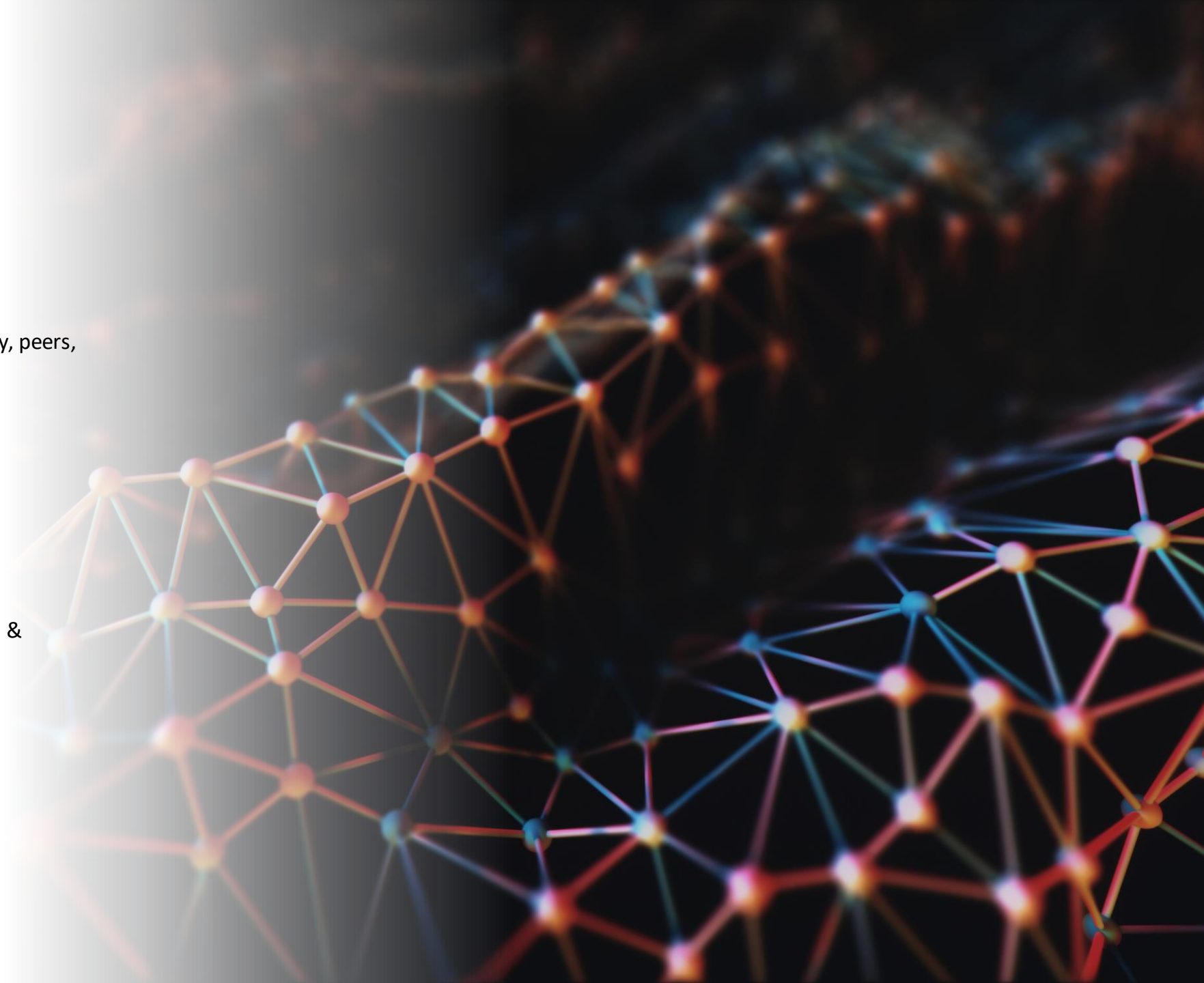
- Pain
- Injury
- Serious illness
- Medical procedures
- Invasive or frightening medical treatment experiences

(CHOP, 2022)



The Patient

- Relationships
 - parents, siblings, extended family, peers, teams, school, etc
- Capacity, ability, pain & symptoms
- Emotions
- Communication
- Behaviour
- Independence
- Opportunity for Normative Experiences & Inclusion
- Respite
- Development
- Time at Home vs Hospital




Joys & Struggles of Siblings



Siblings

- Joys
 - Share home, experiences that no one else has
 - Closeness, love, intimacy, best friend
 - Protection
 - Family relations after parents are gone
- Struggles
 - Equitability/fairness
 - Juggling for 'favorite child' status
 - Sharing parental emotional and physical resources
 - Bullying, victimization
 - Differing personalities
 - Relationships within the family unit (subunits)
 - Fit within the family



What causes sibling rivalry?"
"Having more than one kid.

Tim Allen

JAROFQUOTES.COM

Siblings

Developmental Context

Socialization

Breaks

Structure

Respite

Caregiving

Pre-Existing Sibling Relationships

Future



Family Unit

Family

- Time spent together
- Balancing pre-existing conflicts
- Pre-existing roles and dynamics
- Social Location
- Space
- “Trapped”
- Delays in learning strategies
- Social Determinants of Health



Hospitalizations for Families

- Where do parents sleep?
- Where do parents eat?
- Where do parents shower?
- Where can parents be alone?
- How are children resourced? 1:1; 2:1; 3:1
- What happens to siblings?
- Who can visit?



“The expectation that we can be immersed in suffering and loss daily and be untouched by it is as unrealistic as expecting to be able to walk through water without getting wet”

(Remen 1996)



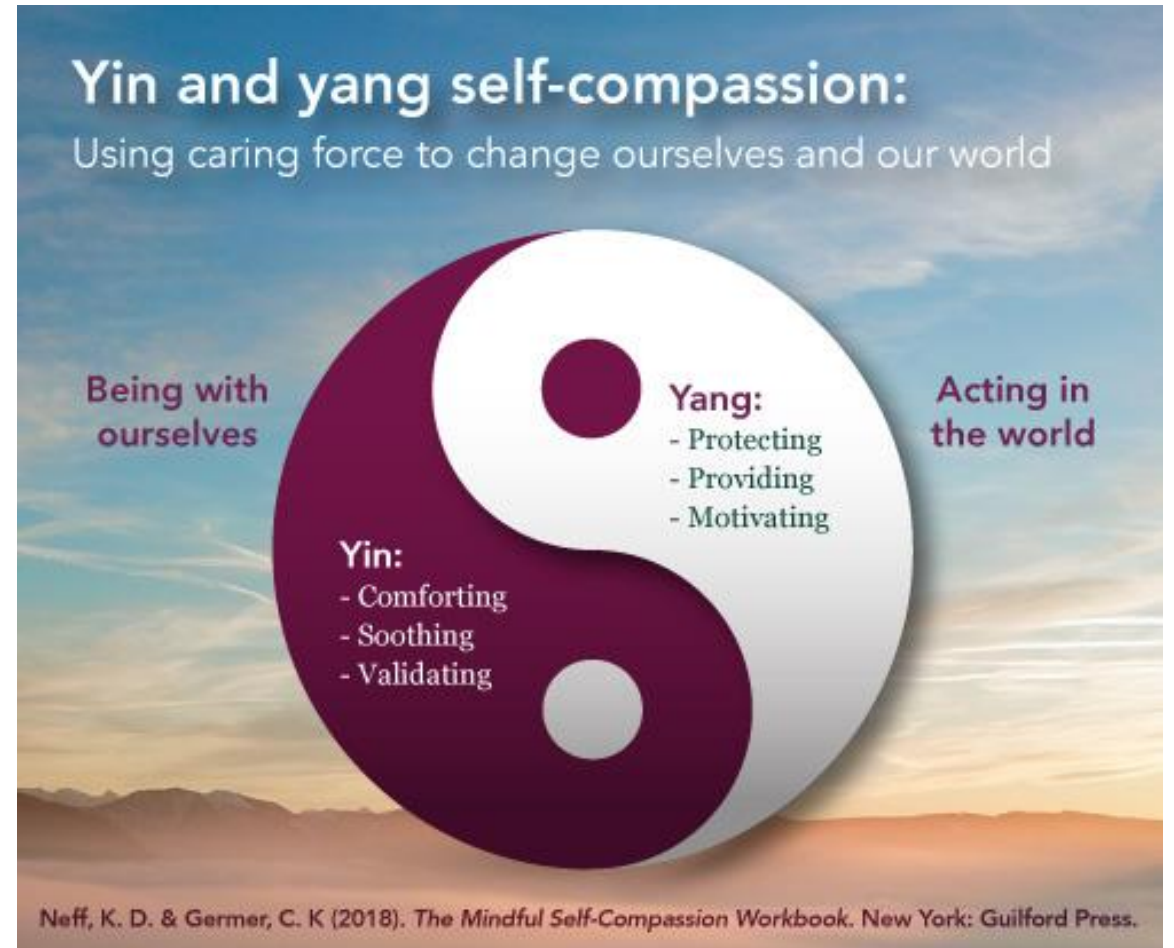


Mindfulness Meditation



Self-Compassion

- Exercise: How Would
- You Treat a Friend



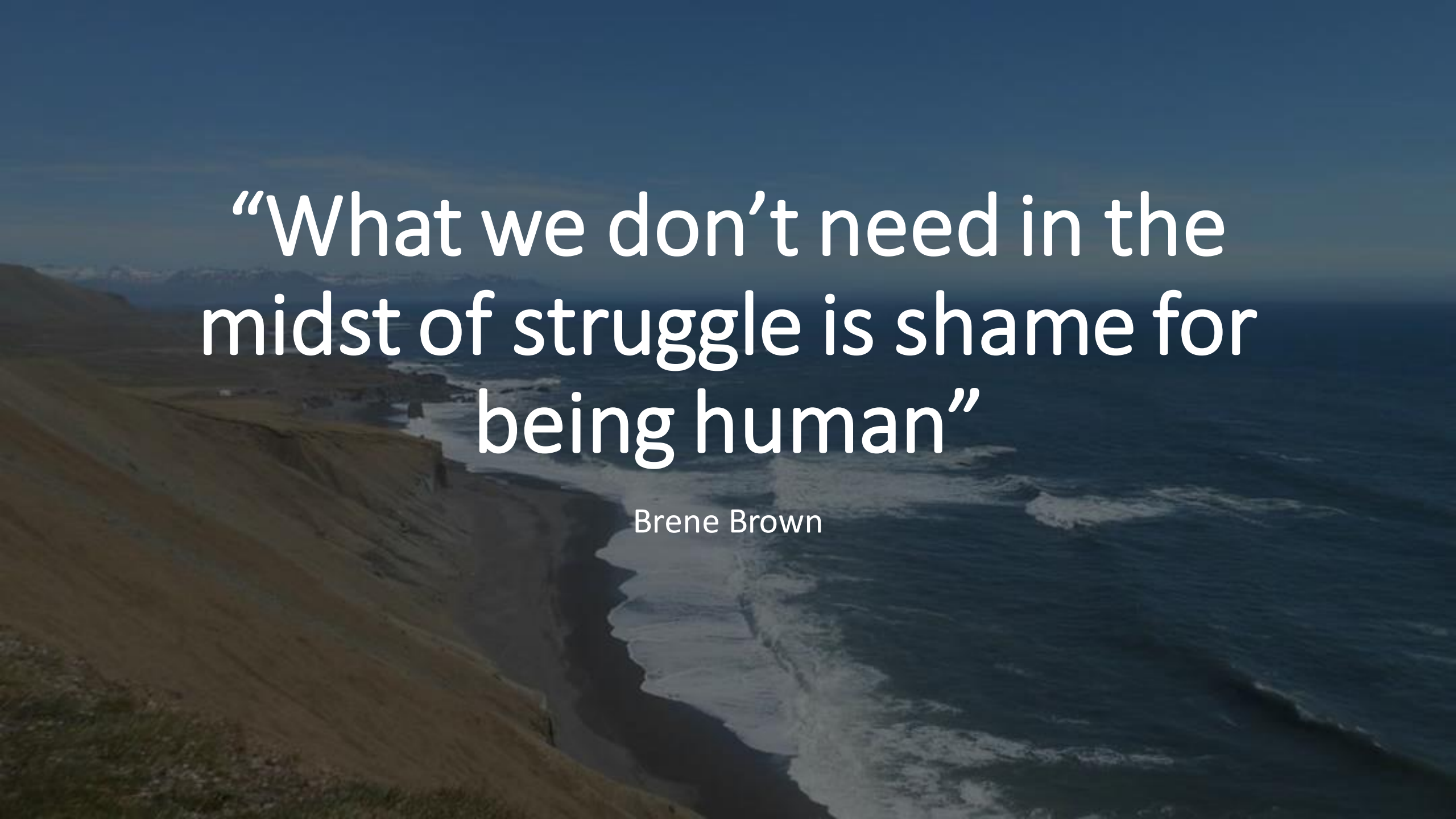
A close-up photograph of a Lantana plant. The image is filled with numerous small, tubular flowers in various stages of bloom, displaying a vibrant color palette of orange, red, and yellow. The flowers are densely packed into clusters. Interspersed among the flowers are large, green, serrated leaves with prominent veins. The background is dark and out of focus, making the plant stand out. Overlaid on the center of the image is the text "Questions & Discussion" in a white, serif font.

Questions & Discussion



What to do? What can be done?

Tune in to: Lessons Learned: Patient, Sibling,
and Parent Psychosocial Care in Complex Care
June 1, 2023



“What we don’t need in the
midst of struggle is shame for
being human”

Brene Brown

Presentation Resources

- Doyle, Glennon. (2020). *Untamed*. Random House Books: New York.
- Germer, C., & S. Geller. (April 26 & 27 2021). Self-Compassion in Clinical Practice, *Mission Empowerment*.
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- Nagoski, E & Nagoski, A. (2019). *Burnout; The Secret to Unlocking the Stress Cycle*. Random House Publishing: New York.
- Neff, Kristin. (October 13, 2021). Self-Compassion: Relating to Others with Kindness, *Mission Empowerment*.
- Neff, Kristin. (November 4, 2021). *Fierce Self-Compassion: Relating to Others Without Losing Ourselves*, *Mission Empowerment*.
- Zlodre, Natalie. (2019). Trauma Counseling for Frontline Workers; *Sick Kids Centre for Community Mental Health*.