

Lessons Learned:

Patient, Sibling, and Parent Psychosocial Care in Complex Care

Project ECHO – Core Competency

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Agenda

- Introductions
- Parenting a Child with Chronic Illness
- Social Work & Complex Care
- Mental Health & Social Work
- Caring for the Caregiver (C4C)
- Therapeutic Relationship
- Grounding & Trigger Management
- Family Systems Theory & Attachment
- Self-Compassion
- Boundaries
- Setting Colleagues Up for Success
- Questions/Discussion



INCLUSIVE COSTUMES

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

Parenting a Child with Chronic Illness

Meta-Analysis > J Pediatr. 2020 Mar;218:166-177.e2. doi: 10.1016/j.jpeds.2019.10.068.

Epub 2020 Jan 6.

Health Outcomes of Parents of Children with Chronic Illness: A Systematic Review and Meta-Analysis

Liel N Cohn¹, Petros Pechlivanoglou², Yuna Lee³, Sanjay Mahant⁴, Julia Orkin⁵, Alanna Marson⁶, Eyal Cohen⁷

Affiliations + expand

PMID: 31916997 DOI: 10.1016/j.jpeds.2019.10.068

Abstract

Objective: To assess health outcomes of parents caring for children with chronic illnesses compared with parents of healthy children.

> Arch Dis Child. 2020 Nov;105(11):1028-1030. doi: 10.1136/archdischild-2019-318729.

Epub 2020 May 6.

Caring about caregivers: the role of paediatricians in supporting the mental health of parents of children with high caregiving needs

Benjamin Rotberg¹, Jean Wittenberg¹, Julia Orkin^{2 3}, Natasha Ruth Saunders^{2 3 4}, Eyal Cohen^{5 3 4 6}

Affiliations + expand

PMID: 32376696 DOI: 10.1136/archdischild-2019-318729

> Acta Psychiatr Scand. 2020 Oct;142(4):264-274. doi: 10.1111/acps.13181. Epub 2020 Jun 10.

Increased maternal new-onset psychiatric disorders after delivering a child with a major anomaly: a cohort study

B Rotberg¹, E Horváth-Puhó², S Vigod^{3 4}, J G Ray^{3 5}, H T Sørensen^{2 6}, E Cohen^{2 3 7}

Affiliations + expand

PMID: 32406524 DOI: 10.1111/acps.13181

Abstract

Background: The birth of a child with a major congenital anomaly may create chronic caregiving stress for mothers, yet little is known about their psychiatric outcomes.

“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



Role of Social Work in Complex Care

Responsibilities

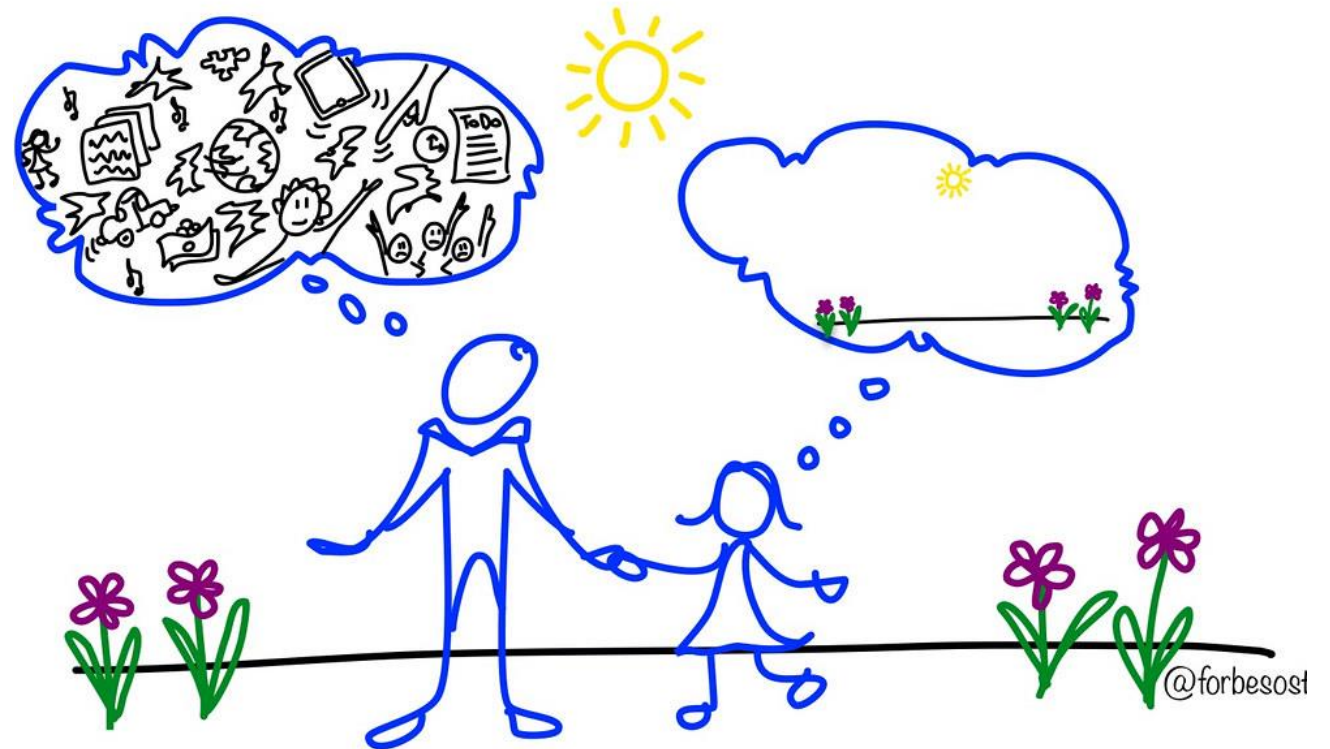
- Crisis Intervention
- Complex child protection/ethical consultation
- Complex resource navigation
- Complex social advocacy
- Psychotherapy (inpatient & outpatient)
- Palliative/end of life work
- Transition support
- Funding applications
- Psychoeducation for staff
- Consulting/supporting team
- Attending multidisciplinary clinic visits

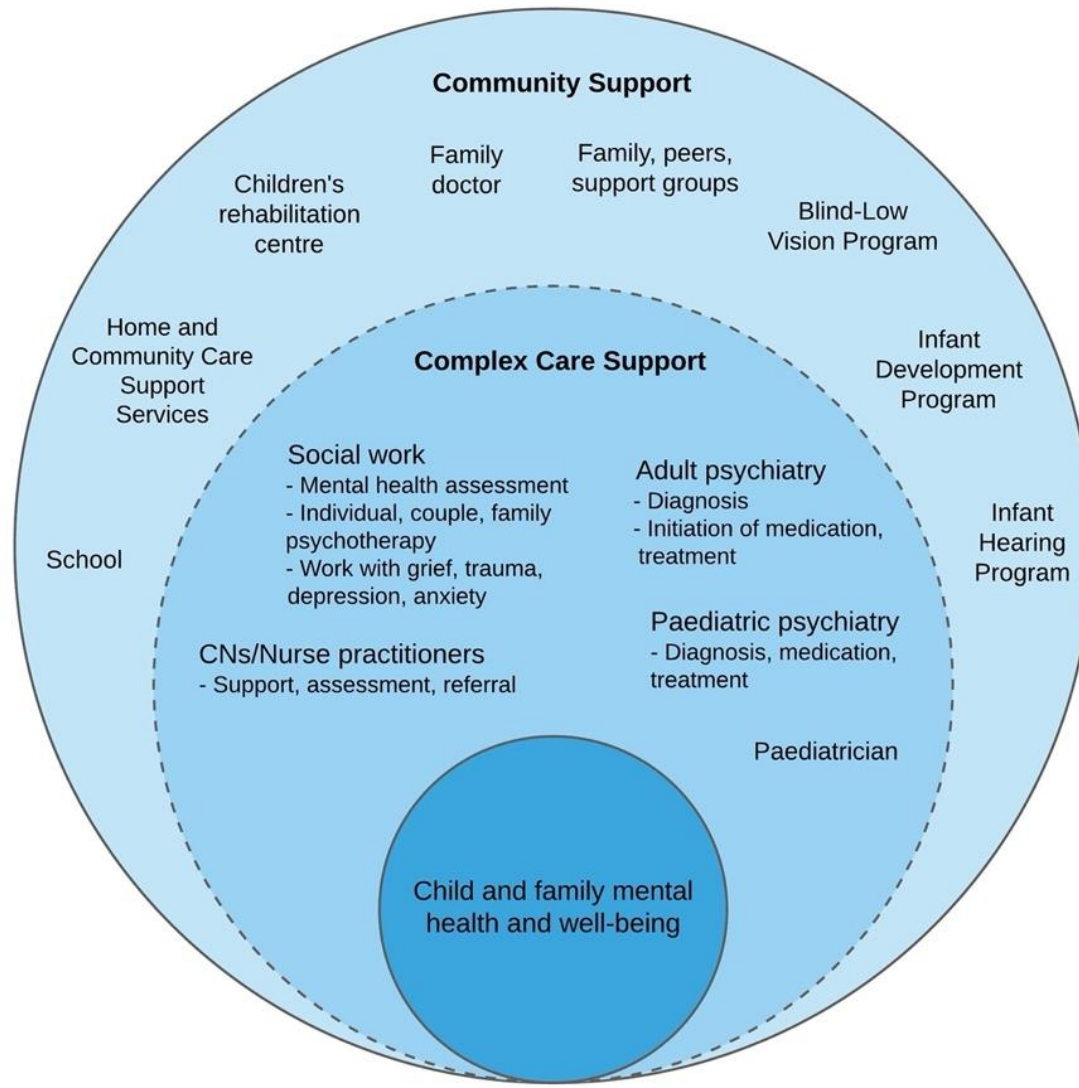


Mental Health & Social Work

- Guiding Principles
 - Strength Based
 - Trauma Informed
 - Anti-Oppressive
 - Anti-Colonialist
- Assessment
- Intervention
 - Narrative Therapy
 - Emotion Focused Therapy
 - Internal Family Systems Therapy
 - Cognitive Behaviour Therapy
 - Dialectical Behaviour Therapy
 - Mindfulness Self Compassion
 - Family Therapy

Mind Full, or Mindful?

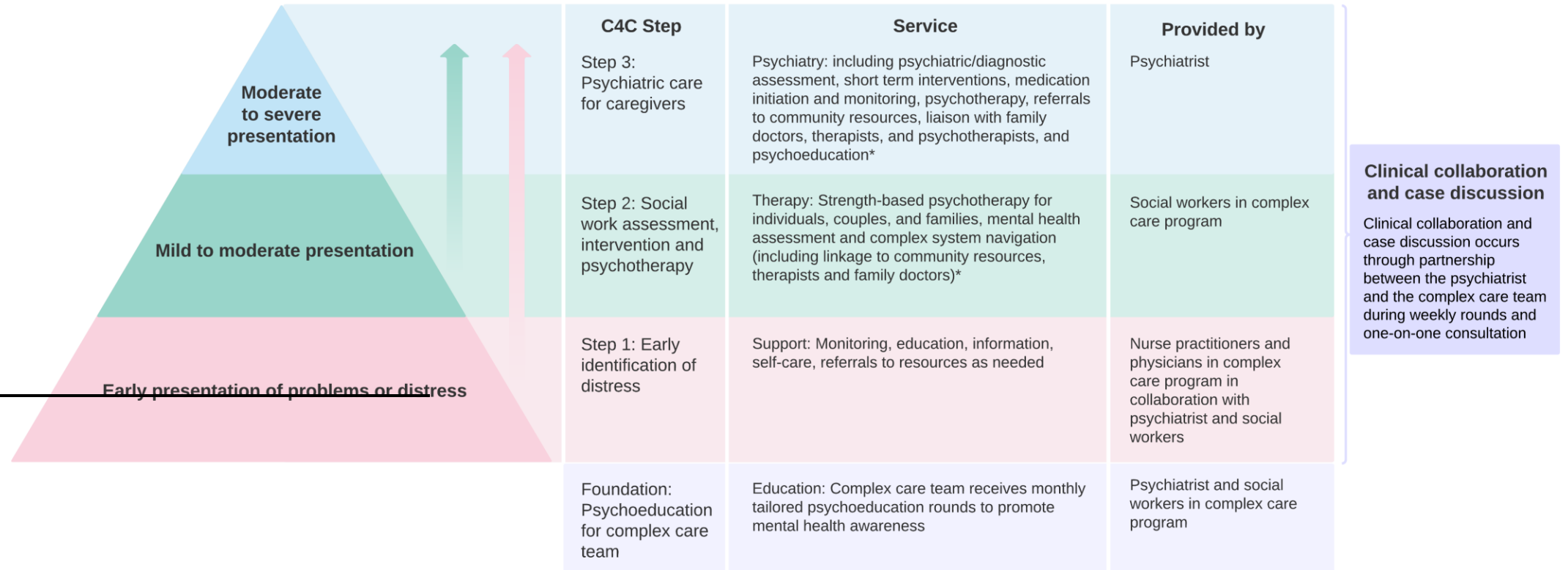




Caring for the Caregiver (C4C): An integrated psychiatric care model to improve caregiver mental health

Analyssa Cardenas MSc¹, Kayla Esser BAartsSc¹, Elisabeth Wright MSc, MD, FRCPC², Kathy Netten MSW, RSW³, Ashley Edwards MSW, RSW³, Julie Rose⁴, Simone Vigod MD, FRCPC², Eyal Cohen MD, MSc, FRCPC^{1,3,5,6}, Julia Orkin MSc, MD, FRCPC^{1,3,5}

C4C Study: Current SK CC Mental Health Model

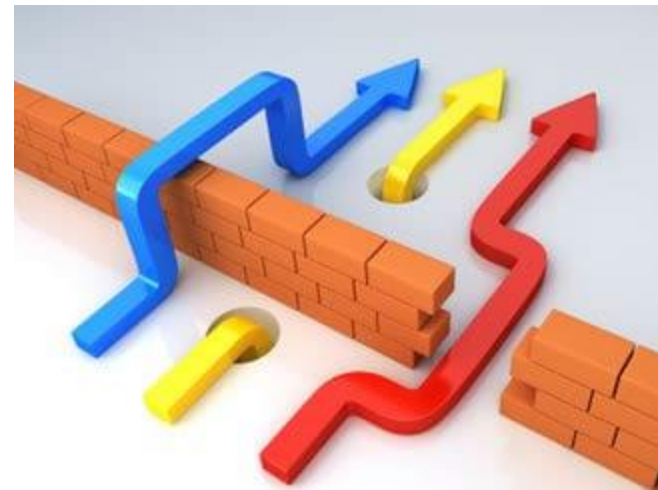


*Previous supports continue to be provided

C4C Study: Current SK CC Mental Health Model

Therapeutic Relationship

- Stabilize the de-stabilized client
- Access the “general factor” of therapy
 - Support
 - Connection
 - Validation
 - Atunement
 - Compassion
- Use therapeutic relationship to process unprocessed content



Increase Emotional Regulation Skills

- Grounding
- Relaxation
 - Progressive
 - Breath Based
 - Within Session
- Mindfulness
- Emotional Discrimination





Grounding

- Mental Grounding
- Physical Grounding
- Soothing Grounding

(Najavits, 2001)

Trigger Management

- Detection of triggered states
- Psychoeducation around distress reduction behaviours
- Harm reduction
 - Delay as long as possible
 - Do as little as possible
 - Replacing/distracting
- ReGAIN for triggered states

(Briere & Brach)



F-Words in Childhood Disability



REVIEW ARTICLE | [Open Access](#) | [CC](#) [BY](#) [NC](#) [ND](#)

The 'F-words' in childhood disability: I swear this is how we should think!

P. Rosenbaum [✉](#) J. W. Gorter

First published: 01 November 2011 | <https://doi.org/10.1111/j.1365-2214.2011.01338.x> | Citations: 252

The copyright line for this article was changed on 18 November 2016 after original online publication

[SECTIONS](#)



PDF



TOOLS



SHARE

Abstract

- Function
- Family
- Fitness
- Fun
- Friends
- Future

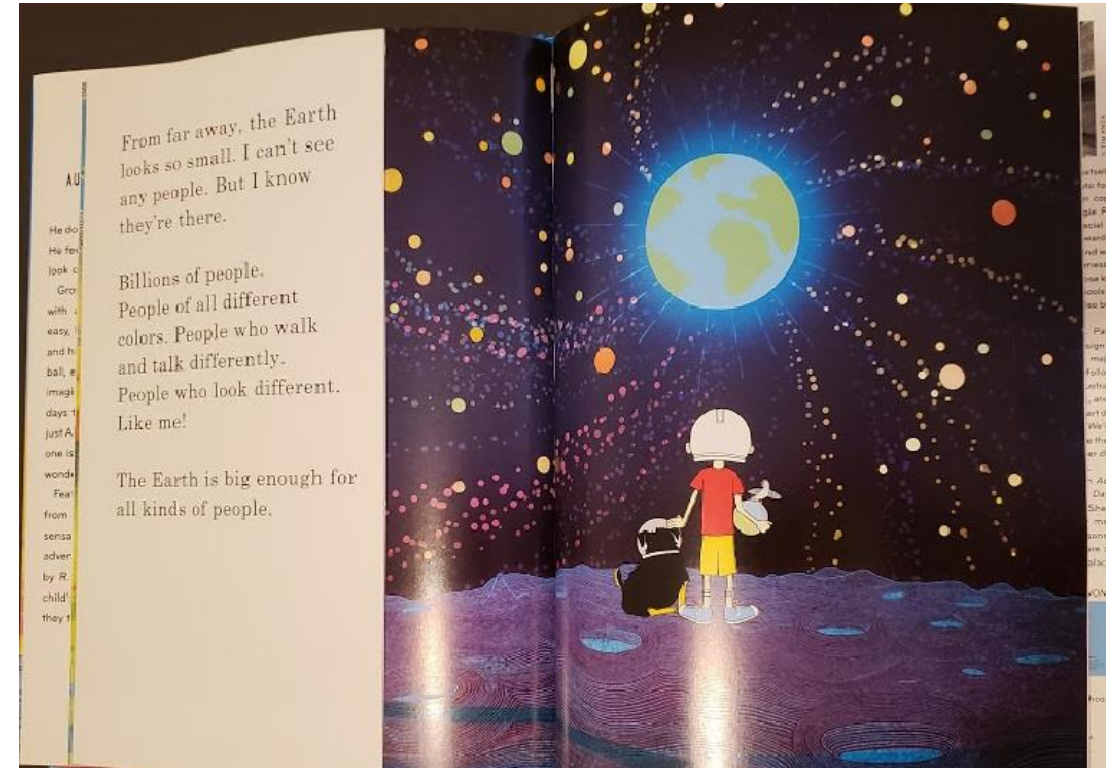
Child/Patient

- Child Life Specialists
- Teachers
- Therapeutic Clowns
- Art Therapy
- Music Therapy
- Consultation Liaison Psychiatry
- Abilities
- Social Work



Social Work & Siblings

- Mental Health
 - With the sibling, parent, family
 - Assessment, treatment/intervention
 - Virtual and In person
- Parenting children with different needs
- Partnership with others
 - Music & Art Therapists
 - Child Life Specialists
 - Infant Development
 - Children's Treatment Centres
 - Care Coordinators
 - Rehab Staff
 - Mental Health Staff
 - Extended family
 - Schools
 - Psychiatry
 - And more!



(Palacio 2017)

Family Systems Theory

- What is a family?
- Family Systems Theory
 - Context
 - Life Cycle
 - Construct/Meaning
 - Values
 - Communication Patterns
 - Family Identity
- Attachment



Strategies

- Limits
- Boundaries
- Validation
- Emotion Coaching

EFFT - Emotion Coaching Framework Cheat Sheet

Step 1 - Validate

A. Convey understanding of their experience (from their point of view):

I could understand you...

I could imagine you...

No wonder you...

It would make sense that you...

When I put myself in your shoes I could imagine you...

...might feel/think/want to/not want to _____

B. Demonstrate that you "get it" with sincerity and in a way that reflects their positive intentions, vulnerable feelings, or attempts for relief from pain:

because 1: _____ because 2: _____ because 3: _____

Example:

I could understand you might feel/think/want to/not want to _____ because #1

No wonder you might feel/think/want to/not want to _____ because #2

It would make sense that you might feel/think/want to/not want to _____ because #3

Step 2 - Support

A: Emotional support ideas

- Comfort (a hand, a hug or loving words)
- Reassurance ("It's going to be ok")
- Communication of understanding ("I understand you"; "I hear you")
- Communication of positive regard ("I know you are doing the best you can right now")
- Communication of belief in the other ("I believe in you; "I believe you can do this")
- Communication of togetherness ("We're in this together"; "I want the best for you too")
- Space* (Why don't I give you a few minutes and we'll try again)

*space can be physical or psychological *and* time-limited in that the plan for reconnection must be clearly communicated

B: Practical support ideas

- Proceed with plan
- Suggest a distraction activity (walk, movie, music, etc)
- Redirect to another thought or activity
- Teach skills
- Exposure to the anxiety-provoking stimulus (in a gradual way)
- Offer solutions to solve the practical problem or take over to solve the problem
- Set a limit
- N/A (sometimes, once the other is validated and supported emotionally, no more is required)



“I’ve learned that
people will forget
what you said. People
will forget what you
did, but they will
never forget how you
made them feel”

Maya Angelou

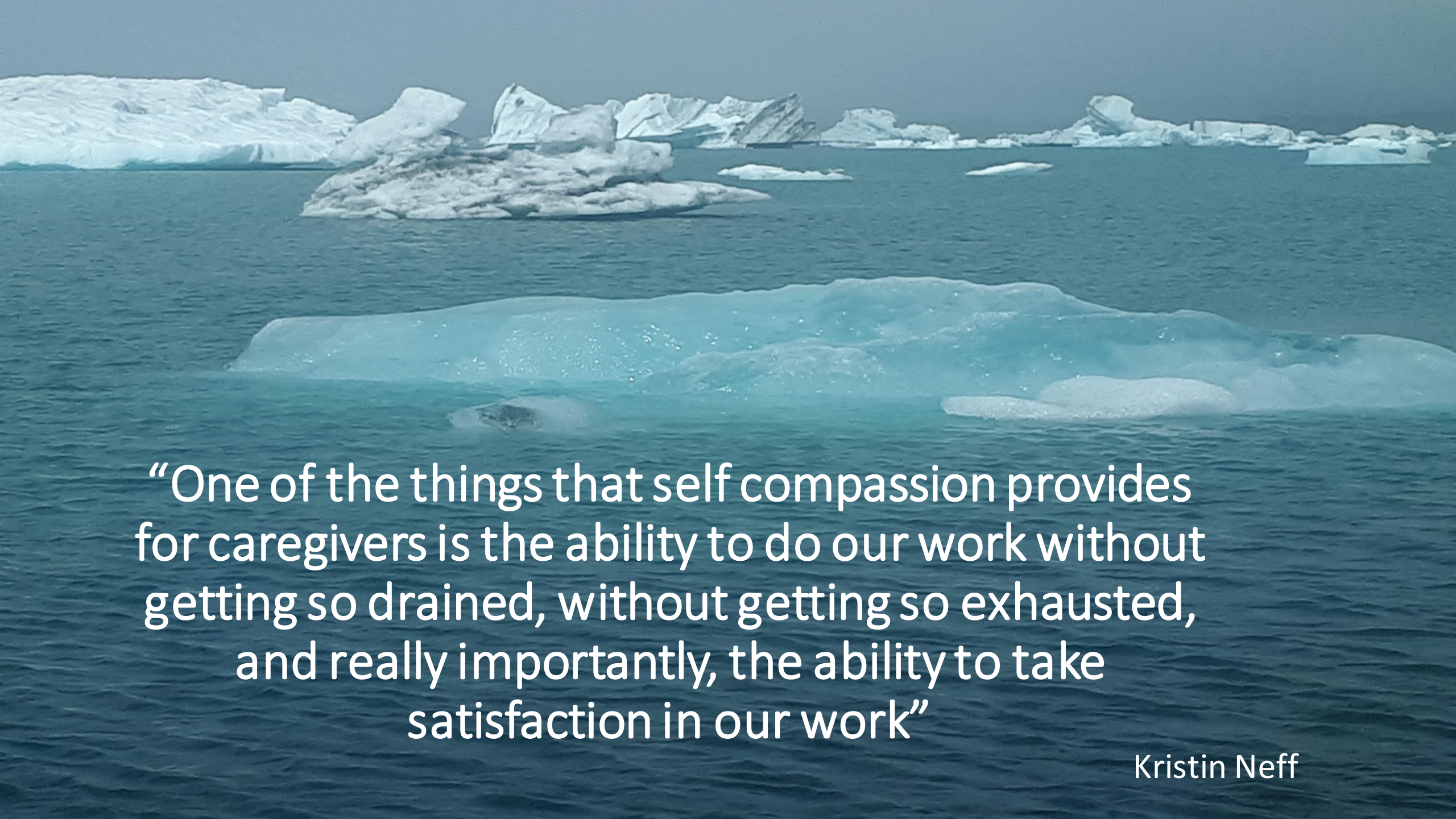




“Self Compassion is the Antidote to
Empathy Fatigue”
(Neff 2021)

Now What: Self Compassion

- **Self Compassion:** “Treating ourselves with the same kindness and understanding as we would treat a dear friend when these things go wrong”
- **Universal expressions of compassion:**
 - Warm gaze
 - Soothing touch
 - Gentle Vocalization
- **Merits of Self-Compassion**
 - Increases in Well-Being
 - Improved affect
 - Reduced Stress & Shame
 - Physical Health Benefit
 - Quality Relationships
- **3 Components of Self-Compassion:** Kindness, Common Humanity, Mindfulness (Neff 2003)

A photograph of several icebergs floating in a dark blue ocean under a clear sky. The icebergs are white and jagged, with some showing signs of melting. The water is a deep, dark blue, and the sky is a pale, clear blue.

“One of the things that self compassion provides for caregivers is the ability to do our work without getting so drained, without getting so exhausted, and really importantly, the ability to take satisfaction in our work”

Kristin Neff

Mindfulness Self-Compassion

- Nurturing
- Fierce



What are Boundaries?

- “something that indicates or fixes a limit or extent”
 - (Merriam-Webster, 2019)
- “Personal **boundaries** are guidelines, rules or limits that a person creates to identify reasonable, safe and permissible ways for other people to behave towards them and how they will respond when someone passes those limits”

(Wikipedia, 2019)



Why are they important?

Why are we talking about them?



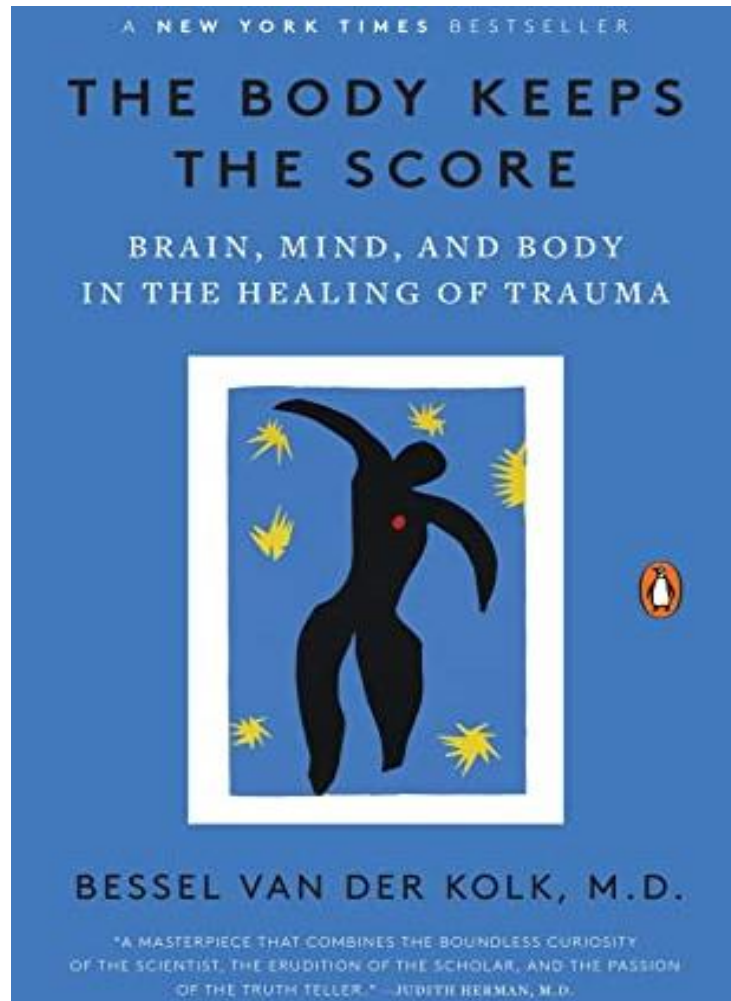
- Set expectations
- Create safety & trust
- Respect
- Vulnerable State: families might be more susceptible to boundary crossing
- Snowballing

A close-up photograph of a white plastic funnel pouring water onto a small green seedling in a dark pot. The water is captured mid-pour, creating a dynamic spray of droplets. The seedling has two small leaves and a thin stem. The background is dark and out of focus.

Tips to Set You & Your Colleagues Up for Success

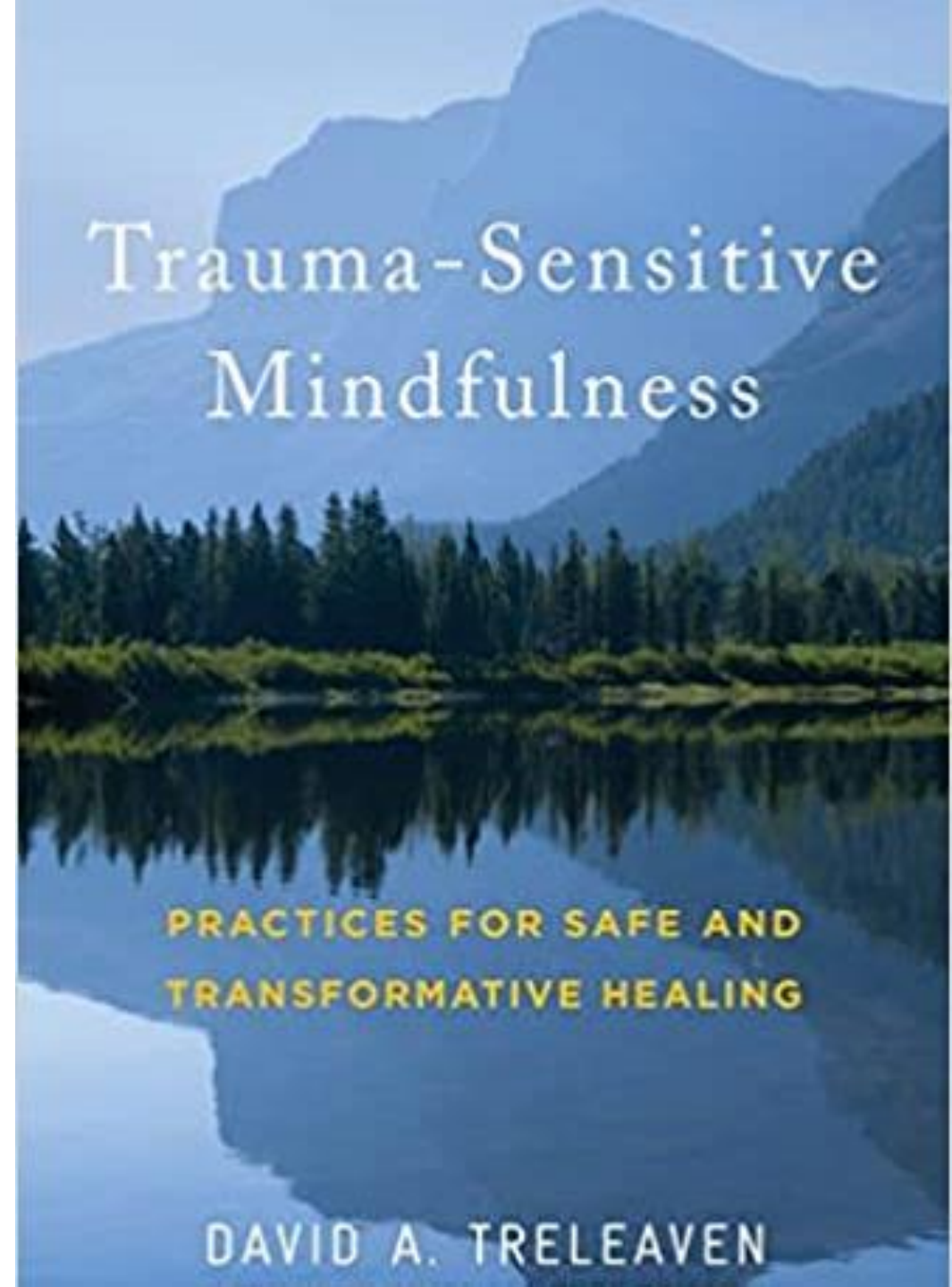
- Consistency
- Under Promise, Over Deliver
- Say No
 - Creates boundary and with compassion
 - Kind and firm
 - Creates safety for speaker and listener
- Validate the Feeling

Trauma & the Health Care Professional



- *The Body Keeps the Score* – Dr. Bessel Van Der Kolk
 - “Being traumatized means continuing to organize your life as if the trauma were still going on—unchanged and immutable—as every new encounter or event is contaminated by the past.” (p53)
 - “Traumatized people chronically feel unsafe inside their bodies: The past is alive in the form of gnawing interior discomfort. Their bodies are constantly bombarded by visceral warning signs, and, in an attempt to control these processes, they often become expert at ignoring their gut feelings and in numbing awareness of what is played out inside. They learn to hide from their selves” (p97)
 - “We have learned that trauma is not just an event that took place sometime in the past; it is also the imprint left by that experience on mind, brain, and body. This imprint has ongoing consequences for how the human organism manages to survive in the present. Trauma results in a fundamental reorganization of the way mind and brain manage perceptions. It changes not only how we think and what we think about, but also our very capacity to think.” (p21)

Trauma Sensitive Mindfulness





Thank You!

Questions/Discussion