

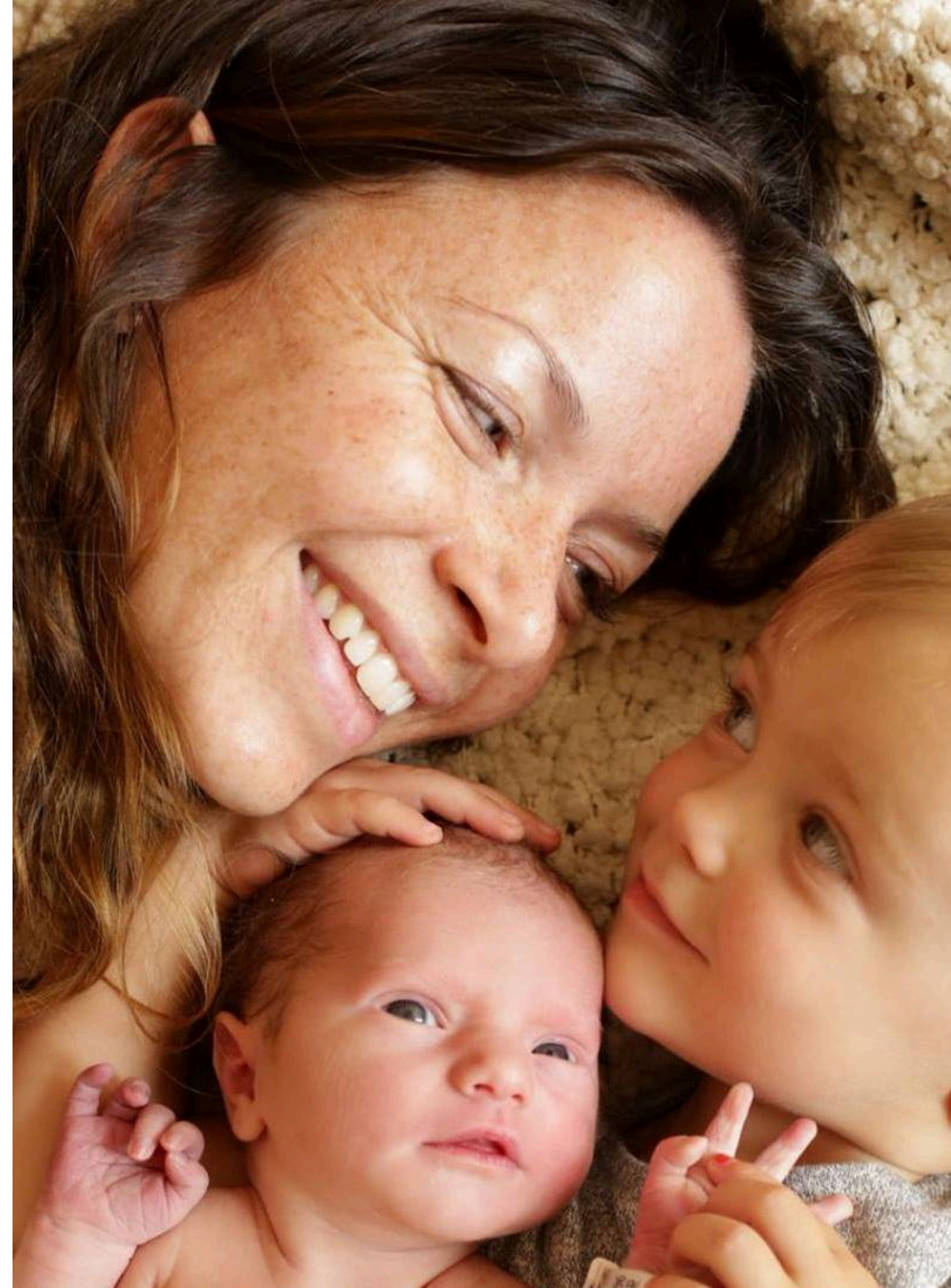
A young girl with a cochlear implant and a woman embracing outdoors. The girl is wearing a yellow sweater and has a cochlear implant on her head. The woman is wearing a white sweater and has her hand on the girl's shoulder. They are standing on a wooden deck with a railing, overlooking a body of water and mountains in the background.

Using Narrative Medicine to inform best practices in Early Intervention

by Megan Nix, MFA
Author of *Remedies for Sorrow*, Doubleday 2023

My Story

- 2nd daughter, Anna, born in 2015
- At 10 days, found out she had **congenital CMV**
- Ubiquitous virus, never heard of it
- **90% of women** in the U.S. haven't heard of CMV
- Leading cause of “birth defects”
- And non-genetic deafness
- At 1 month, found out she was profoundly deaf
- We live on a **remote island** in Alaska
- **Isolation** of her disease
- **Isolation** of place
- **Isolation** of language



The Impact of Illness

- **Identity:**
 - Retroactive thinking: 1 out of 3 toddlers carry CMV
 - Outrage: OBs are instructed NOT to discuss with pregnant women
 - Living with uncertainty
- **Marriage:**
 - Pacificist / realist
 - Settings and their purpose
- **Time**
 - Therapies
 - Research
- **Emotions**
 - Confusion about VAST silence of CMV
 - Desired answers and a common yearning
 - Also...wanted to tell our story



REMEDIES FOR SORROW

An Extraordinary Child, a Secret
Kept from Pregnant Women, and a
Mother's Pursuit of the Truth

MEGAN NIX



The story of my book

- 8 years to research, write, and find a publisher
- During year 6, I realized...
- Maybe it was not just **the narrative of CMV** missing from medicine
- What if MOST of medicine was **missing its patients' narratives?**

Dr. Rita Charon: founder of Narrative Medicine

- Physician at Columbia University in the '90s
- From Henry James's *The Wings of the Dove*:

“So crystal clean **the great empty cup of attention** that he set between them on the table...it was like **an absolute possession, a new resource altogether**, something done up in the **softest silk** and tucked away **under the arm of memory**...She hadn't had it when she went in, and **she had it when she came out**, she had it there under her cloak, but dissimulated, **invisibly carried.**”
- Returned to Columbia for PhD in Literature
- Started a program in Narrative Medicine
- Wanted **all** medical students to **study literature** to better understand the stories of their patients



Reading literature can transform provider-patient relationships

- **Skills** built through deep reading:
 - To adopt **alien perspectives**
 - To follow the **narrative thread** of the story of another
 - To be **curious** about others' motives and experiences
 - To tolerate the **uncertainty** of stories
- Provider and patient enter an "**attentive present**" together





Early Intervention is where I found the “attentive present”

- Early Interventionist, Susie Broderick
- ASL teacher, Cathy Noble-Hornsby
- AVT, Joanna Stith
- Audiologist, Alison Biever

“Health care professionals might be among the few **trained confidantes** available to individuals in ordinary life, replacing the confessors or spiritual advisors of former times as **the vessels**, sworn to secrecy, of **others’ fears and sorrows**...they incur obligations toward patients’ **total well-being** by virtue of what their patients tell them.” –Dr. Rita Charon, *Narrative Medicine*



Mutual Benefit

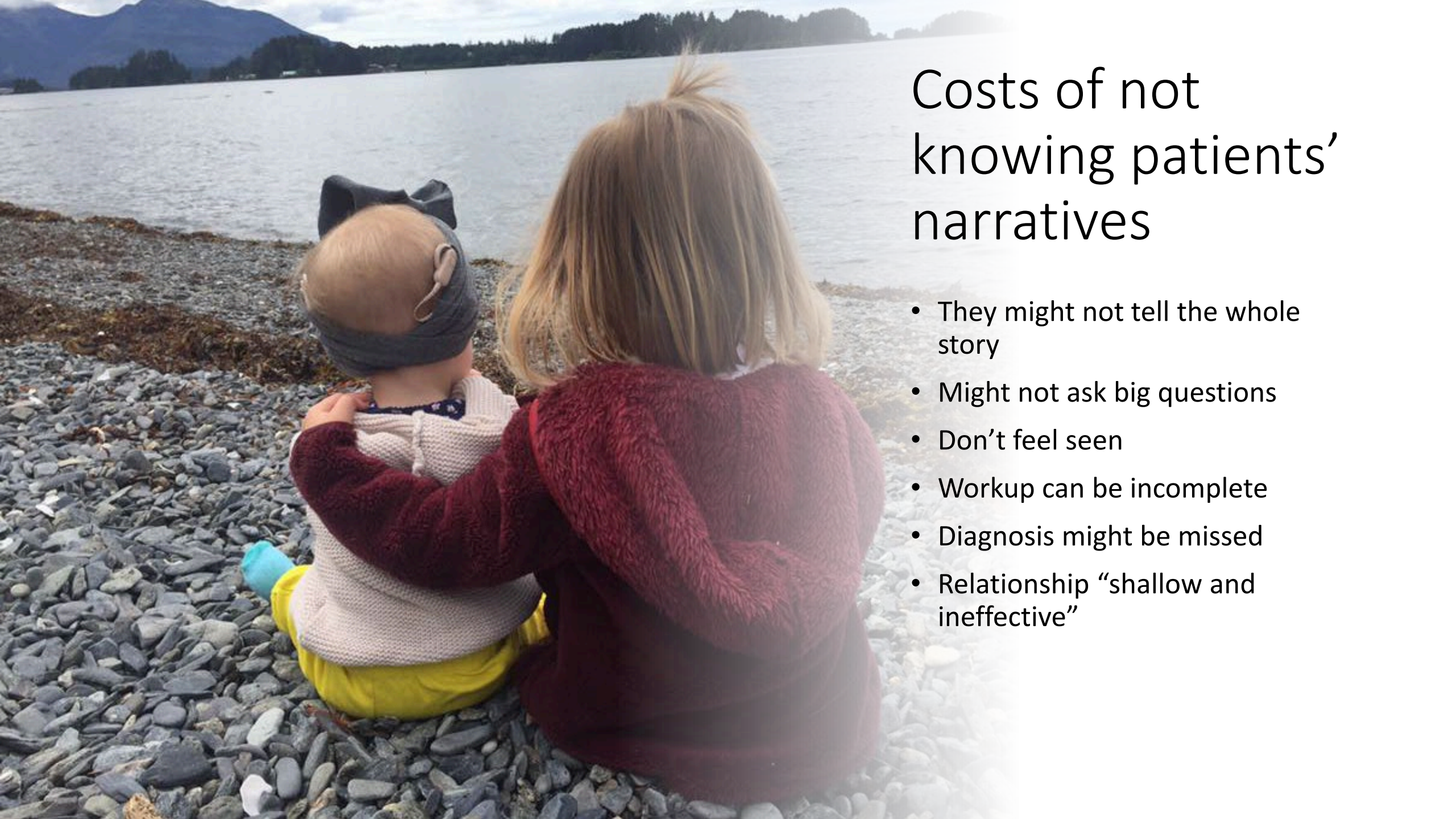
- “Do we not feel **exhilarated** when we can achieve this empty attention, when we can place ourselves **at the disposal** of the other, letting the other talk through us?...
- **Attention** may be the most pivotal value in all our work—to attend **gravely, silently, absorbing oceanically** that with which the other says, connotes, displays, performs, and **means.**”
–Dr. Rita Charon, “Narrative Medicine,” *JAMA* 286

The Three Traits of Narrative Medicine

- 1. Attention
 - Paying attention to the patient **in their entirety**
- 2. Representation
 - Writing down the story of the patient **in your own words**, even poetically, so as to discover something new about them, yourself, **humans**
- 3. Affiliation
 - The **lasting connection** made, which hopefully becomes an **illuminating** affiliation with all humans
 - And the “**fear** and **hope** and **love** exposed in sickness” (RC)

Excerpt from *Remedies for Sorrow*, page 280





Costs of not knowing patients' narratives

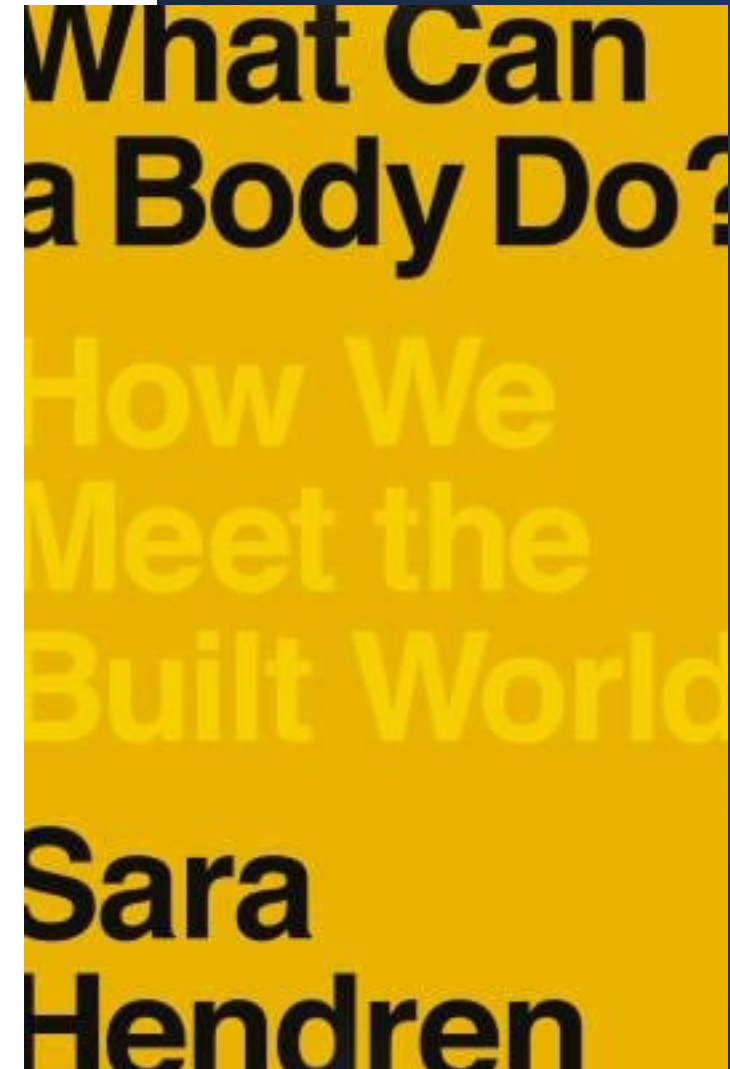
- They might not tell the whole story
- Might not ask big questions
- Don't feel seen
- Workup can be incomplete
- Diagnosis might be missed
- Relationship "shallow and ineffective"

Exercise #1: Read

From Virginia Woolf's essay "How Should One Read a Book?"

"Open your mind as widely as possible, then signs and hints of almost imperceptible fineness...will bring you into the presence of a human being unlike any other."

- Exercise: Choose one person at your table to read an excerpt aloud from WHAT CAN A BODY DO? and discuss at your table
- What lines hint at the "almost imperceptible fineness" of this narrator?
- Where is the narrator in the text? Close to the subject or at a distance OR both?
- Do you feel any of your own assumptions have been challenged by this passage?



Exercise #2: Pay Attention

Imagine an interaction you had with a patient / student / your child.

Place yourself back in that setting for five minutes and notice everything you can.

“Actively mute inner distractions to concentrate the full power of presence...

Attention can be **complex**, **demanding**, and **difficult** to achieve.” (RC)



Exercise #3: Representation

- Represent / document what you have witnessed
- “When health professionals write, **in whatever genre and diction they choose**, about clinical experiences, they, as a matter of course, **discover** aspects of the experience that, until the writing **were not evident to them.**”
- In Dr. Charon’s practice, initial intake note reads:
- *Severely ill 52 yo man*
- After listening to his story of joy, hard work, hard play, and a sudden loss of autonomy, her medical note begins:
- *Man of tremendous courage.*
- Medical students report: *Yes, now that I have written that description, I understand what I thought or felt about this patient.*

Write for 10 minutes about someone you’ve worked with in your practice. Try to choose someone whose story you can “tell from the beginning.”

Parents, you can choose your child or you can choose one of their providers.

You can write a poem or prose.

You may want to focus on one interaction you had with this person. Be moved by all that you notice.

...about them and about yourself.



Exercise #4: Affiliation

- I **can do things** for my patients / my child / my clinic as a result of **narrative actions**
- I can **reach my colleagues** and teammates more **personally** and **consequentially**
- I **can build community** through **deep attention** to the people around me
—from *Narrative Medicine*, Rita Charon



Exercise #5: Brainstorm ways to incorporate narrative medicine

- Example: Minnesota EI **study guide** for *Remedies for Sorrow*
- Exercise: Write down **two ways** you could bring narrative medicine into your organization / personal practice

REMEDIES FOR SORROW Book Study

Author: Megan Nix
Created 2023



BOOK STUDY GUIDE - MINNESOTA

The following book study prompts were created with the purpose of supporting educational practitioners in Minnesota. The following people contributed to the creation of this resource:

- ★ Ann Mayes, Minnesota Low Incidence Projects
- ★ Brandy Johanson Sebera, Minnesota DeafBlind Project
- ★ Carla Larson, Metro Deaf School
- ★ Deanna Rothbauer, Minnesota DeafBlind Project
- ★ Gina Liverseed, Minnesota Department of Health
- ★ Jess Moen, Minnesota Low Incidence Projects
- ★ Jodi Altringer, Minnesota Center of Excellence for Young Children with Disabilities
- ★ Mary Cashman-Bakken, Minnesota Department of Education

PURPOSE:

Each book study group may have varying needs. For that reason this document has many prompts and resources for each part of the book. The book study facilitator is encouraged to select the prompts and resources that make the most sense for the group participating in the shared learning.

The MN Low Incidence Projects and this initiative are made possible with a grant from the MN Department of Education, federal award Special Education-Programs to States, CDEA 84.027A. Unless otherwise specified, this activity is not reflective of official policies or recommendations of the MN Low Incidence Projects, Brightworks MN, the MN Department of Education, or local education agencies.

REMEDIES FOR SORROW Book Study

Author: Megan Nix
Created 2023



Part 1 - Weeping

Reflections for early intervention providers:

1. How did the author's observations, opinions and descriptions of the medical culture during her pregnancy and confirmation of a diagnosis surprise you or confirm your thinking?
2. This section takes the reader through Anna's birth and the process of getting the initial diagnosis. The author seeks honesty and talks about anxiety, guilt and uncertainty as she searches for information and clues. What do you think the author wants you to understand and learn from this part of their story?
3. What themes emerged around the feelings she and others were experiencing throughout this part of their story?
4. How might the first part of Anna's story been different if her family hadn't had the support or resources that were described? How can we support equitable access to interventions for all babies with cCMV?
5. On page 8 Megan writes, "I'm sorry, but she actually failed on both sides." (referencing hearing screening). "She gives me no hope that Anna will be able to hear - which I appreciate later - just the information the wires have given her: sound met with silence." How professionals deliver information matters. How do these words set the stage for Anna's future care?
6. On page 20 and 21 the author notes the impact of the environment in the doctor's office on her experience and feelings. When looking at the pictures of the children on the walls she noted the lack of hearing aids, walkers, wheelchairs and glasses. What connections might be made to how educational environments impact families? How does your program ensure that they are creating as welcoming of an environment as possible?
7. On pages 23-24 Megan writes, "It's only when you're facing a diagnosis of congenital CMV (when the information is nine months too late) that you begin to learn about the disease - a condition the medical world has contested disclosing to pregnant women for the last seventy-some years." Many families that enter early intervention might know

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Recommended Reading

- *Narrative Medicine: Honoring the Stories of Illness* by Rita Charon
- *Raising a Rare Girl* by Heather Lanier
- *This Boy We Made* by Taylor Harris
- *The Spirit Catches You and You Fall Down* by Anne Fadiman
- *The Still Point of the Turning World* by Emily Rapp Black
- *The Diving Bell and the Butterfly* by Jean-Dominique Bauby
- *Hidden Valley Road* by Robert Kolker
- *True Biz* by Sara Novic
- *What Can a Body Do? How We Meet the Built World* by Sara Hendren
- *Remedies for Sorrow* by Megan Nix



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Follow me on Instagram [@remediesforsorrow](https://www.instagram.com/remediesforsorrow)

