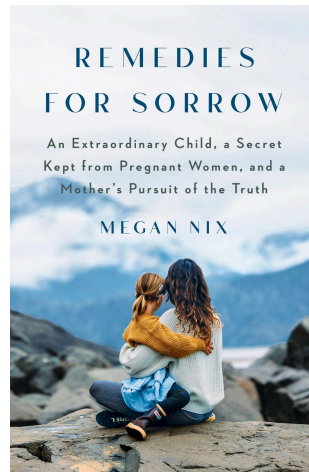


# REMEDIES FOR SORROW Book Study

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.

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## INDEX: REMEDIES FOR SORROW BOOK PARTS:

- ★ [Part 1 Weeping](#)
- ★ [Part 2 Contemplation](#)
- ★ [Part 3 Company](#)
- ★ [Part 4 Pleasure](#)
- ★ [Part 5 Caretaking](#)

## REMEDIES FOR SORROW RESOURCES:

- ★ [Megan Nix on her Memoir Remedies for Sorrow and risks of cCMV](#) - 2 minute YouTube video
- ★ Podcast from the National CMV Foundation titled "[Meet Megan Nix, CMV parent and author](#)" – 45 minutes

## CONGENITAL CYTOMEGALOVIRUS RESOURCES:

- ★ Minnesota Department of Health [Congenital Cytomegalovirus Information for Families and Caregivers](#)
- ★ Minnesota Department of Health [Cytomegalovirus and Congenital Cytomegalovirus](#)
- ★ [National CMV Foundation](#)

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## 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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little about their child's diagnosis. How can we reach women sooner to educate about CMV? What can we do to support families who are still learning about CMV themselves?

8. "We don't always say something's hard when it's happening." (page 34) Families often have many things they are juggling, working through, learning about, etc... How can we as practitioners learn to recognize and respect whatever stage of their process they are in? What supports and/or resources can we offer? What language might we consider using?
9. We learn that Congenital CMV can manifest with notable symptoms or the baby can look typical but exhibit progressive symptoms over time and the spectrum of those symptoms are broad. The nature of Congenital CMV might result in a great deal of uncertainty and anxiety as the progression unfolds. How can early interventionists support families in "guarding their imagination" (page 57) as they seek information about their child's diagnosis? How might we support them through the uncertainty? Some children do not have physical signs of Congenital CMV...how does this impact early interventionists and working with children?
10. Paul Slovic (p. 40) shares about "compassion fade" (responding to mass tragedies with little interest, even apathy, as soon as our perception of an event extends beyond impacting an individual into impacting many.) How can the education field move beyond compassion fade?
11. On page 48 Megan writes, "I can feel she's concerned and listening. I will look for this audible compassion in every provider we see." How do we as early interventionists show our compassion? What does this look like, sound like, and feel like?
12. "Lynne tells me not to believe any predictions placed upon Anna's life." (page 57) Might this be similar for early interventionists? How can we check ourselves from only believing predictions and leave expectations open-ended?

## Resources to support early intervention providers:

- ★ [Minnesota Department of Health EHD](#)
- ★ [Minnesota Department of Health CMV and Congenital CMV](#)

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- ★ [Early Hearing Detection and Intervention National Technical Resource Center](#) (EHDI NTRC)
- ★ [National CMV Foundation](#)
- ★ [Marlana VanHoose](#) (mentioned on page 50)

## Notable Quotes and/or Facts from Part 1 Weeping:

*What was surprising about the facts or statistics you remember from this part of the reading?*

*Which quote resonates with you and why?*

*What connections to your work did you make after reading these quotes?*

*What other quotes or facts would you add?*

*Choose a quote and reflect on the author's intended message.*

- ★ "Hearing loss is the most common irregularity in infants from birth - and frequently a sign of systemic disease." (page 7)
- ★ "All former stability has undergone a silent but seismic shift." (page 13)
- ★ "I can't handle anything but honesty at this point." (page 21)
- ★ "In America, around 40,000 babies are born each year with CMV, of whom 6,000 to 8,000 will end up with lifelong disabilities. Children disabled by congenital CMV outnumber children disabled here by any other congenital condition or disease, including down syndrome, spina bifida, cystic fibrosis, and pediatric HIV." (page 25)
- ★ "And the percentages seem to silence a harrowing fact: that 100% of babies born with CMV have the potential to end up with permanent delays." (page 25)

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- 
- ★ “Congenital CMV is the leading cause of birth defects and developmental delays in the US.” (page 26)
  - ★ “I realize it might feel like a summer of saying no, but maybe it isn’t. Maybe it’s a season of learning a different yes.” (page 55)
  - ★ “Guard your imagination.” (page 57)

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## Part 2 - Contemplation

### Reflections for early intervention providers:

1. How did Zaley's acceptance of Anna impact the author?
2. What was the author's intended message about the medical culture and women as she described ACOG's stance on counseling pregnant women about CMV?
  - a. On page 69 the author tells her OB/GYN that Anna has CMV and asks if he ever counsels his patients about CMV, he replies; ACOG doesn't recommend it, plus women won't want to worry about one more thing.
3. On page 63 the author talks about the stigma of the disease and being upset that she needs to educate every woman about it. Consider how EI providers can support families as they prepare to explain, advocate, and share information about their child's diagnosis with family, friends and even other professionals.
4. "Who gets to decide what we can handle?" How do we make decisions on what information to share with parents/caregivers? In reference to the Abilene Complex described on page 67.
  - a. *The **Abilene paradox** is a collective fallacy, in which a group of people collectively decide on a course of action that is counter to the preferences of most or all individuals in the group, while each individual believes it to be aligned with the preferences of most of the others.*<sup>[1][2]</sup> (quote from Wikipedia)
5. On page 73, the author provides statistics regarding the number of infants with a CMV diagnosis compared to the prevalence of CMV. How might Minnesota change this narrative for our state because of the cCMV newborn testing we are doing? What does this potentially mean for Help Me Grow referrals? For early interventionists?
6. On page 87, the author outlines the process for her to secure the medicine needed for Anna, to be transported to rural Alaska. She states she feels like James Bond in her effort to get what her daughter needs. How might this feeling parallel what families in Minnesota might experience who are striving for resources/services/supports in all areas

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of our state? How can we advocate for our education system to support families equitably, no matter where they live?

7. The author discusses the differences in how she and her husband respond to stressors, specifically navigating insurance. (page 89) What are your stress relievers?
8. On page 103, the author talks about her feelings and thoughts after receiving confirmation that Anna can't hear. She feels guilty for not using more signs, for not erring on the side of caution that Anna had always heard nothing. What do you think the author would change? What might she have wanted professionals to do differently?
9. Families seek to talk about profound matters and moments of exchange. (page 105) How are practitioners facilitating and participating in that?
10. This chapter included information about their decision to have the cochlear implant surgery. What can our field learn from this? What practices, skills and competencies does our field need to call upon to support families in making informed decisions? How did this broaden your perspective about the complexity of some of the decisions families encounter? What strong beliefs or biases might you have noticed emerging as you read about their decision making? How might these impact any future conversations you might have with families about this topic?
  - a. DEC Recommended Practice F2: Practitioners provide the family with up-to-date, comprehensive, and unbiased information in a way that the family can understand and use to make informed choices and decisions.

## Resources to support early intervention providers:

- ★ [Roadmaps for reflection-support series](#): The roadmaps serve as a tool for planning a conversation or as a “guide on the side” during conversations related to helping families meet their family outcomes. The roadmaps guide practitioners in using coaching interaction practices during these conversations. There are guides for 18 different topics.
- ★ [Do service coordinators coach?](#) -this tool is a one page infographic summarizing how coaching interaction practices might look during service coordination.

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- ★ [Supporting Family Member Informed Decision Making](#): Practice Guide from ECTA. This practice guide provides strategies for involving family members in informed decision making.
- ★ [Involving Families in Obtaining Supports and Resources](#)-Practice Guide from ECTA: This guide includes strategies for actively involving caregivers in accessing family identified supports and resources in ways that build on family strengths and interests.
- ★ [“Washing Our Hands of the Congenital Cytomegalovirus Disease Epidemic.”](#) Mike Cannon, epidemiologist at the CDC, (referenced on page 86)
- ★ On page 93 Megan shares a conversation she has with Somer, audiologist, where Somer provides the information that two months of delay at such an early age could impact Anna’s language development noticeably. Watch the video by Dr. Rush and Dr. Shelden, [“Sharing My Expertise”](#) which discusses how early intervention specialists might consider providing families with information.

## Notable Quotes and/or Facts from Part 2 Contemplation:

***What was surprising about the facts or statistics you remember from this part of the reading?***

***Which quote resonates with you and why?***

***What connections to your work did you make after reading these quotes?***

***What other quotes or facts would you add?***

***Choose a quote and reflect on the author’s intended message.***

- ★ “5 minutes of counseling might have saved us from everything we are experiencing and about to experience.” (page 66)
- ★ “The truth I am after is proof that women can handle the facts-no matter how inconvenient, no matter how complex.” (page 66)
- ★ “Our kids won’t live common lives, they’ll live extraordinary ones.” (page 117)

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## Part 3 - Company

### Reflections for early intervention providers:

1. On page 125, Megan writes, “But I don’t feel like there’s any centralization of Anna’s information among all the specialists we’ve seen.” As early interventionists what systems do we have in place (or strive to have in place) that support the centralization of information?
2. Reflect on ableism themes that emerged in this section. Discuss wows, wonders, wishes and worries that resulted from the reading. A few examples:
  - a. Page 170: I decide I’ll never subtract from where Anna is, in her moment again.
  - b. Page 169: After Anna’s activation I am ready to get rid of the ableist equations.
  - c. Page 169: The Anat Baniel Method rejects the idea that all children would be held accountable to a typical timeline. Children who develop differently are not objects to be fixed but works in progress to whom we can play close attention and deeply connect.
3. On page 122, Megan writes, “I can see Luke filling the freezers in our garage with fish, and I envy him the ability to manage tasks without being destroyed, as I am, by the inexorable changes of our lives.” This is an opportunity to reflect on how different family members process information, change, and uncertainty in different ways at different speeds and with different types of support. How might we individualize strategies and interventions so that they meet the unique needs of fathers, siblings, and other family members?
4. On page 134 Karina talks about Jayden saying, “We took him everywhere and did everything with him whether or not he could fully participate. The point was to build an experience and memory.” What implications does this have for EI providers and programs? How does this perspective reflect the importance of following DEC Recommended Practices? What might these practices have looked like in action with Jayden’s family?
  - a. DEC RP E1: Practitioners provide services and supports in natural and inclusive environments during daily routines and activities to promote the child’s access to and participation in learning experiences.
  - b. DEC RP F3: Practitioners are responsive to the family’s concerns, priorities and

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Author: Megan Nix

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changing life circumstances.

- c. DEC RP F4: Practitioners and the family work together to create outcomes or goals, develop individualized plans and implement practices that address the family's priorities and concerns and the child's strengths and needs.
- 
5. Reflect on the impact of her informal support network that emerged in this section. Her friends helped with Zaley, learned sign language, fashioned a headband to solve a problem and brought her breakfast sandwiches. What does the DEC Recommended Practice (RP) F7 look like in your program? What conversations do you have with families that might help them identify the informal resources and supports they have and might access?
    - a. DEC Recommended Practice F7: Practitioners work with the family to identify, access and use formal and informal resources and supports to achieve family-identified outcomes or goals.
  6. On page 143, Megan writes the following about her new friend Lee's daughter, "But Anna's challenges are the kind you can't see: she's had to battle the tease of a seemingly typical body that isn't actually typical when it applies itself to the things she wants to do." How often does this happen in educational settings when a child's body appears 'typical'? As an educator, reflect on how you might place expectations on the students you work with? How might the student's physical body characteristics impact the expectations you set?

## Resources to support early intervention providers:

- ★ [Listen Foundation](#) - funded Anna's expensive speech therapies for three years. (page 142)
- ★ [Minnesota Deaf Mentor Program](#)
- ★ Ableism
  - [PBS Wisconsin Education Ableism](#) (6 minutes)
  - Access Living, [Ableism 101](#)
  - Inclusion Canada, [This is Ableism](#) (1 minute)

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- ★ [National CMV Foundation](#)
- ★ [National CMV Foundation Registries](#)
- ★ Warrior Beads: [Beads of Courage](#)

## Notable Quotes and/or Facts from Part 3 Company:

*What was surprising about the facts or statistics you remember from this part of the reading?*

*Which quote resonates with you and why?*

*What connections to your work did you make after reading these quotes?*

*What other quotes or facts would you add?*

*Choose a quote and reflect on the author's intended message.*

- ★ "Per 1,000 live births, 3 white infants are infected with CMV versus 9.5 Black infants. And Black children are up to twice as likely to die from CMV-related complications than white children." (page 130)
- ★ "CMV can lie dormant in the cells of the body, waiting for an opportunity to reactivate, similar to the herpes virus." (page 138)
- ★ "I just remember in the beginning, I was so angry," Lee says, "I was so mad that no one had told me about CMV." Staying silent does not help people to process what is happening and what has happened and the impact on the family and child." (page 143)
- ★ "Watching your child alter course due to any inability will heavy the heart." (page 143)
- ★ "Congenital does not just mean "from birth;" it means CMV will impact children until their deaths." (page 145)
- ★ "And their excitement about her makes me so excited, too." (page 170)

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## Part 4 - Pleasure

### Reflections for early intervention providers:

1. On page 188 Megan discusses her encounter with Kate, a medical student, who she explains was the first - and one of the only - medical professionals who openly, actively showed her willingness to learn more. And that she could learn from a parent. How do we, as early interventionists, show our willingness to learn from families?
2. On page 183 Megan writes, "There seemed to be no middle ground between anxiety and complacency, no option for me to both be supportively empowered and appropriately prepared." Later, on page 218, the author shares that OSHA characterizes CMV as a recognized hazard, but there has never been any federally recognized policy to educate childcare workers about the risk of CMV. What awareness does the organization you work for have regarding CMV? What could this look like in the future? Who would need to be involved in these discussions?
3. "While I believe most doctors work *from* a place of goodness, Dr. Vastola also works *toward* it." (page 187) In early intervention, what does working from/toward a place of goodness look like, sound like, etc?
4. On page 215 Megan mentions she watched a video of Kathleen Muldoon. In the video Kathleen discusses how our own biases impact what students in the medical field learn and also how they respond to conditions in the future. Reflect on how biases you might have regarding child development, conditions, etc.. impact the support you provide to families.

### Resources to support early intervention providers:

- ★ Kathleen Muldoon [cCMV Research & Public Awareness: Kathleen Muldoon explains a common birth-defect virus](#) (page 215)
- ★ National and Minnesota CMV Families Facebook group
- ★ Dr. Mark Schleiss, is a Professor of Pediatrics at the University of Minnesota Medical School and Megan mentions the research he is doing with CMV on multiple occasions in the book. U of M Pediatric Infectious Disease CMV; <https://cmv.umn.edu/>

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## Notable Quotes and/or Facts from Part 4 Pleasure:

*What was surprising about the facts or statistics you remember from this part of the reading?*

*Which quote resonates with you and why?*

*What connections to your work did you make after reading these quotes?*

*What other quotes or facts would you add?*

*Choose a quote and reflect on the author's intended message.*

- ★ That some bodies don't do what other bodies do ever. That to expect this is to perpetuate the prejudice that people aren't whole, unless they live in a standardized body instead of their own. (page 194)
- ★ Women are the subjects of 24% of global news pieces. (page 210)

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## Part 5 - Caretaking

### Reflections for early intervention providers:

1. “Our ability to exchange media today can draw stark contrasts visible only to the more sensitive of the two sides.” (page 229) How might families of children with cCMV be impacted by what is seen or reactions they receive on social media?
2. How might different families/parents feel about balancing the complex needs of some children with cCMV? On page 255 Megan noted one CMV mother online said, “Having a child severely disabled by CMV is like having a newborn all the time.”
3. On page 272 the author talks about finding a doctor who valued exchange and she noted that when communication works, we feel deeply known. In your practice, how do you know communication is working? What are important considerations in communicating with families?
4. Early intervention specialists can practice the remedy of narrative medicine which is a form of caretaking, lifting sorrow for parents. (page 278-281) After reading about narratives in medicine, what impact would this practice have on relationship building in early intervention? How does it align with family centered practices?
5. “If there’s one way medical professionals could have supported you better, what would it be?” The author talked about how this question was what was missing from her care. She also noted that someone saying, “tell me the whole story from the beginning” was missing. (page 276 & 281) How can early intervention programs begin this conversation and relationship building from the beginning? What might this look like and sound like in practice?
6. Minnesota is the first state to screen all newborns for cCMV. Why? How are you talking about this? How can you raise awareness? What can you change about your environment to support increased awareness of cCMV?

### Resources to support early intervention providers:

- ★ [Listening to the family’s story](#): Blog post from Virginia El
- ★ [Family Centered Practices Practice Checklist](#) from Early Childhood Technical Assistance (ECTA) Center

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## Notable Quotes and/or Facts from Part 5 Caretaking:

***What was surprising about the facts or statistics you remember from this part of the reading?***

***Which quote resonates with you and why?***

***What connections to your work did you make after reading these quotes?***

***What other quotes or facts would you add?***

***Choose a quote and reflect on the author's intended message.***

1. "Like Black children, Native American children with CMV have double the mortality rate of white children born with the disease." (page 235)
2. "One of the greatest lessons CMV has imparted to me is relativity: that you don't really know where you are in your struggles until you know other people and theirs." (page 257)
3. "People who are deaf, blind, or have issues with their mobility are victimized by crime at a higher rate than the rest of the population. In fact, children like Gideon with developmental or intellectual delays are four to ten times more likely to be sexually abused..." (page 258)
4. "In fact, one CMV mom online posted: *People ask me all the time, 'How long does he have to live?'* Her response: *'What, do you think he has an expiration date printed on his ass?'*" (page 259)
5. "Your pain, your journey, your joy are absolutely yours. Everyone has a story, no matter what." (page 259)
6. Page 263 states that Doctors in many European countries routinely test pregnant women for CMV, but we do not yet do that here in the US and pregnant women may experience serious pushback when requesting CMV antibody tests. If the ultrasound shows: echogenic bowel, hydrops, placental enlargement, intrauterine growth restriction,

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enlarged liver or spleen, or microcephaly or if the pregnant woman is experiencing a mono-like illness, then they should push for CMV testing. Correct interpretation of the test results and data is critical.

7. "Silence is not healthy nor is it an ethical way to handle the reality of cCMV." (page 264)
8. After reading Henry James's *The Winds of the Dove*, Dr. Rita Charon describes 'narrative medicine' as "the empty cup of ridding of ego and distraction and unnecessary noise", helps the doctor to listen to the story of his patient, a woman utterly changed by the invisible power of his absolute attention. This is a form of *hesed*: the doctor's attentiveness which would become medicine-altering. An entire field was created, called "narrative medicine." "the doctor and the patient enter an "attentive present" together. Trust is restored. Curiosity is lit. Empathy is stoked. And healing begins." (pages 278-279)

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## Summary

### General Questions

1. Throughout the book, what themes around equity emerged?
2. Throughout the book, what themes around ableism emerged?
3. How might you use this information to support the successful transition of a child with cCMV from Part C to a school based setting? How might you support the family in sharing information and advocating for the child throughout the transition process?
4. What implications does this information have for teams using the Primary Service Provider model? How are you ensuring that all needed team members are included on the plan (including low-incidence disability specialists) and are accessed when needed?

### Additional Resources

- ★ [Help me Grow](#)
- ★ [Help Me Connect](#)
- ★ Ableism
  - [PBS Wisconsin Education Ableism](#) Video 6 minutes
  - Access Living [Ableism 101](#)
- ★ [Minnesota Deaf Mentor Program](#)
- ★ [Minnesota Hands and Voices](#)
- ★ [Minnesota DeafBlind Project](#)
- ★ [MN Low Incidence Quick Cards](#)

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