

WRITING REMEDIES FOR SORROW

AND WHAT I TALK
ABOUT WHEN I
TALK ABOUT CMV

BY MEGAN NIX

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WHAT I TALK ABOUT

WHEN I TALK ABOUT

RUNNING

a memoir



REMEDIES FOR SORROW

An Extraordinary Child, a
Medical Secret, and a Mother's
Quest to Break the Silence

MEGAN NIX



THE BEGINNING

- I had never heard of CMV during pregnancy
- Anna was born in 2015
- Small for gestational age
- Microcephalic
- Didn't pass hearing tests
- No mention of CMV even though we saw ten providers
in the first week of her life
- Pediatrician tested her at 10 days old
- Received diagnosis on remote island in Alaska



ONE
PEDIATRICIAN,
ONE
AUDIOLOGIST,
POPULATION
6,000



- Born silent
- Intuitive feeling something was different
- This gut feeling would drive all my efforts toward CMV prevention
- I started writing about Anna in the night, when she was two weeks old





1. RESEARCH

- ACOG document deciding what's “burdensome” for me
- *Shock, anger, motivation*
- “The idea of preventive medicine is faintly un-American. It means, first recognizing that the enemy is us.” –Nicholas Von Hoffman in *The Chicago Tribune*, 1975
- *Giant embarrassment of CMV*
- *Benevolent deception*: omitting information out of “benevolent” motives
- Usually only employed when patient would be incapacitated by information
- Banned by the American Medical Association



- Study from 2013: “CMV is the leading cause of birth defects and developmental delays in the United States.” –Rosemary Thackeray
- In resource-limited countries: “The aggregate number of children born with congenital CMV infection is likely to be **enormous**.” –Tatiana Lanzieri
- “There are many wonderful things about our culture, but I’m sorry, it is a phobic culture. People do not want to confront the existential mess that is life. They want to check things off—okay, you’re okay.”—Megan O’Rourke in *The Long Goodbye*
- THIS IS NOT OKAY

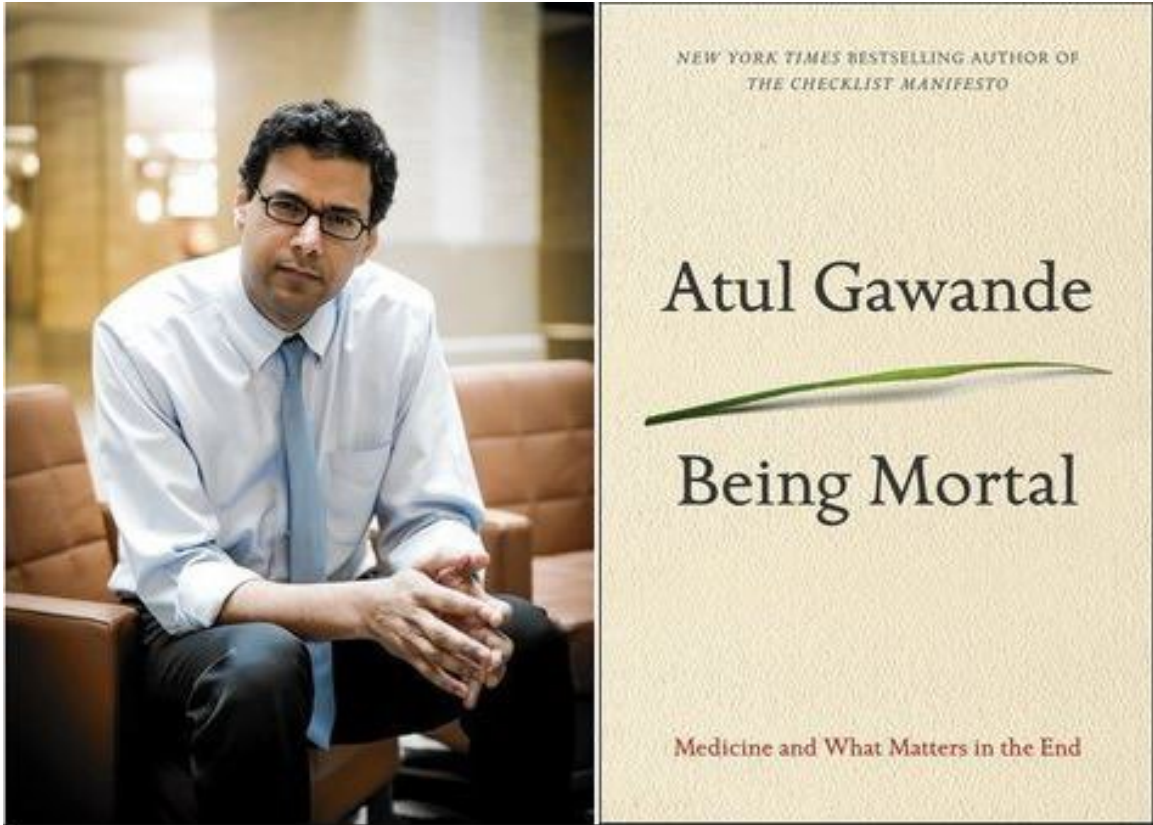
- I didn't meet another CMV family till Anna was 1.5 years old
- “HIPAA has impeded communication about risks to the public, contributed to inefficient care of patients by limiting physician communication, deterred medical research through the high cost of compliance, and **stolen physician time from patients.**” –Kim Lien-Nguyen in *Medical Economics*
- **The fight to end CMV is a fight for radical medical reform**





2. HUMILITY

- “CMV is a very serious disease. I’m going to have to do some research from home.” –Dr. David Vastola
- *Stealth Virus* by Dr. Paul Griffiths
- “Guard your imagination.” – Aunt Lynne
- “CMV is a constant education.” –Stephanie McVicar, today
- “Don’t let the perfect be the enemy of the good.” –Dr. Mark Schleiss



“What I found over time, trying to follow and emulate people that were focused on achieving something more than **competence**, is that they weren’t smarter than anybody else, they weren’t geniuses. Instead, they seemed to be people that could come to grips with their inherent **fallibility**—fallibility in the systems that they work in, and with what it took to **overcome** that fallibility.” –Dr. Atul Gawande



THE ABILENE COMPLEX

Pausing

Seeing where dangerous
choices have led us

Going back

Outside of this room,
largely missing in
medicine for CMV

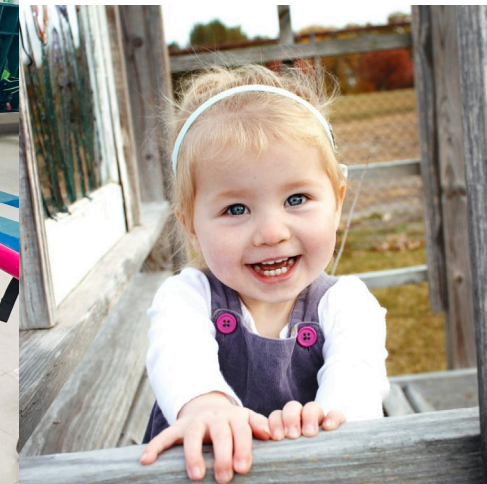
3. CONTRIBUTION

- *Hesed*. Hebrew word
- To feel compelled to contribute something of import to another person or to society
- Often motivated by kindness, but it's a stronger gesture—a sense of love and purpose so great you *act*
- Medicine, research, artmaking, parenting
- So many doctors here practice this!



- “It’s too big of a problem for me to teach everyone that all life has value. What I can do is bring Gideon to Target with us when we go and show everyone the fun we’re having and allow him access to his voice so he can share himself with the world.” –Kathleen Muldoon
- “To a child who suffers from a disability, deficiency, mutilation, poverty, sickness, ignorance, abandonment, or from any other cause, our internal disposition or external attitude should be dominated by a profound feeling of respect and veneration.” –Carlo Gnocchi, 1957







NARRATIVE MEDICINE

- “**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
- Adopting alien perspectives, following the narrative thread of the story of another, being curious about other people’s motives and experiences, and ***tolerating the uncertainty of stories***
- So needed, in medicine, for CMV!





- “Tell me the whole story from the beginning...”
- This is how we should talk about CMV:

The whole story

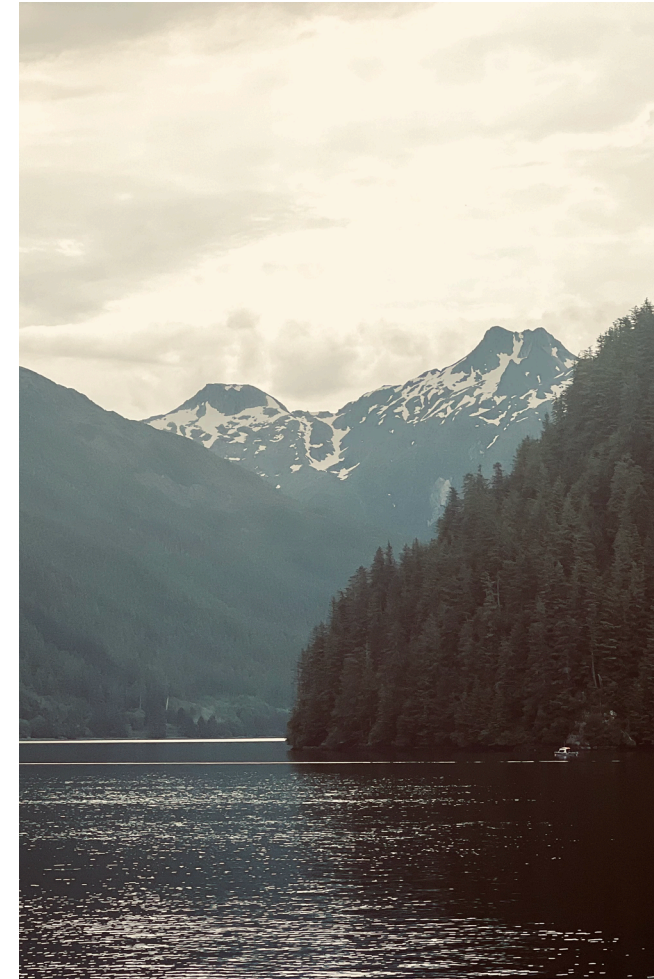
from each personal beginning

- When the whole person is lacking:
“The patient might not feel heard or ask the right questions...The correct diagnosis might be missed...Clinical care might be marked by noncompliance...The therapeutic relationship might be shallow and ineffective.”

Narrative IS prevention.

4. PERSISTENCE

- Book rejected by every major nonfiction editor in New York
- Found a new agent who would fight for me, who called CMV's lack of publicity "stupefying"
- Revised, revised, sent my work back out
- Acquired by an editor who'd seen it before
- "You never know who's going to become your fiercest ally." –Elaine Angelo, CMV mom



Thank you to everyone who read my book or plans to! And please review it on Amazon!

Remedies for Sorrow
is available at
Penguin Random House
and on Audible

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