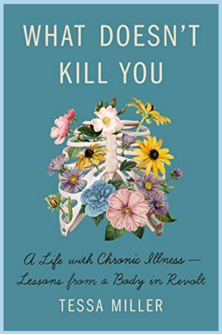
Discussion Guide



What Doesn't Kill You: A Life with Chronic Illness – Lessons from a Body in Revolt

Tessa Miller

Henry Holt and Co
2021
320 pages
ISBN: 978-1250751454

Autoimmune Disease

Summary

Tessa Miller was an ambitious twenty something writer in New York City when, on a random fall day, her stomach began to seize up. At first, she toughed it out through searing pain, taking sick days from work, unable to leave the bathroom or her bed. But when it became undeniable that something was seriously wrong, Miller gave in to family pressure and went to the hospital—beginning a years-long nightmare of procedures, misdiagnoses, and life- threatening infections. Once she was finally correctly diagnosed with Crohn's disease, Miller faced another battle: accepting that she will never get better.

Today, an astonishing three in five adults in the United States suffer from a chronic disease—a percentage expected to rise post-Covid. Whether the illness is arthritis, asthma, Crohn's, diabetes, endometriosis, multiple sclerosis, ulcerative colitis, or any other incurable illness, and whether the sufferer is a colleague, a loved one, or you, these diseases have an impact on just about every one of us. Yet there remains an air of shame and isolation about the topic of chronic sickness. Millions must endure these disorders not only physically but also emotionally, balancing the stress of relationships and work amid the ever-present threat of health complications.

Questions

1. What are your thoughts about how the book opens and how we meet the author? What were your first impressions?

2. What do you think motivated Miller to share this very personal story? What ideas was the author trying to convey?

3. Were you surprised by any of the information on health equity and the difference of care for different groups of people? If yes, what? If no, why not?

4. What new perspectives did the book provide you with about autoimmune disease and chronic illness?

5. Were there any quotes (or passages) that stood out to you? Which ones and why?

6. What passage or excerpt was most difficult to read?

7. On page 70, Miller quotes clinical psychologist, Dr. Paul Chafetz, Ph.D.:“We go through life with an illusion of safety and guaranteed health, even immortality,” he said. “Acquiring a chronic illness pierces this illusion, and this is a loss. Grieving this loss is an integral part of adjusting to the illness.” What do you think of this quote and the presence of grief in illness?

8. Miller repeats this phrase: “You can feel sad and create a meaningful, joyful life.” (p. 84) What does this phrase mean to you?

9. What are the most important things you learned from this book?

10. Miller shares seven secrets that she believes “chronically ill folks keep; seven secrets that our loved ones should know.” These are:

    Secret #1: We’re sick (no pun intended) of unsolicited advice.

    Secret #2: We want people to stop commenting on what we eat.”

    Secret #3: We wish people would stop asking if and when we’re going to have kids.

    Secret #4: “Inspirational” isn’t exactly a compliment.

    Secret #5: Yes, we really do need this much rest.

    Secret #6: We aren’t unreliable – our illnesses are.\

    Secret #7: We just want to be believed.

    Do any of these resonate with your experience? If yes, which ones? If no, why not?

11. Miller talks about systems and the challenges of navigating them as well as the importance of advocacy. Did any of the examples surprise you (health care, work, insurance, etc.)?

12. How does Miller find support and community in her journey?

13. Would you recommend this book to friends and family? Why or why not?

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