

Not Fade Away: A Memoir of Senses Lost and Found

by Rebecca Alexander with Sascha Alper



About the Book

Thirty-four-year-old Rebecca Alexander is a psychotherapist, a spin instructor, a volunteer, and an athlete. She is also almost completely blind, with significantly deteriorated hearing. NOT FADE AWAY is a deeply moving exploration of the obstacles we all face --- physical, psychological, and philosophical. Like THE DIVING BELL AND THE BUTTERFLY, Rebecca's story is an exquisite reminder to live each day to its fullest.

When Rebecca was 12, her parents were told that she would be completely blind before she turned 30. At 18, she fell through a window, shattering her body. In college, she found out that due to a rare genetic disorder --- Usher Syndrome Type III --- she was losing her hearing as well. Since then, she has earned two Master's degrees from Columbia University, ridden a 600-mile bike race, hiked the Inca Trail, and established a thriving career --- all while maintaining a vibrant social life.

In NOT FADE AWAY, Rebecca charts her journey from a teenager who tried to hide her disabilities, to a woman who is able to face the world exactly as she is. She meditates on what she's lost --- the sound of laughter and skies full of stars, which she can now only imagine (though, she quips, "It's not like anyone can see stars in New York anyway") --- and what she's found in return: an exquisite sense of intimacy with family and friends who've stuck by her, and a profound appreciation for everything she still has. Even though Rebecca inhabits a gradually darkening world, she refuses to let that stop her from living life with joy and enthusiasm.

Discussion Guide

1. Most of us take our senses for granted. Has reading NOT FADE AWAY changed your awareness of just how much we rely upon them? Which sense do you value most?
2. Rebecca holds tight to her visual and auditory memories because she knows that she is losing her abilities to generate new ones. What are some "sense" memories that you particularly cherish?
3. How well does Rebecca capture the experience of being a disabled person in an abled person's world?
4. Are Rebecca's determination and resilience a part of her essential character, or did she work to develop them?
5. Was it surprising to read that Rebecca was drinking and having teenage sex despite her disabilities? In what other ways does she contradict the stereotype of a disabled person?
6. Her father's lesson of *tzedakah* (giving back to the community) clearly shaped Rebecca's identity and the path she took in life. Yet, she is often reluctant to be on the receiving end. Does this ultimately help or hinder her?
7. Rebecca experienced rejection when men she was dating learned about her disabilities. Would you consider becoming romantically involved with someone who faces Rebecca's challenges?
8. Alan's diagnosis of Hodgkins Lymphoma is a reminder that good health is a gift that can disappear in a flash. Do you think that he ever expected to need more care than Rebecca? How --- if at all --- do you think it affected their relationship?
9. Rebecca believes that her brother's struggles with mental illness are much more difficult than her own experiences with Usher. Do you agree that she is the luckier twin?
10. When Rebecca learned that she was losing her vision and hearing, her parents tried to shield her from the news about what the future might bring. How would you handle discussions with your own child if you learned that s/he was facing this type of diagnosis?
11. If you were in Rebecca's position, would you opt to have a cochlear implant?
12. Has Rebecca motivated you to attempt activities that you have been too daunted to try? Has her story inspired you to change your attitude about difficulties in your own life?

Author Bio

Rebecca Alexander is a psychotherapist, spin instructor, volunteer, and an extreme athlete who is almost completely blind and deaf. Born and raised in the San Francisco Bay area, she currently lives in New York City.

Critical Praise

"A remarkable story of resilience and heart, NOT FADE AWAY follows Rebecca Alexander as she must navigate the world cursed with a rare genetic disorder that will one day rob her of both sight and hearing. Bereft of self-pity, funny, and bursting with honesty, NOT FADE AWAY will get its hooks in you. I promise that by the end of her story, you will fall just as in love with Rebecca as I have."

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