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# Floppy: Tales of a Genetic Freak Of Nature at the End of the World

A MEMOIR BY

# Alyssa Graybeal

The first book of its kind to explore the emotional landscape of living with Ehlers-Danlos syndrome from a patient's perspective; a playful story of falling down, getting back up again, and realizing you should have gone to the hospital sooner.

When ten-year-old Alyssa is diagnosed with the rare genetic connective tissue disorder Ehlers-Danlos syndrome, she vows not to let it stop her. Unfortunately, her efforts to avoid being "too sensitive" lead her to neglect not only her health but other aspects of her life as well. Twenty years later, she's finally forced to confront the reality of her condition head on as the threat of the 2012 apocalypse looms. When she finds herself tangled in an unwieldy combination of chronic pain, a library job for which she is particularly ill-suited, and her wife's mystifying health problems, her body starts to unravel in ways she can no longer ignore. If pushing through is not the answer, what does homecoming to her floppy body even look like?

# **ADVANCE PRAISE**

Alyssa Graybeal is a genius. This refreshing coming-of-age memoir with its sick, queer perspective will remind you that humor is essential and sensitivity is a strength. Graybeal's voice is like a great, weird friend, and you can trust her to tell the truth even when it's painful.

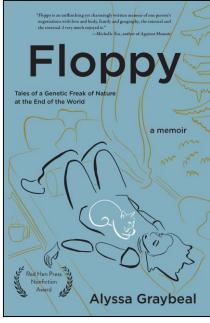
— **Ariel Gore**, author of We Were Witches and The End of Eve

In a spiral through time, Graybeal knits a wise, generous story of resilience and beyond. It's about alignment and aligning-with the body, with everybody. It's also a story about connection and connectivity and a larger ideal of care. With a hardwon and ever-present sense of humor, this is a powerful story with a cure for the ableism that ails us all.

— **Jenny Forrester**, author of Narrow River, Wide Sky and Soft-Hearted Stories.

# **ABOUT THE AUTHOR**

Alyssa Graybeal is a queer writer and cartoonist whose work focuses on the emotional landscape of living with chronic illness and disability, in particular the connective tissue disorder Ehlers-Danlos syndrome. *Floppy: Tales of a Genetic Freak of Nature at the End of the World* is her first memoir and won the 2020 Red Hen Press Nonfiction Book Award. She has a BA from McGill University and an MLIS from Dalhousie University, and she works as an editor and writing coach. You can find her online at <a href="https://www.alyssagraybeal.com">www.alyssagraybeal.com</a>. She lives in Astoria, Oregon.



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# MORE PRAISE FOR FLOPPY: TALES OF A GENETIC FREAK OF NATURE AT THE END OF THE WORLD

In these exquisitely written recollections, Alyssa Graybeal spins a richly imaged and often hilarious story from the fibers of her own quest for life while navigating the challenges of having a rare genetic disorder. Graybeal's sharp wit and keen attention to details makes reading *Floppy* an intimate journey across the Canadian landscape to the Pacific Northwest and into a queer body with Ehlers-Danlos syndrome, a condition that wreaks havoc on connective tissue. An exemplar on how to DIY a beautiful life, despite having a body insistent on falling down and coming apart. It's both a tale of self-care and a call for change in a healthcare system that has historically gaslit people with chronic illnesses.

— **Rebecca Fish Ewan**, author of By the Forces of Gravity and Doodling for Writers

Graybeal, a self-labeled genetic freak who was diagnosed as a child with Ehlers-Danlos syndrome, pulls us into the landscape of her floppy body with precision and grace. Brimming with queer love, cats, and the awkwardness of being human, *Floppy* is a roadmap for how we must learn to fight for the truth of our experiences, and how we can love the broken, beautiful body-homes we all live in.

— **Laraine Herring**, author of A Constellation of Ghosts: A Speculative Memoir with Ravens

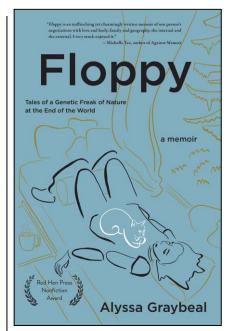
# FROM FLOPPY: TALES OF A GENETIC FREAK OF NATURE AT THE END OF THE WORLD

Pretending I had control over every misaligned cell spun the story of self-blame disguised as wisdom. If my problem was structural, however, a wobbly foundation that could never be permanently stabilized, I could build around it with important limitations in mind.

"I think there's an EDS personality," my physical therapist continued. "We tend to be overachievers. We tend to overwork and take on what would be too much even for a healthy person."

I wrote that one down so I would remember to let it sink in later. Did I have an EDS personality? Had I overachieved myself into a pile of unsupported fluff? Someone else's cane fell to the floor with a clack. Was it common for the audience of a specialized medical conference to be half-filled with patients?

I guess we often ended up having to DIY our own health care.



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