Invisible illnesses & disabilities

READ


This brief article provides examples of how real families are balancing their medical conditions and the societal expectation to “act normal”, as well as advice to help those without a condition interact successfully with the invisibly disabled.

Hadid, Yolanda with Bender, Michele. *Believe Me: My Battle with the Invisible Disability of Lyme Disease*. St. Martin’s Press, 2017. [https://scld.overdrive.com/media/3348564](https://scld.overdrive.com/media/3348564)

In early 2011, Yolanda Hadid was struck by mysterious symptoms including brain fog, severe exhaustion, and migraines. Over the months and years that followed, she went from being an outspoken, multi-tasking, hands-on mother of three and reality TV star to a woman who spent most of her time in bed. Yolanda was turned inside out by some of the country’s top hospitals and doctors, but due to the lack of definitive diagnostic testing, many were quick to treat her symptoms but could never provide clear answers to their possible causes.


The top specialists in the world were powerless to help, and research on Julie Rehmeyer’s disease, chronic fatigue syndrome, was at a near standstill. Going against both her instincts and her training as a science journalist and mathematician, she followed the advice of strangers she’d met on the Internet. Their theory—that mold in her home and possessions was making her sick—struck her as wacky pseudoscience. But they had recovered from chronic fatigue syndrome as severe as hers. To test the theory that toxic mold was making her sick, Julie drove into the desert alone, leaving behind everything she owned. With only her scientific savvy, investigative journalism skills, and her dog, Frances, to rely on, Julie carved out her own path to wellness—and uncovered the shocking scientific neglect and misconduct that had forced her and millions of others to go it alone.

DIGITAL RESOURCES

*Consumer Health Database*

Access this resource at [www.scld.org/consumer-health](http://www.scld.org/consumer-health)

And search “invisible illness” or “chronic illness”.

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The authors address such practical aspects as hiring a doctor, managing chronic pain, coping with grief and loss of function, winning battles with health and disability insurers, countering the social bias against the chronically ill, and recognizing the limitations of care for chronic illness and charting a path for change and more.

WATCH


Based on the true story of Susannah Cahalan, a capable journalist for the *New York Post* who cannot explain her sudden erratic behavior. She explains to her parents that it feels like her “brain is on fire,” but there are many diagnoses before her neurological disorder is found and treated.


When Harvard Ph.D. student Jennifer Brea is struck down by a fever that leaves her bedridden, she sets out on a virtual journey to document her story. Doctors tell Jennifer it’s “all in her head.” Determined to live, she turns her camera on herself and her community, a hidden world of millions confined to their homes and bedrooms by ME (myalgic encephalomyelitis), commonly called chronic fatigue syndrome.

LISTEN


*Made Visible* is a podcast that gives a voice to people with invisible illnesses. This podcast aims to change the conversation around invisible illnesses, helping those who experience them—whether as patients, caregivers, or friends or family members—feel more seen and heard.

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