



EAT YOUR CATFISH

DELVE DEEPER READING LIST



This list of fiction and nonfiction books, compiled by Penny Talbert, MLIS of Ephrata Public Library, provides a range of perspectives on the issues raised by the POV documentary Eat Your Catfish.

Kathryn's neuromuscular disease has left her paralyzed and her family's relations in tatters. Though despair finally overwhelms her, she holds on to see her daughter's wedding. Drawn from 930 hours of footage shot from Kathryn's point of view and without a crew present, this groundbreaking, personal portrait of a family pushed to its breaking point offers a brutally intimate view of disability and in-home caretaking.

Contributors



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ADULT NON-FICTION

Acheson, Alison. *Dance Me to the End: Ten Months and Ten Days with ALS*. Brindle & Glass, Victoria, British Columbia, 2019.

A profoundly honest and intensely personal story of a woman who cares for her husband after the devastating terminal diagnosis of ALS. Marty, age 57, was given a preliminary diagnosis of ALS by his family doctor. Seven weeks later, the diagnosis was confirmed by a neurologist. Ten months and ten days later, Marty passed away. *Dance Me to the End* is an evocative memoir about the emotional impact of witnessing a loved one suffer from a neurological, degenerative, and terminal disease. This is a detailed account of grief, shock and pain coexisting with the levity, laughter and love shared with her husband and sons in those final months of Marty's life.

Barkan, Ady. *Eyes to the Wind: A Memoir of Love and Death*. Atria Books, New York, 2019.

At thirty-two, Ady Barkan had everything he wanted: a fulfilling career in the progressive movement, a brilliant wife, and a beautiful newborn son. Then his luck ran out. What he thought might be carpal tunnel was in fact ALS, a neurological disease that would probably paralyze and kill him quickly. But then, with his life slipping away and American democracy under grave threat, he turned a devastating diagnosis into his most potent tool. [This book] is a rousing memoir featuring intertwining narratives about determination, perseverance, and now to live a life of purpose. The first traces Ady's battle with ALS. The second shows his journey from a goofy political nerd to a prominent figure in the progressive movement, becoming one of today's most vocal advocates for social justice. [This book] is an evocative and unforgettable memoir about activism, dedication, love and hope.

Boris, Eileen and Jennifer Klein. *Caring for America: Home Health Workers in the Shadow of the Welfare State*. Oxford University Press, New York, NY, 2015.

In this sweeping narrative history from the Great Depression of the 1930s to the Great Recession of today, *Caring for America* rethinks both the history of the American welfare state from the perspective of care work and chronicles how home care workers eventually became one of the most vibrant forces in the American labor movement. Eileen Boris and Jennifer Klein demonstrate the ways in which law and social policy made home care a low-waged job that was stigmatized as welfare and relegated to the bottom of the medical hierarchy.

Bromberg, M. B. *Navigating Life with Amyotrophic Lateral*. Oxford University Press, New York, NY, 2017.

Navigating Life with Amyotrophic Lateral Sclerosis provides accessible, comprehensive, and up-to-date information about the challenges patients, family members, and caregivers face when confronted by ALS, a disease that affects approximately 5,600 Americans every year, with as many as 30,000 people managing the disease at any given time.

Methot, Nate. A Life Derailed: My Journey with ALS. Onion River Press, Burlington, VT, 2022.

A Life Derailed is an honest and unapologetic memoir about a young man's journey navigating the relentless and ever-increasing challenges of a life with ALS. It's a story about loss, self-reflection, and growing up.

O'Donnell-Ames, Jodi. Someone I love has ALS: A Family Caregiver Guide. People Tested Media, New Jersey, 2015.

Kevin and Jodi O'Donnell, were a young New Jersey couple busy raising a toddler and making plans for their future when they received life-altering news in 1995 that changed everything as they knew it. Kevin was only 30 years old when he was told that his health problems were the result of a rare, terminal disease called ALS (Amyotrophic Lateral Sclerosis), or Lou Gehrig's disease. Kevin and Jodi had not heard of ALS until then and had no idea how those three letters would challenge everything they thought to be certain. After more than 20 years of working with ALS families, Jodi realized that more information and better resources could be available to help families who are coming to grips with the challenges of the disease and the caregiving responsibilities that are involved. In the Introduction to "Someone I Love Has ALS: A Family Caregiver's Guide," Jodi recounts the journey she took as a caregiver, advocate and writer and embraces and shares the lessons learned throughout the pages of this wonderful guide, "This guide was created by a variety of caregivers and professionals who have years of experience with various aspects of ALS. It was written by volunteers and experts who care about ALS and your journey. It is the resource that I wish we had received along with the shocking diagnosis." Although Kevin died of ALS in 2001 at the age 35, the disease never won the battle. ALS only strengthened Kevin and Jodi's love for God and each other and it created an even bigger purpose and plan: the creation of Hope Loves Company®, the only non-profit whose mission is to support the children and grandchildren caregivers of PALS (people with ALS).

Moss, Marissa. Last Things: A Graphic Memoir of Loss and Love. Conari Press, Newburyport, MA, 2017.

After returning home from a year abroad, Marissa's husband, Harvey was diagnosed with ALS. The disease progressed quickly and Marissa was soon consumed with caring for Harvey while trying to keep life as normal as possible for their children. This is not a story about the redemptive power of terminal illness.

ADULT FICTION

Genova, Lisa. *Every Note Played*. Scout Press, New York, 2018.

A once accomplished concert pianist, Richard now has ALS. As he becomes increasingly paralyzed and is no longer able to live on his own, Karina becomes his reluctant caretaker. As Richard's muscles, voice, and breath fade, both he and Karina try to reconcile their past before it's too late. This is a masterful exploration of redemption and what it means to find peace inside of forgiveness.

Lish, Atticus. *The War for Gloria*. Alfred A. Knopf, New York, 2021.

Corey Goltz is fifteen years old when his mother, Gloria, is diagnosed with ALS. Estranged from his father, and increasingly responsible for meeting both his mother's needs and his own, Corey is determined to be the hero Gloria needs --at any cost. But when his father Leonard re-enters the picture, Corey's beliefs--about honor and love, duty and devotion, and the uses and misuses of power--are sorely tested. Charismatic and cruel, Leonard is a man of outsize influence and dubious moral character, a man whose neglect of his wife and son amounts to a kind of barbarism. The closer Corey gets to understanding his father's role in their family, the closer he comes to unmasking a violence that is beyond even his worst imaginings. Set against the backdrop of a small town in Massachusetts in the early 2000s, where the working class world collides with the professional and academic worlds of nearby Boston and Cambridge, *The War For Gloria* tells the story of a young man straddling childhood and adulthood, whose yearning to protect his mother requires him to dismantle the myth of--and possibly destroy--his father.

YOUNG ADULT NON-FICTION

Abramovitz, Melissa. Lou Gehrig's Disease (Diseases and Disorders). Lucent Books, Detroit, 2006.

Examines Lou Gehrig and the disease named after him. Describes the symptoms, causes, and treatment options for Lou Gehrig's disease, and provides a brief biography of the famous baseball player for whom the disease is named.

Engdahl, Sylvia. Lou Gehrig's Disease. Gale, Cengage Learning, Detroit, 2012.

The Perspectives on Diseases and Disorders series provides clear, careful explanations that offer readers insight into what these conditions are, what causes them, how people live with them, and the latest information about treatment and prevention.; This new volume in the Perspectives on Diseases & Disorders series provides an overview of Lou Gehrig's Disease (ALS), including diagnosis, prevention, and current research.

Wade, Mary Dodson. ALS-Lou Gehrig's Disease. Enslow Publishers, Berkeley Heights, NJ, 2001.

Explores the history of this incurable disease, from its initial diagnosis to the sophisticated techniques used today for treatment and for helping patients cope with the disease.

YOUNG ADULT FICTION

Benwell, Fox. *The Last Leaves Falling*. Simon & Schuster, New York, 2015.

Abe Sora is going to die, and he's only seventeen years old. Diagnosed with ALS (Lou Gehrig's disease), he's already lost the use of his legs, which means he can no longer attend school. Seeking a sense of normality, Sora visits teen chat rooms online and finally finds what he's been longing for--friendship without pity. As much as he loves his new friends, he can't ignore what's ahead. He's beginning to lose the function of his hands, and he knows that soon he will become even more of a burden to his mother as the illness takes his freedom piece by piece. So he has to make a difficult decision.

Cronn-Mills, Kirstin. *Wreck*. Sky Pony Press, New York, 2019.

Set on the shores of Lake Superior, *Wreck* follows high school junior Tobin Oliver as she navigates her father's diagnosis of ALS (Lou Gehrig's Disease). Steve's life as a paramedic and a runner comes to an abrupt halt just as Tobin is preparing her application for a scholarship to art school. With the help of Steve's personal care assistant (and family friend) Ike, Tobin attends to both her photography and to Steve as his brain unexpectedly fails right along with his body. Tobin struggles to find a 'normal' life, especially as Steve makes choices about how his own will end, and though she fights hard, Tobin comes to realize that respecting her father's decision is the ultimate act of love.

BOOKS FOR YOUNGER LEARNERS AND CHILDREN

Blair, Jamie L. And Love Speaks: Helping Children Understand ALS. Euphoria Publishing, Fort Worth, TX, 2021.

Amyotrophic Lateral Sclerosis (ALS) is a very challenging disease that affects all types of people: parents, grandparents, aunts, uncles, and friends. Of course, it also has an enormous impact on the children who love those who've been diagnosed with ALS. Children bring kisses, hugs, caregiving, and joy to those living with ALS, but at the same time, those children may be experiencing confusion, fear, and worry as they watch the person they love face a scary disease.

Lay, Brandy. Walk Like Penguins. Palmetto Publishing Group, LLC, Charleston, SC, 2016.

Gabby adores her Pop-Pop; they have so much fun together! But lately, Gabby has been wondering why Pop-Pop cannot do all the things other grandpas can do, like taking her fishing or going swimming with her. After talking to her mother, Gabby learns that Pop-Pop has Amyotrophic Lateral Sclerosis (ALS), a disease that weakens his muscles and makes it hard for him to move around. Despite Pop-Pop's ALS, Gabby and her brother Brennan learn to create their own special memories with their grandfather, starting with walking like the penguins at the zoo. WALK LIKE PENGUINS is a sweet and informative book for children with friends or relatives who have ALS. Through Gabby's, Brennan's, and Pop-Pop's journey, your child will learn that there are plenty of activities ideal for someone who has limitations-and that not all memories need to fit the cookie-cutter mold.

Makechnie, Amy. Ten Thousand Tries. Atheneum Books for Young Readers, New York, 2021.

Twelve-year-old Golden Maroni starts eighth grade determined to be master of his universe, but learns he cannot control everything on the soccer field, in his friendships, and especially in facing his father's incurable disease.