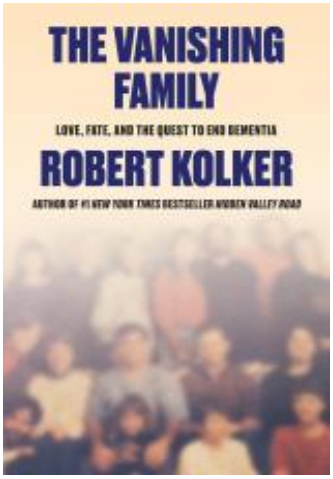
# The Vanishing Family: Love, Fate, and the Quest to End Dementia

by Robert Kolker




## About the Book

**From the #1 *New York Times* bestselling author of HIDDEN VALLEY ROAD comes the heart-wrenching journey of a family facing an unthinkable destiny, whose flawed genetic code might hold the long-sought key to a cure for dementia.**

In the idyllic American town of Pleasant Hills, Pennsylvania, there lived a family with nine siblings, the youngest a girl named Barb. As the older children headed off to college and started their lives, only Barb was home to see their beautiful, still-young mother fall under a gothic spell, changing into someone she didn?t recognize: withdrawn, neglectful, uncaring.

Thus begins THE VANISHING FAMILY, journalist Robert Kolker?s superb follow-up to HIDDEN VALLEY ROAD (?Deeply compassionate and chilling,? wrote *The Washington Post*). This family, we learn, has a genetic mutation that causes dementia, but with an especially cruel twist. As early as their 40s, formerly loving parents and hard-driving executives will lose their jobs, have affairs, take up drinking --- shed all inhibitions and sense of responsibility --- and become people their families hardly know. Their former personalities seem to vanish --- and there is a 50-50 chance that it will happen to their children, too.

THE VANISHING FAMILY unfolds like a heartbreaking thriller as the siblings begin to realize that what happened to their mother is happening to them: first one, then two, three, four and more begin to change. Sue, in search of a calling, finds her place in caring for the others. Barb sets out to find a cure. Alongside their story, Kolker weaves in the dramatic scientific fight against dementia. After decades of blind alleys, this family?s rare form of FTD (frontotemporal dementia) might lead to a breakthrough in the prevention and treatment of all dementia --- including the scourge of Alzheimer?s disease.

Moving, intimate, unexpectedly hopeful and redemptive, THE VANISHING FAMILY is an enthralling narrative about one family?s fate, and a medical detective story that speaks to all of us who fear losing ourselves at the end.

## Discussion Guide

**1.** In THE VANISHING FAMILY, Barb watches her mother transform from a loving, engaged parent into someone she barely recognizes. How did this early experience shape Barb?s understanding of her family, and how did it influence the choices she made later in life?

**2.** One of the most heartbreaking aspects of frontotemporal dementia (FTD) is that it can fundamentally alter a person?s personality. How does the book challenge traditional ideas about identity? When someone?s behavior, values and relationships change dramatically, what remains of the person they once were?

**3.** Throughout the book, family members respond differently to the burden of caregiving and uncertainty. Compare the paths taken by Sue and Barb. What motivates each sister, and how do their different approaches reflect broader ways people cope with crisis?

**4.** How does THE VANISHING FAMILY portray the emotional toll of caregiving? What sacrifices do family members make, and how do they shape their identities and relationships?

**5.** The book unfolds partly as a medical detective story. How did learning about the science of dementia and this family?s genetic mutation affect your reading experience? Did it affect the way you viewed the family?s struggles?

**6.** Genetic testing presents both opportunities and challenges. If you were a member of this family, would you choose to learn whether you carried the mutation? What factors would influence your decision?

**7.** Many of the affected family members begin displaying behaviors that strain or damage relationships long before receiving a diagnosis. How does the book encourage readers to think differently about accountability, illness and compassion in these situations?

**8.** The title THE VANISHING FAMILY suggests more than the loss of individual family members. What do you think is ?vanishing? throughout the book --- memories, relationships, identities, a way of life or something else?

**9.** Robert Kolker balances deeply personal stories with broader questions about medical research. What ethical responsibilities do researchers have when working with families affected by inherited diseases? What does the family gain --- and risk --- through participation in research?

**10.** Despite its devastating subject matter, the book ultimately offers hope. What role does hope play in the narrative? Is it found in scientific progress, family bonds, personal resilience or something else?

**11.** The book explores the tension between fate and agency. To what extent are the family members defined by the mutation they carry, and to what extent do they retain the power to shape their own lives and legacies?

**12.** How does the author?s portrayal of FTD differ from common public perceptions of Alzheimer?s disease and other

forms of cognitive decline? What did learning about FTD help you understand about dementia more broadly?

## Author Bio

Robert Kolker is a contributing writer at *The New York Times Magazine* and the author of the #1 *New York Times* bestseller HIDDEN VALLEY ROAD, named an Oprah?s Book Club pick, a *New York Times Book Review* Top 10 book of the year, a *GQ* Best Book of Literary Journalism of the 21st Century, and a *Kirkus Reviews* Best Nonfiction Book of the Century. His first book was LOST GIRLS, named a *New York Times* Notable Book and a *Publishers Weekly* Best Book of 2013. His latest book is THE VANISHING FAMILY: Love, Fate, and the Quest to End Dementia.

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