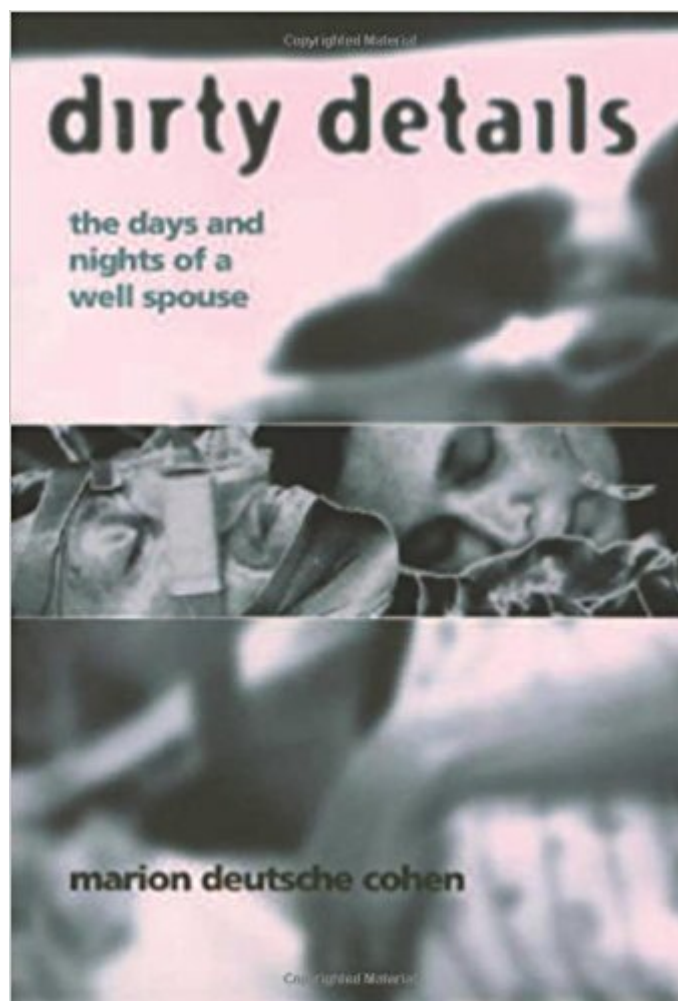


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# Dirty Details



## Synopsis

In 1977, at the age of 36, Jeffrey Cohen, a physicist at the University of Pennsylvania, was diagnosed with multiple sclerosis. But it wasn't until 10 years later when the disease had progressed to the point where he could not transfer himself out of his wheelchair. This book chronicles the author's lives in the context of her husband's disease.

## Book Information

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## Customer Reviews

Teacher/author Cohen, whose husband was disabled by progressive multiple sclerosis (MS), chronicles with raw intensity and candor the "dirty details" of caring daily for the chronically ill?i.e., "nights," "lifting," and "toilet." She elaborates: "...'nights' does not mean lying awake in fear listening for his breathing. 'Lifting' does not mean dragging him by the feet along the floor. And 'toilet' does not mean changing catheters." Cohen spares the reader nothing: endless sleep deprivation; frustration with inadequate or nonexistent support; catch-as-catch-can home care and respite services; crazy-making bureaucracy; and self-doubt, fear, and anger. Unlike the standard guides for MSers (e.g., David Carroll's *Living Well with Multiple Sclerosis*, LJ 5/15/93), Cohen's work offers no handy how-tos. More primal scream than primer, it is an uncommon acknowledgment of the dire straits in which well caregivers find themselves. Recommended for medical and caregiving collections. ?Anne C. Tomlin, Auburn Memorial Hosp. Lib., N.Y. Copyright 1996 Reed Business Information, Inc.

"Marion and her family have done a wonderful job of showing that there is life after innocence... And while each episode is a cry for help--a proof that 'one person, one family cannot do this alone'--it is also a testimony that no matter how late in the game help arrives, it will not be too late. Her message, then, to society is: mark us 'fragile' but don't leave us for dead." --Maggie Strong, Founder, Well Spouse Foundation and author of *Mainstay*

*Dirty Details* is an account of love failing. "More and more," Marion Cohen writes, "I felt less compassionate toward Jeff, less able to love him strongly, to say a long tender goodbye to the love of my life, and to mourn the gradual losing of him and to anticipate the sudden loss of him. We all know what a well spouse or a son or daughter or sibling is supposed to do when caring for a family member with a completely debilitating disease. We're supposed to be compassionate. We're supposed to be loyal and true, to rise to the occasion, to sacrifice our own lives. Not only that, we're supposed to keep our resentment buried, our desperation in line, our fury and hatred out of sight. Marion Cohen doesn't work like that. She has written a relentlessly honest book that tracks down, like a ferret (I am fond of ferrets), every aspect of her grief, her rebellion, her love of her family, and her frustration with social workers, the caregiving industry and sappy well-wishers. I've read lots of caregiver books, and this is the one I want. I can find the nice emotions anywhere. Here I find the truth that, I'm convinced, all of us would eventually feel when taking care of an invalid for year after year. In Cohen's case, it's been going on for 16 years and more, and the hard details and revelations keep coming. After one of her tantrums (she has plenty, she's that kind of woman), Cohen notices one of her sons looking hurt. "I went over to him and quietly said, 'It's not my job to hide what I'm feeling. And it's not your job to hide what you're feeling.' No, her job was to write a book like this, and I am grateful for it.

Marion Cohen's book was important for me to read. I spent three years as primary caregiver for my wife while she was in the terminal phase of brain cancer and therefore could not work, drive, do most household chores, manage her emotions well, or think clearly. For me, being caregiver was a fulltime job and definitely the most difficult challenge I have ever faced. Cohen lays it on the line here, pulling the veil away from what it means to be a primary caregiver for a loved one whose needs for assistance involve such basics as pooping, peeing, eating, breathing, and moving. She blows the lid off what it really like for a caregiver to put his or her life on hold and attend to such

needs. Her book is brutally honest and disarmingly direct, presenting the negatives of caregiving (as well as many blessings) that few among us wish to talk about openly...if at all.

I've owned three copies of this book. The first two copies, read at the beginning of my career as a caregiver, were thrown away in horror and disgust. At that time, my reaction was: "how could anyone be that angry?" and "it's a very different situation, so the outcome won't be the same..." For twelve years, I've been caring for a stroke-survivor spouse. The syndrome is classified as Organic Brain Disease with Executive Dysfunction: not a true dementia but with an equally devastating effect on personality, family and quality-of-life. I explain to others that my husband died sometime in 2000, that I care for "a family member who is a stranger, a homeless person, an out-of-control adolescent..." Certainly not my husband... The experience made me tough as tempered glass but survival took a huge emotional toll. There were days when I wasn't certain that I WAS still part of the human race. Like the author, I finally reached the point when I knew that I couldn't be a caregiver any longer. It's the hardest decision I've ever made. Every well spouse should probably read this book. But don't throw it away: you may need to read it again.

This is a unique insight into the experience of a caregiver. I read it when I first became a caregiver some years ago. There were few, if any support groups for caregivers and it provided some personal relief that other caregivers suffer from frustrations and burn-out. It is a must-read, even though not everyone will face the same challenges.

I don't understand the precise meaning of this psychological term, but I do know that it is not possible to diagnose the supposed mental condition of author of a book of this kind just by reading it. This book is a very honest account of a wife who was left almost completely alone for many years to care for her severely and increasingly afflicted husband, an experience few of us, fortunately, have to undergo. I was greatly impressed by the author's strength, courage, and love. Her writing skill brought her experience vividly to light.

This book is difficult to read, but difficult to put down as well. The unimaginably difficult life of a person with severe MS is virtually ignored by his spouse as she describes her daily routine of caring for her husband. This bothered me at first, but there are other books about those who live with MS -- this book is about how this disease cripples the life of a spouse who is in perfect health. My husband has MS and I have to say, this book scared me to death. Yet it was a comfort to know

there are others who understand the frustrations, guilt, and anger a well spouse experiences.

This book is painful to read and even more painful to live. That is why it proved to be necessary medicine for this well spouse. A testament to the fact that I am not alone, I am not crazy, and there is "life after innocence." I will cling to that as I trudge this path of "chronic bereavement." For a Well Spouse, this read is a must for surviving the isolation and endless hard work imposed upon unwitting victims of devastating, chronic illness. Thank you Marion D. Cohen, God bless you for your brutal honesty.

I read this book when I was caring for my son-in-law. The book helped me understand how the extreme and unrelenting demands on caregivers can leave them exhausted. Thank you Marion for not sugar-coating the truth.

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