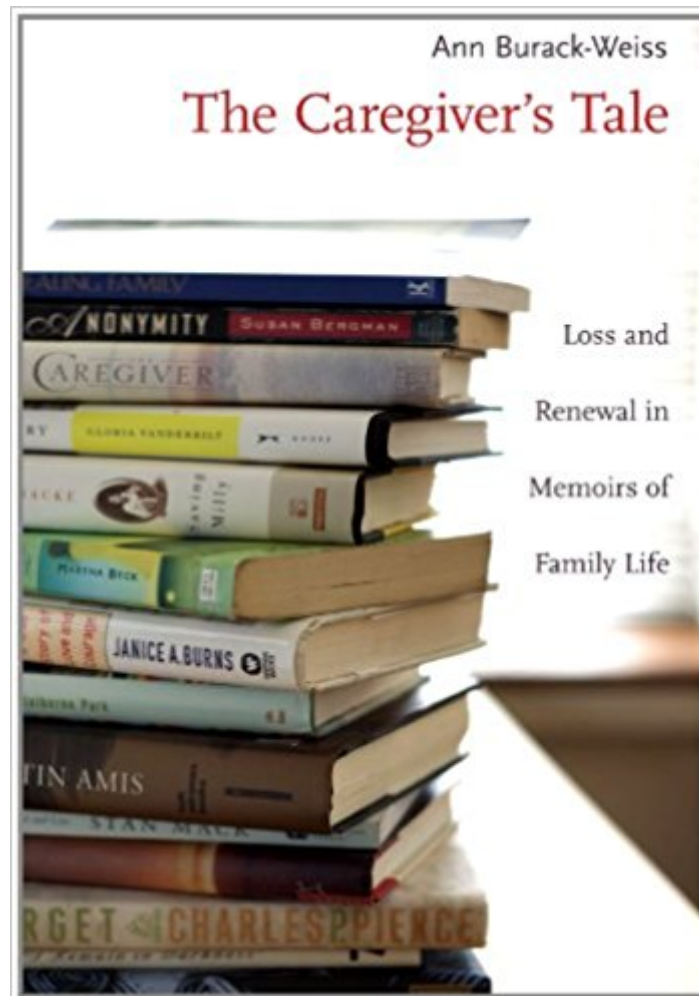




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# The Caregiver's Tale: Loss And Renewal In Memoirs Of Family Life



## Synopsis

Ann Burack-Weiss explores a rich variety of published memoirs by authors who cared for ill or disabled family members. Contrary to the common belief that caregiving is nothing more than a stressful situation to be endured, memoirs describe a life transforming experience-self-discovery, a reordering of one's priorities, and a changed view of the world. *The Caregiver's Tale* offers insight and comfort to individuals caring for a loved one and is a valuable resource for all health care professionals. Identifying common themes, Burack-Weiss describes how the illness career and social meaning of cancer, dementia, HIV/AIDS, mental illness, and chemical dependence affect the caregiving experience. She applies the same method to an examination of family roles: parents caring for ailing children, couples and siblings caring for one another, and adult children caring for aging parents. Jamaica Kincaid, Sue Miller, Paul Monette, Kenzaburo Oe, and Philip Roth are among the many authors who share their caregiving stories. Burack-Weiss provides an annotated bibliography of the more than one hundred memoirs and an accompanying chart to help readers locate those of greatest interest to them.

## Book Information

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## Customer Reviews

Readable and well researched... *The Caregiver's Tale: Loss and Renewal in Memoirs of Family Life* is a useful book. (Delese Wear, PhD Journal of the American Medical Association) A unique and useful contribution to the knowledge of the family caregiver experience... A useful educational tool. (Nicole A. Graves Journal of Marriage and Family) A unique and valuable contribution to the social

work literature and offers a deeply human view of... of caregiving. (Michelle Estile The New Social Worker Online)

Ann Burack-Weiss, a licensed clinical social worker, has taught two generations of students at the Columbia University School of Social Work. She is the coauthor of *Gerontological Social Work Supervision and Social Work Practice with the Frail Elderly and Their Families: The Auxiliary Function Model*. Ann Burack-Weiss, DSW is Adjunct Associate Professor at Columbia University's School of Social Work. She also maintains a private practice and is a frequent contributor to The New York Times. She has co-authored three books: *First Encounters between Elders and Agencies*, *Gerontological Social Work Supervision*, and *Social Work Practice with the Frail Elderly and Their Families*.

It makes a lot of sense to have, in one place, a list (although not complete, but is any list ever complete?) of caregiver memoirs. Although there are sites online where such lists exist, this is more complete and goes into more detail. Many caregiving situations are considered and many caregiving relationships, and there are many interesting passages in the Introduction. The main reason I'm rating it 4 rather than 5 stars is the emphasis on the "positive and life-enhancing" (as the author writes elsewhere) aspects of the caregiving experience. There are, I believe, "positive and life-enhancing" aspects to pretty much EVERY situation, but those, at least to me and to many of the authors of the memoirs profiled in this book, are not at all the main aspects. For me -- forced into the situations that prompted me to write my two caregiving memoirs -- the reactions to finding myself a caregiver (for 26 years) were on the order of "What?! Society really expects this of its citizens" and, increasingly, "I want out". On the back cover of the book appears: "Contrary to the common belief that caregiving is nothing more than a stressful situation to be endured, memoirs describe a life-transforming experience... The Caregiver's Tale offers insight and comfort to individuals caring for a loved one..." I don't like that! Billing this book in that way might make it more palatable to some, but it's far from an accurate picture of its subject. Throughout my horrendous and unfair experiences, I survived and thrived (I wrote, published, landed a fulltime mathprof position, and had a new baby -- not in that chronological order), and did indeed learn much. As, again, I hope I learn from all that life has to offer. HOWEVER, after "nights, lifting, and toilet", and the "dire straits" imposed on our family by society and its laws and policies, and especially after the verbal and financial abuse by my unwell spouse brought on by multiple sclerosis, I did not consider him a "loved one". And yes, for many years the situation was "nothing more than" stressful, and I couldn't

wait to not have to "endure" it. And math is my first passion (besides my family); I wonder how much more math research I would have done if I hadn't been so busy being a well spouse and writing about it. This book can be helpful to many readers and/or professionals, but I'd say take some of its "message" with a grain of salt.

This book is absolutely stunning. A great learning experience.

This is a wonderful example of bibliotherapy. The author drew on dozens of medical memoirs and related writing to discuss care and caregiving in families with members facing medical challenges. She extends traditional definitions of caregivers by examples from the many volumes she read and reviewed for their insights on care in families. I highly recommend this book.

Man survives because he cares and is cared for.... Civilization is, at least in part, a form of crystallized love. --William Gaylin in *The Caregiver's Tale*

Ann Burack-Weiss's work, *The Caregiver's Tale*, is something of a strange book. It is in actuality a meta-book, in the sense of being a book about books. Ms. Burack-Weiss, a Clinical Social Worker and instructor at Columbia University School of Social Work, decided to expand and amplify an article she published in 1995 entitled "The Caregiver's Memoir: A New Look at Family Support." She says in her prologue, "It was a topic close to my heart. For thirty years I'd practiced clinical social work with ill and disabled people and their families. ...caregiving was not an intrusion on family life but an intrinsic part of it, a crucible in which the crux of relationships was revealed; an occasion not only of stress and burden, but of growth, possibility, and meaning.... How do family caregivers 'keep on keeping on'? How do their views on family and on the meaning of life itself change over the course of caregiving? How can their hard-won wisdom be used to sustain others faced with the same challenges?" Her method for answering these questions is to utilize published memoirs as research texts. The main bulk of *The Caregiver's Tale* is a sweeping (though perhaps not entirely comprehensive) review of books about child-care, peer-care, and parent-care relationships. Ms. Burack-Weiss takes as her definition of caregiving "the sense that clinicians and researchers use the word: hands-on help with personal and instrumental tasks of daily living undertaken by one family member on behalf of another--usually for a time-limited period--of greater or lesser duration--of illness or disability." The book is divided into three parts. Part 1 concerns itself with (and divides itself into) "Care Situations": caring for those with cancer, dementia, HIV/AIDS, mental illness or chemical dependence. The section begins with a look at the cultural context of the various illnesses/disabilities. Each care

situation entails differing challenges, problems, obstacles, pains, and its own characteristic flavor of anguish. None is perhaps more difficult than the section on HIV/AIDS which describes the profound stigma those stricken often felt about their diagnosis (though hopefully and presumably this has diminished over the years). With HIV/AIDS there also exists the distinct possibility of surprise. Because it was often contracted through "culturally disapproved behaviors such as IV drug use and homosexual sex" there is sometimes in these memoirs a "...kind of secret that rocks authors to the depths of their beings: suddenly learning that the loved one they thought they knew was another person entirely." In several of the memoirs, the caregiver finds out about adultery, unknown promiscuity, or unsuspected homosexuality. Elizabeth Cox finds out that her husband has not only been adulterous, but with a man. Susan Bergman sees that her father's "persona as a churchgoing husband and father of four is a sham...." In Part 2 it is "Care Relationships" that are examined: a parent or parents caring for a child, sibling care, couple care, and finally (and certainly most inevitably) children caring for their parents. "Memoirs of sibling and parent care show that there is no easy formula. Sisters may be estranged, fathers may have been alcoholic or neglectful, mothers may have thwarted their early attempts at independence, causing them to flee. Yet their siblings and their children return to care." The caregivers are often faced with stark, and ghastly choices: a wife must decide whether to take a vacation with a husband with severe heart disease, a sister must decide whether to authorize sterilization of a mentally disabled sister, "an adult child deciding whether a mother with Alzheimer's disease can safely live alone...." Several choices may today seem odd. Many readers would (I suspect) be surprised to read how before 1970 "the necessity for secrecy (rationalized in the name of maintaining hope) was unquestioningly accepted. Simone de Beauvoir's mother was never given the name of her illness. John Gunther maintained the pretense that his son, Johnny, was going off to Harvard in the fall even when it was clear that he would never leave his hospital bed." Part 3 "The Memoirs" is a succession of one paragraph summaries of the memoirs. The chapter is fifty pages long, and I must admit I found it nearly pointless except for research purposes. Unlike Ms. Burack-Weiss's writing throughout the rest of the book which is often both wonderful and profound, the summaries are brief, dry, lacking in humor or warmth, and offer little or no actual insight into the works covered. They felt like filler to me: Ann Hood, *Do Not Go Gentle: My Search for Miracles in a Cynical Time* (Picador, 2000). Hood does not want the reader to miss the point of her memoir. In a prologue she writes that it is the story of her "spiritual Odyssey." The inward journey described coexists with an outer journey--the search for a cure for her father, who was dying of inoperable lung cancer. Scenes of coping with the disease on the home front (where Hood and her young son lived close enough to visit her parents daily) alternate with scenes

from a trip to Mexico to bring home a "miracle" and later to Europe to discover her family's roots. Hood's efforts did not prevent the inevitable. Her father's death and the memories of the family's response to the sudden death of Hood's beloved brother some years before add depth and pathos to the story. Part 3 aside, overall, *The Caregiver's Tale* is often a fascinating read. And yet it also felt like a published doctoral dissertation, with some of the flaws inherent in such an adaptation. The book was at times a bit over-academic-y. (As in the sweeping, but requisite-in-a-thesis, literature review.) Nevertheless, on the whole it is a fascinating gathering and analysis of works which, in many ways illuminate the core of what makes us truly human beings: that we care for one another. It is when Ms. Burack-Weiss gathers insights into patterns perhaps evident only to a reader of many many memoirs that she offers us her best, and most useful understandings. "...comfort and support is seldom available to those who suffer more subtle losses: 'deaths' of parts of the family member's personality long before his body is laid to rest. The mother who used to offer sage advice is now mute. The husband who is no longer the sexual partner and confidant he once was. These losses are often endured in silence--for who can complain when the one you are caring for suffers so much more? Also lost are parts of the author's identity in relation to the ill or disabled family member. No longer being a son, a mother, a wife--with all the cultural expectations and privileges attendant on the role--leaves many feeling as if a part of them has died along with their loved one." Ms. Burack-Weiss's writing is at times quite marvelous, and the morsels harvested from the books she references and cites are tasty, tantalizing and alluring. Many of the memoirists are famous, or the people for whom they cared were: Philip Roth, Sue Miller, Kenzaburo Oe, Jamaica Kincaid, Kate Millett, Joe Heller, Isabel Allende, Martin Amis, Calvin Trillin, Elizabeth Swados, Danielle Steele. Much of the writing quoted from these books made me wish that we could get a great deal more than merely snippets. But I suppose the answer to that predicament would be to use *The Caregiver's Tale* as a tasting menu, and then go out and consume many of the splendid, illuminating, and affecting memoirs themselves.

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