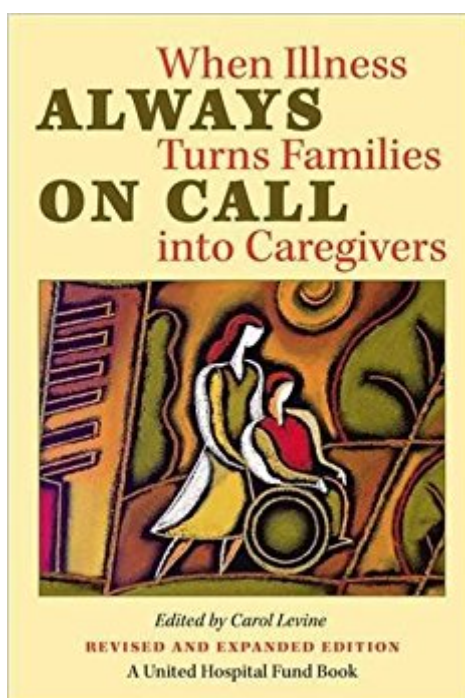


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# Always On Call: When Illness Turns Families Into Caregivers (United Hospital Fund Book S)



## Synopsis

Combining powerful personal stories with astute analysis and recommendations, *Always on Call* reveals the hidden struggles of the more than 25 million family caregivers in the United States. While family members have always provided care for one another, recent changes in health care have placed tremendous new responsibilities on them—responsibilities that, only a decade ago, were a routine part of hospital care. The prevalence of chronic rather than acute illness, trends toward shorter hospital stays, increased outpatient care, and limited insurance benefits for in-home care now leave family caregiving as the only option for many Americans. This book, first published in 2000 and now substantially updated, presents an intimate look at the world of family caregiving. The compelling narratives by caregivers capture the intensity of the caregiving experience, while chapters by noted health care professionals, many of whom speak of their own experiences, analyze the impact of caregiving, urge more professional advocacy on behalf of caregivers, and offer insightful suggestions for building partnerships for change and fostering improvement. This second edition includes: - caregiving as a workplace dilemma- the added burdens of end-of-life caregiving- clinician-family conflicts (and new approaches for resolving them) - new federal and state policy initiatives- resources for families and professionals- a new section on innovative caregiving programs- new chapter on the financial impact of caregiving. Designed for family caregivers, health professionals, administrators, pastoral care providers, policymakers, patient and caregiver advocates, and human resource professionals, *Always on Call* is an essential book for understanding the current realities of family caregiving. Equally important, it builds a compelling case for change. A United Hospital Fund Book

## Book Information

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## Customer Reviews

Always on Call provides useful advice to anyone who ever has been or will be a family caregiver, and it adds insights and policy suggestions that should enrich the broader health-care debate in this country. --Philadelphia Inquirer In bold and compassionate essays, caregivers, activists and physicians take on the current 'process of market-driven health care' and turn it inside out, offering resources for caregivers and practical ideas for momentous change.--Publishers Weekly. . . a wonderful book. the straightforward and simple style makes it a friendly resource for professionals and non-professionals.--Journal of Social Work in Long-Term Care Levine and her authors cover most of the essential dimensions of caregiving, including several richly detailed and emotionally powerful caregiver narratives that touch on a wide range of caregiver experiences. These intimate accounts reflect the grinding hardship, mundane routines, constant challenges, and spiritual fulfillment of caregiving.--The Gerontologist

Twenty-five million men and women in the United States provide essential care to family members who are sick. The economic value of their work (the amount they would earn if treated as employees) is \$196 billion. But since they are loved ones, these caregivers, who are often required to provide high-tech assistance or perform the same tasks as professional nurses or physical therapists, not only receive no pay for their work, but little respect, training, or support. Why the demands on family caregivers are growing and how the health care system could better meet their needs are the focus of the United Hospital Fund's new book, *Always on Call*. Edited by Carol Levine, *Always on Call* illuminates the broad spectrum of family caregiving and challenges the health care and social service community to support family caregivers in substantive ways. Carol Levine has a unique perspective for evaluating and critiquing the health care system. Not only is she currently the director of the United Hospital Fund's Families and Health Care Project, but she has been a family caregiver for her husband for the past ten years, ever since he was seriously injured in a car accident. When her husband was discharged from the hospital, she was left to not only pay for essential home care services for her husband, but also provide vital services herself. *Always on Call* combines personal stories that reveal the way caregiving is experienced, with professional insight, in order to show how these problems can and should be addressed. The final

section, a resource guide, provides caregivers with a wealth of information unavailable elsewhere. Families and health care have both changed dramatically in the past century. Prior to the 20th century and the prevalent use of antibiotics, most people who suffered serious illness either recovered fully or died. As a result of medical advances, better nutrition, and safer jobs, there are now three times as many Americans aged 65 or older as there were in 1900 and 33 times as many people 85 years or older. Families, too, have changed: there are more women in the workplace, and families are more diverse and less likely to include multiple generations (and the support they can bring). The prevalence of chronic rather than acute illness and trends toward shorter hospital stays, increased outpatient care, and limited insurance benefits for in-home care all leave family caregiving as the only option for many Americans. Whether they are enthusiastic volunteers or pressured by guilt or crisis, family caregivers suffer enormous burdens, both personal and financial. Many are virtually tethered to patients who require hourly medication and need help using the bathroom and other constant care. Caregivers must sacrifice personal interests, social activities, and paid work. In addition to the financial strain caused by lost income, they incur out-of-pocket expenses not covered by insurance. Long-term care is covered neither by most insurance plans nor by Medicare. Medicaid does offer some long-term care alternatives, but only to those below the poverty line. Always on Call demands a policy change—a revision in our health care policies to provide long-term care services to middle- and working-class patients. Levine and her co-authors also demand that, for those who choose to or have no alternative but to provide care themselves, the health care community offer training, advocacy, and emotional support to family caregivers—including improved discharge planning, negotiating with insurance companies, and ongoing education and technical assistance. For family caregivers, health care professionals, administrators, policy makers, and advocates, Always on Call offers support, resources, and concrete suggestions for building partnerships and fostering improvement in our health care system. --This text refers to the Library Binding edition.

An experienced caregiver loaned me the book. I decided to buy the book for myself and a second copy to give to a new caregiver. The personal stories of caregivers in Part I illustrate many dimensions of heartaches and joys, challenges and adaptations. In those chapters, only once is a companion animal mentioned. These days the ill and the well often have animals which need attention just as much as other family members and friends. Part II presents the workplace and accommodation to caregivers as somewhat hostile and focused on productivity. I would have thought today's supervisors and managers would be more creative with employees who are also caregivers. Part III addresses the policy issues related to caregivers' needs. This widens the scope

of the conversation with some examples of creative programs. Part IV offers resources which could take up volumes if comprehensive. All parts of the book provide starting points for the new, family caregiver.

Have not read it. Expect it to be what I always heard it would be - informative and reaffirming.

Extremely revealing as it brings to light the many ways each person and family might find themselves in a caregiving life situation by sharing a broad spectrum of 'anytime in life' real situations written as narratives by real people.

This is a collection of people's stories of caregiving. I hoped it would give me ideas as to government or other help I could get caring for my 92 year old mother with Alzheimers. It did not offer much help to me.

I got it to help with a family member with alzheimers good bood, not needed, donated to another. She said it was good.

The book is very interesting, I needed it for school and it has helped me undrestand the rols of caregivers and how they affect everyone around them...

Are you providing care for a loved one? If so, you're not alone (although it may sometimes feel that way). As this timely book relates, about 26 million Americans are looking after an ill or disabled relative or friend. These "informal caregivers" are providing an average of 18 hours of care a week, often while holding down full-time jobs or raising families, or both. If these caregivers were paid for their work, their economic value would total \$200 billion a year-one-fifth of national health care expenditures. This is far more than we spend on home health care and nursing home care--combined. This book, a collection of essays by different authors, looks at why the demands on family caregivers are growing and how the health care system can better meet their needs. The book combines the personal stories of caregivers, often movingly told, with professional insights on the impact of caregiving on workers and families. What comes through all the chapters is the lack of social support for caregivers under our current system. The cost constraints of managed care have shifted costs and caregiving responsibilities to families. Often family caregivers are required to provide high-tech assistance and perform the work that nurses or physical therapists used to

perform. In trying to cope, caregivers are going it alone for the most part, and the stresses are sometimes unimaginable. In one particularly heart-wrenching chapter, Gladys Gonzalez-Ramos describes how her father finally buckled under the isolation of years of caring for his wife, who had advanced Parkinson's disease. With his wife's apparent consent, he shot her and then killed himself. Such dramatic action, of course, is not the norm. Most caregivers struggle on in silence, internalizing the stress and pain they feel. Many could benefit from psychotherapist Barry Jacobs' brief but extraordinarily helpful chapter, "From Sadness to Pride: Seven Common Emotional Experiences of Caregiving." But caregivers need more than emotional support. As Rabbi Gerald I. Wolpe puts it in his account of caring for his wife, most caregivers "are in an almost constant state of caregiving." They need breaks, they need more help from a medical system that off-loads patients onto families as quickly as possible, and they need relief from insurance companies and HMOs that are reluctant to pay for home health care. *Always on Call* is a much-needed step in the right direction. It is written for a broad audience--family caregivers, health care professionals, administrators, policymakers and advocates. Through its powerful first-person accounts and resources section, the book offers solace to caregivers struggling under our current system. Through its concrete suggestions for improving that system, *Always on Call* also offers them hope for a better future.

This book brings home many of the realities people who care for relatives and friends face each and every day. It uses personal stories to illustrate the many ways people find themselves in the role of caregiver: the editor was catapulted into the role when her husband was in a car accident. Others found their caregiving increased as relatives slipped into the grip of Alzheimer's disease or AIDS. Beyond anecdotes, the book also asks key policy questions: like whether there are any limits to your responsibility for caring for a family member, whether the health care system is able to communicate clearly with family caregivers and accommodate their needs. It also offers clear suggestions for those who find themselves giving care including web resources and advice on how to go about looking for the help you need. This book helps put your experiences into context...both with other caregivers, and within the existing health care system. Most of all, it points up the systemic flaws, and offers suggestions for repairing a system that runs on the emotions, savings and lives of millions of American caregivers. If you don't need the information here right now, you are likely to need it in the future.

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