

The Challenges of Family Caregiving: What Experts Say Needs to Be Done

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Distinguished voices are raising the visibility of the “new normal”^{1,2} of family caregiving for an aging relative or friend through books, articles, and media. This In Brief summarizes 10 themes derived from 10 authors who are reaching out to family caregivers and to those who need to better understand their needs and challenges, especially health care professionals and public policy makers.

A number of prominent authors have recently chronicled their personal experiences with family caregiving in advice books, novels, and articles that call for a reexamination of policies and strategies to better support and strengthen caregiving families. Deeply frustrated with the bewildering complexity and fragmentation of our health care and long-term services and supports (LTSS) systems, these authors seek to call national attention to addressing the growing challenges of caregiving. Experts point out that this is particularly important as the baby boomers reach older age, and at a time of change in the way health care and supportive services are delivered and reimbursed.

These authors expose the difficulties of caregiving and offer practical advice to family caregivers³ and those who support them, especially health care professionals and public policy makers. This brief overview of their work identifies common themes that will be enhanced through discussion at the AARP Solutions Forum, *The Challenges of Family Caregiving: What Needs to Be Done?*

Distinguished Voices

To highlight key themes and explore potential solutions to the challenges that caregivers face, we selected a range of authors who write from various vantage points. Some are long-time experts in the health or caregiving field (Kane, Levine, Mintz, Rabins, Woodson), while others are well-known writers who have recently turned to this topic for personal or professional reasons (Gleckman, Gross, Mosley, Rauch, Sheehy).

Together, this distinguished group of authors (see box on page 2) provides intensely personal and at times raw insights that reflect the struggles of many American families and may jar policy makers and health professionals into seeking creative solutions. Their work offers far more practical advice than can be captured here, especially the advice targeted to family caregivers themselves.

Caregiving Authors

Howard Gleckman, *Caring for Our Parents: Inspiring Stories of Families Seeking New Solutions to America's Most Urgent Health Crisis* (New York, NY: St. Martin's Press, 2009).

Jane Gross, *A Bittersweet Season: Caring for Our Aging Parents—and Ourselves* (New York, NY: Knopf, 2011).

Robert L. Kane, MD, with Jeannine Ouellette, *The Good Caregiver: A One-of-a-Kind Compassionate Resource for Anyone Caring for an Aging Loved One* (New York, NY: Penguin Group, 2011).

Carol Levine, editor, *Always on Call: When Illness Turns Families into Caregivers* (Nashville, TN: Vanderbilt University Press, 2004).

Suzanne Geffen Mintz, *A Family Caregiver Speaks Up: "It Doesn't Have to Be This Hard"* (Herndon, VA: Capital Books, Inc., 2007).

Walter Mosley, *The Last Days of Ptolemy Grey* (New York, NY: Penguin Group, 2010).

Peter V. Rabins, MD, MPH, with Nancy L. Mace, *The 36-Hour Day: A Family Guide to Caring for People Who Have Alzheimer's Disease, Related Dementias, and Memory Loss*, 5th ed. (Baltimore, MD: The Johns Hopkins University Press, 2011).

Jonathan Rauch, "Letting Go of My Father," *The Atlantic*, April 2010.

Gail Sheehy, *Passages in Caregiving: Turning Chaos Into Confidence* (New York, NY: HarperCollins, 2010).

Cheryl E. Woodson, MD, *To Survive Caregiving: A Daughter's Experience, A Doctor's Advice on Finding Hope, Help and Health* (West Conshohocken, PA: Infinity Publishing.Com, 2007).

Themes

1. Caregiving Is a Role (and a Relationship)

Caregivers are mainly wives and adult daughters or daughters-in-law, but increasingly men are becoming caregivers too. Most caregivers are related by blood or marriage, but partners, friends, and neighbors are also caregivers. Caregiving is based on a relationship, but caregiving is an additional role that requires preparation, acceptance, support, and resources. Adult sons and daughters caring for their parents often experience their new roles as intensely personal, profoundly meaningful and rewarding, and a way to give back to a parent the love and care they were given as children.

Yet, despite its rewards, the caregiving role is also complicated, bewildering, and frustrating. It is also stressful to many American families because of the range of situations they face and the high costs of care. Most caregivers are employed at a paying job in addition to their caregiving responsibilities.

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Older adults with chronic care needs or disabilities depend on family caregivers for assistance with daily activities and providing transportation, managing complex care, navigating the health and LTSS systems, understanding housing options, learning new and complex legal and financial information, and communicating with health care professionals, often with little preparation or time to make choices.

“Roles, responsibilities, and expectations within the family change when one person becomes ill.” — RABINS, P. 195

“I came to dread the ring of the telephone: it might be my father on the floor, asking me to come over and pick him up, or it might be emergency medical services, summoned by a neighbor or the call button.”

— RAUCH, P. 56

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“By default, family caregivers are the health system’s care coordinators.”

MINTZ, P. 52

“When we became caregivers, my family unwillingly joined one of the least exclusive clubs in America. It is a silent society—one whose members rarely know one another and almost never discuss their struggles. They don’t even see themselves as caregivers. They are just...helping.”

— GLECKMAN, P. 18

2. Families Benefit from Discussing Preferences and Decision Making with Each Other and with Health Care Professionals

One of the most difficult and heart-wrenching challenges that caregivers face is to make medical care decisions in the event of loss of capacity for a loved one facing serious and advanced illness. Many family members are especially fearful of a spouse or aging parent suffering from Alzheimer’s disease or another dementing illness. Family caregivers feel burdened by making decisions when they don’t know what their older relative or close friend would want.

Knowing a loved one’s expressed values, goals, and preferences in the event that the individual can no longer participate in decision making can provide a great sense of relief for family members and can help to avoid emotional burden in the future. For the older person, it can be comforting to know that family members and health care professionals have heard his or her personal preferences and wishes. Health care professionals and

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public policy makers should promote better ways to encourage discussions and decisions before there is a crisis.

“The best strategy [for advance care planning] is to start having such conversations early and often, and before the crisis.” — SHEEHY, P. 60

“In some cultures, [people] expect physicians to communicate directly with families and expect particular family members to be responsible for decision making.” — LEVINE, P. 172

“Families have told us that unless you plan in advance, you may have little control over what takes place, and things may be done differently from the way you and your family member would have wished.” — RABINS, P. 118

“Do you want to live to see a hundred? No, Doctor, I on’y need a few months.” — MOSLEY, P. 127

3. Long-Term Services and Supports Are Expensive

Home is where the great majority of older people want to live. Yet, when most American families begin their caregiving journey, they are unaware that Medicare does not pay for LTSS for people with chronic illnesses and disabilities, and they are often stunned at the high cost of care. The national average cost of nursing home care (about \$75,000 per year in 2010)—at 241 percent of the average annual household income of older adults⁴—is beyond the reach of most middle-class families today.

The high cost of care is an enormous financial and emotional worry for persons with disabilities or chronic care needs and their families. Many people with LTSS needs will exhaust their life savings in order to receive public assistance through the Medicaid program. About 70 percent of people over age 65 will need some type of supportive services for an average of three years; more than 40 percent will need care in a nursing home.⁵

“Costs come both in dollars and in the toll it takes on everyone involved.” — KANE, P. 9

“[LTSS] takes love, for sure. But it also takes money. Great gobs of it.” — GLECKMAN, P. 131

“The question I hear most often is ‘What do you mean Medicare doesn’t cover it [LTSS]?’” — GROSS, P. 80

“Medicare pays for procedures and machines, but Medicare does not cover supervision, or supportive services that could keep a senior in the community.” — WOODSON, P. 132

4. Communication, Coordination, and Collaboration Are Fundamental to Good Care

Good care for older people with chronic care needs and functional limitations requires a team of health care professionals and a focus on person- and family-centered care. This collaborative approach integrates family caregivers into the care team, engaging them as partners in care with health care professionals and direct care workers, and developing tools to provide greater support to family caregivers.

Health care and LTSS should be delivered in a way that responds to an individual's needs, values, preferences, and goals. Initiatives to promote shared decision making to enable individuals, their families, and their health care providers to better communicate together can foster shared and informed decisions about care options, build trust, and reduce caregiver strain.

“Education for doctors, nurses and social workers should include understanding the needs of family caregivers.”

— LEVINE, P. 105

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“A family meeting is one of the most effective ways to help families cope and plan.”

— RABINS, P. 203

“Between doctor [or other health professional] and patient and caregiver, treatment must be a collaborative process.”

— SHEEHY, P. 19

“When you get old you begin to understand that no one talks unless someone listens, and no one knows nuthin' less somebody else can understand.”

— MOSLEY, P. 160

5. The Most Vulnerable and Traumatic Points in Health Care and LTSS Are Transitions from One Setting to Another

Better transitional care for older adults when they move from one setting to another is necessary to improve the discharge and follow-up process from hospitals to other care settings, lessen unnecessary hospital readmissions, reduce costs, and improve quality of care. Older people who transition from hospital to home are particularly vulnerable. Family caregivers frequently experience unmet needs and high levels of dissatisfaction with the current transitional process from one setting to another.

“Leaving the hospital can be just as dangerous as entering it, even more so.”

— KANE, P. 206

“Shuttling [the person] in and out of acute care hospitals at the sign of a new symptom or unrelieved pain is debilitating for the patient and defeating for the caregiver.”

— SHEEHY, P. 277

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“Although I repeatedly asked to attend a team meeting to discuss his prognosis and care, I was never given that opportunity. Nor was there ever any follow-up at home, a common complaint among caregivers.” — LEVINE, P. 105

“Every time Michael and I relocated my mother, she suffered a steep decline in her ability to function, physically and emotionally.” — GROSS, P. 243

6. Some Help and Support to Care for the Caregiver Is Available if It Can Be Found

Family caregivers of older people with chronic care needs and functional limitations frequently feel alone and isolated by the all-consuming tasks of caregiving. Caregivers who experience social isolation from a loss of social contacts may experience high levels of stress, jeopardizing their own health. They may also not recognize that as family caregivers, it is essential for them to take care of themselves in order to provide good care, and they will need help and support. The type of help and support needed can change over time as the course of illness grows more intense. Health care professionals and public policy makers need to help family caregivers find help.

“Family caregivers may feel isolated, but they do not exist in isolation.”
— LEVINE, P. 2

“A worn-out caregiver cannot give very good care. The FAA makes pilots take rest periods to refresh themselves to prevent plane crashes. Caregivers need to prevent care crashes.”
— KANE, P. 39

“Taking care of you IS taking care of them.” — WOODSON, P. 154

“All successful caregivers need to know three things: where to find help, how to arrange breaks, and how to cope with runaway emotions.”
— SHEEHY, P. 221

7. Being “Proactive” Is the Key

Family members who are thrust into the role of caring for an older relative or friend often have little or no training or preparation in handling their coordination responsibilities with health care professionals, providing direct personal care, or carrying out medical or health tasks in the home. Few have any idea of what to do.

Since caregiving for an older relative or friends will affect nearly every family in America, the public and private sectors need to be proactive in providing the following:

- Proactive public policies and programs to help people know where to find the right kind of care and help even before they need it, at an affordable cost
- Health care professionals who ask if you are helping to care for another family member or friend, and provide proactive, anticipatory guidance and support

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- Communities that anticipate and offer both practical and emotional support
- Family and friends who are proactive “help seekers” for themselves and for those for whom they care

“How can it be that so many people like me are so completely unprepared for what is, after all, one of life’s near certainties? What I needed was for the experts to find me and tell me what I needed.”

— RAUCH, P. 58

“I didn’t ask any of the right questions.”

— GROSS, P. 103

“We are rarely provided the solid training we need [as family caregivers] to feel comfortable and competent in the role of health care provider.”

— MINTZ, P. 47

8. Public Policy Solutions Are Crucial

Public policy plays an important role in supporting the private sorrows of family caregivers to lessen the strain in the daily lives of caregiving families in the United States. Policy solutions can include the following:

- Family-sensitive policies that protect the well-being and vital interests of families
- Workplace policies that recognize and accommodate employed family caregivers
- System change to improve the quality of life for family caregivers
- Comprehensive care coordination to address LTSS needs along with medical needs
- A payment system that provides resources for a comprehensive and culturally sensitive assessment of needs, including caregiver assessment and the need to identify the person’s and the family’s goals for care, offer practical and affordable resources to support care delivery and coordination, and reimburse consultations with family members

“The problem is not that public policy looks first to families but that it generally looks only to families and fails to support those who accept responsibility. The availability of family caregivers does not absolve policy makers of their own responsibility to make sure that their actions assist rather than destroy families.”

— LEVINE, P. 103

“We should all be given time off work at age 40 to take a class on elder care.”

— RAUCH, P. 58

9. Advocacy, at Both the Individual and System Levels, Is a Fundamental Part of Caregiving in Today’s World

Family caregivers play a central role as advocates for their aging relative or friend getting good care from health care professionals in all care settings—the home, clinician’s office, hospital, assisted living, nursing home, or other setting. Family caregivers advocate with health care professionals for individualized care, provided in a culturally and linguistically

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appropriate manner, and based on an assessment of the person's (and, as appropriate, family caregivers') needs, values, preferences and goals for care.

"The presence of a family member who will act as a fearless advocate is not just essential—it is a matter of survival." — SHEEHY, P. 20

"It is clear that American health care is out of sync with the reality of life in America today, in which chronic illnesses and family caregiving have the starring roles."

— MINTZ, P. 49

"My role [as the son] was to provide respite for my mom and companionship for my dad, and to serve as an advocate for them both."

— GLECKMAN, P. 13

"She was his eyes and ears in a world just out of reach." — MOSLEY, P. 126

Getting involved in advocacy and activism for broader system change is also an increasingly important part of family caregiving. As baby boomers confront the challenges of their aging parents, experience the enormous fragmentation of both health care and LTSS systems that are not set up to meet their caregiving needs or the needs of those for whom they care, and begin to consider how they themselves will want to be cared for, they are the natural advocates "to speak up and speak out" for a future of better care for older people and their families.

"Families often tell us that participating in advocacy efforts is a way to fight back against this terrible disease."

— RABINS, P. 244

"Join forces in a growing and powerful wave of political advocacy toward reforming our current system and creating a better one for the people we love, and, in the end, for all of us."

— KANE, P. 8

"Keeping today's invisible infrastructure of caregivers out of sight is as stressful and wasteful and pointless as leaving millions of women feeling stranded at home once was."

— RAUCH, P. 58

"We can make something of this crisis, or we can endure the experience until it's over and then escape back into the daily buzz of our lives until suddenly it's our turn."

— GROSS, P. 5

10. Culture Change Is Needed

As more people experience the "new normal" of being a family caregiver, a social movement that demands recognition of family caregivers may be looming. Caregiving is now a normal part of life, yet family caregivers remain invisible, isolated, coping stoically, getting random advice—rather than using a cohesive system that becomes easy to find and easy to use, with systematic and practical advice and support. Caregiving

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families need public acknowledgement, supportive workplace environments, and antidiscrimination laws.

“It is clear that American health care is out of sync with the reality of life in America today, in which chronic illnesses and family caregiving have the starring roles.”
—MINTZ, P. 49

“It was not a matter of paying for her care; the challenge was finding the right kind of care we wanted to pay for.”
—KANE, P. 307

“Home care requires more than just health aides. It also requires a place to live. And for many, that is a huge—and often ignored—challenge.”
—GLECKMAN, P. 161

“What we need...is for our nameless problem to be plucked out of the realm of the personal and brought into full public view, where help can find us.”
—RAUCH, P. 58

Implications

These authors make clear that our costly and fragmented system of health care and supportive services is a source of great worry and frustration to family caregivers, and impedes quality of life and quality of care. Their deeply personal stories call for policy solutions to address the needs of family caregivers. As more American families experience the “new normal” of being a family caregiver, public policy and community initiatives to better support and sustain caregiving families merit priority on the public agenda.

Endnotes

¹ L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*, AARP Public Policy Institute Insight on the Issues 51 (Washington, DC: AARP, June, 2011).

² G. Sheehy, *Passages in Caregiving: Turning Chaos Into Confidence* (New York, NY: HarperCollins, 2010).

³ The term *family caregiver* is broadly defined and refers to any relative, partner, friend, or neighbor who has a significant relationship with, and who provides a broad range of assistance for, an older adult or an adult with chronic or disabling conditions.

⁴ S. C. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP, The Commonwealth Fund, and The SCAN Foundation, September 2011).

⁵ U.S. Department of Health and Human Services, National Clearinghouse for Long-Term Care Information, http://longtermcare.gov/LTC/Main_Site/Planning/Importance/Know.aspx.

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