

## A Call to Action: What Experts Say Needs to Be Done to Meet the Challenges of Family Caregiving

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The AARP Public Policy Institute recently invited 10 authors who have written about the challenges of family caregiving to participate in an AARP Solutions Forum on the issue. These authors collectively call for a reexamination of policies and strategies to strengthen caregiving families. This Spotlight highlights their recommendations at the Forum and summarizes common themes in their written work about the difficulties family caregivers face that must be addressed in policy and practice.

Deeply frustrated with the bewildering complexity and fragmentation of our health care and long-term services and supports (LTSS) systems, a number of prominent authors are raising the visibility of the “new normal”<sup>1,2</sup> of family caregiving for an aging relative or friend.

These authors call for national attention to address the growing challenges of caregiving. In their books and articles, they expose the difficulties of caregiving and offer practical advice to family caregivers<sup>3</sup> and those who support them, especially health care professionals and public policy makers. 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.

Ten of those authors came together on December 1, 2011, at an AARP Solutions Forum to raise awareness about the centrality of families in the lives of older adults and to discuss policy options needed to better support family caregivers. Susan Dentzer, editor-in-chief, *Health Affairs*, served as moderator of the Forum, along with Susan Reinhard, AARP senior vice president and director of the Public Policy Institute. An archived webcast of the event can be viewed at: [www.aarp.org/ppi](http://www.aarp.org/ppi).

This report presents insights from the Forum, summarizes themes emerging from the authors’ written work on the struggles faced by caregiving families, and identifies four areas in which public policies and communities can respond to the needs of family caregivers:

- Greater public education and awareness
- More financial relief
- Better communication, coordination, and collaboration with health care professionals
- Heightened recognition of and support for family caregivers in policy initiatives

### **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: the 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).

### **Distinguished Authors Discuss the Struggles Family Caregivers Face**

The Solutions Forum, "The Challenges of Family Caregiving: What Needs to Be Done?" featured 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, these authors provided intensely personal insights that reflect the struggles of many American families and may jar policy makers and health professionals into seeking creative solutions. They made 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:

**Suzanne Mintz** explained that family caregivers become care coordinators by default, because the current system does not reimburse health care professionals for

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care coordination. Unfortunately, family caregivers are thrust into this role without preparation, training, or support. Caregiving is not only a role and a relationship, but it is also viewed, by some, as a job. Mintz noted that family caregivers are basically “undocumented” in the health care system—there is not a place on medical records that asks if you have a family caregiver, or if you are caring for someone with a chronic illness or disability.

**Walter Mosley** observed that age is the great equalizer among races, because all older people are marginalized by society. He urged family caregivers to try to understand and speak their loved one’s language once a person suffering from dementia loses the ability to use words—even as that person’s capabilities diminish. Mosley emphasized that, although caregiving is difficult, it fosters a powerful level of intimacy that one would not have experienced otherwise.

**Peter Rabins** shared three pieces of advice from the wife of one of his longtime Alzheimer’s patients. First, it is critical for caregivers to take breaks and get out of the house. Second, caregivers should focus on maximizing what their loved one can do—but accept what the person can no longer do. This concept is particularly critical when caring for someone with Alzheimer’s disease. Third, Dr. Rabins said that people need to anticipate that they will become caregivers; educate themselves that there will be physical, emotional, family, and financial issues; and talk to others.

**Jonathan Rauch** spoke of an invisible, isolated army of caregivers—each operating as a force of one with little social infrastructure and cultural support. When he decided to be open about his caregiving struggles, he discovered many of his colleagues and acquaintances were facing the same challenges and frustrations. Rauch called for a caregiver social movement similar to what occurred with the feminist and gay rights movements.

**Gail Sheehy** advised new family caregivers to look for a doctor or nurse who can serve as their health care “quarterback.” This individual can help them assemble a care team and create a care plan that incorporates integrated medicine and health and social services. Sheehy explained that caregiving was a passage that she was totally unprepared for. She emphasized the particular challenge faced by families when a loved one is discharged too soon from a hospital to home or another care setting.

**Howard Gleckman** noted that family caregivers will face an even greater burden in the near future as budget cuts exacerbate flaws in the current system. He suggested focusing on engaging communities and faith-based institutions as a way of supporting caregivers. He stressed the need for better communication between health care professionals and family caregivers. He also called for a renewed discussion around how Americans approach advanced illness care.

**Jane Gross** observed that the question she hears most often from family caregivers is, “What do you mean Medicare doesn’t pay for long-term services and supports?” She shared the frustrations she experienced when her mother was in assisted living, including many avoidable trips to the hospital emergency room. She spoke candidly about her guilt and shame when she finally moved her mother to a nursing home, but acknowledged that ultimately the nursing home ended up being the better option for her mother.

**Robert Kane** said that we are “throwing” millions of Americans into the caregiving business with no preparation. He emphasized the need to improve transitions from one

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setting to another, and to train all health professionals to communicate better with the individual and family. Caregivers, as well as care recipients, should be asked about their goals and given access to a professional who can help them select the care option that best aligns with those goals. Dr. Kane spoke about the need for meaningful, practical tools to help families make informed decisions.

**Carol Levine** advised that health care professionals be incentivized to include family caregivers as partners in care. Bringing together the medical and social service systems to improve transitions in care is especially important, but it isn't easy. She also explained that it is difficult to mobilize family caregivers when so many Americans do not understand the basics of the health care and LTSS systems.

**Cheryl Woodson** noted that when she was a caregiver, no one ever asked her about her goals. She had to tell the health professionals about her own preferences. Dr. Woodson stressed that primary care physicians need more training about illness versus normal aging. Also, given the shortage of geriatricians, their primary role should be as consultants to primary care physicians rather than serving as general practitioners for older adults.

## **Policies to Better Respond to the Needs of Family Caregivers**

In their remarks at the forum and in their written work, the authors emphasize that addressing the challenges of family caregiving requires both top-down and bottom-up approaches. Their deeply personal stories call for a social movement and a national strategy to better recognize and address the needs of family caregivers. Specifically, they call for public policies and community efforts to promote greater public education and awareness; provide more financial relief; support better communication, coordination, and collaboration with health care professionals; and increase recognition of and support for family caregivers in policy initiatives.

### **Promote Greater Public Education and Awareness**

- Educate Americans about what Medicare does—and does not—cover.
- Promote ways that people can talk to each other and share their stories. Family caregivers have a wealth of “locked up” knowledge. Much could be learned from one another if people were more open about their personal caregiving experiences, shared their stories, and became more aware of the practical tools and resources that may exist in the community to provide greater support to caregiving families.
- Urge a national discussion about how Americans approach advance care planning. Because an individual's goals and preferences for care may change over the course of an illness or chronic condition, both health professionals and family caregivers need to have these discussions with family members early and often. They also need guidance in how to start the conversation and encourage meaningful discussions before there is a crisis.
- Engage communities and faith-based organizations to offer both practical and emotional support to family caregivers and make communities more livable.
- Educate health care professionals, older adults, and their family caregivers about palliative care<sup>4</sup> and how it can be integrated with health care and supportive services.
- Advance 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.

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### **Increase Financial Relief**

Better options are critically needed by American families to help them pay for long-term services and supports. This must be a public policy priority.

One idea is for working caregivers—those employed at a paying job in addition to their caregiving responsibilities—to have the option of putting pretax dollars into flexible spending accounts to help pay out-of-pocket costs for eldercare expenses irrespective of whether or not the older adult is a legal dependent of the caregiver.

### **Develop Better Communication, Coordination, and Collaboration with Health Care Professionals**

- Encourage primary care clinicians and other health care professionals to routinely ask every Medicare beneficiary if he or she is a family caregiver. This question embraces the concept of person- and family-centered care, and an orientation to the “whole person.” It would also open the door for discussions about caregivers’ needs, including their own physical and emotional health status, and spur providers to offer proactive, anticipatory guidance and support.
- Pursue the adoption of electronic health records that include a line designating the primary family caregiver (where appropriate), in addition to documenting personal medical history and medications. This change would help health professionals identify and better support family caregivers.
- Advance comprehensive care coordination to address LTSS needs along with health care needs.
- Educate health care professionals and family caregivers about caregivers’ rights to receive health care information about their loved one when they are directly involved with the individual’s care. Some family caregivers have reported difficulties accessing information because of misconceptions about the federal law that protects medical information, the Health Insurance Portability and Accountability Act (HIPAA).<sup>5</sup>
- Install computer stations with caregiver education and training courses in hospital waiting areas. The countless hours that family caregivers spend at the hospital could be utilized for education so that they are better prepared.

### **Heighten Recognition of and Support for Family Caregivers in Policy initiatives**

- Develop and implement a national strategy to better support America’s family caregivers. The strategies would identify the actions that government and communities should take to better support family caregivers and those for whom they care.
- Create a national council of family caregivers and advocates, including celebrities, to heighten attention to family caregiving issues, to protect the well-being and vital interests of families, and to identify potential solutions to meet the growing needs.
- Advance a payment and delivery system that provides for a comprehensive and culturally sensitive assessment of needs, including caregiver assessment, and the identification of both the person’s and the family’s goals for care. Such a system would offer practical and affordable resources to support care coordination, and reimburse health care and social service professionals for consultations with family members.
- Require all government agencies with programs that potentially effect family caregivers to include a “family caregiving impact statement” for assessing the expected or potential

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effects of a proposal or rule on family caregivers. It is especially important to consider the practical impact of proposed policy changes on caregiving families, given the state of the economy and funding cutbacks for health care and social programs.

- Charge all new models of care to be tested under the Innovations Center at the Centers for Medicare & Medicaid Services to assess and address family caregivers' needs.
- Strengthen workplace policies that recognize and accommodate employed family caregivers.

## Addressing the Challenges of Caregiving: Common Themes

From the written work of these authors, 10 common themes emerge that reflect the daily struggles of 62 million<sup>6</sup> family caregivers in the United States. These themes also make clear that public policy and community initiatives to better sustain caregiving families merit priority on the public agenda.

### 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.

*“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

Yet, despite its rewards, the caregiving role is 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. Some family caregivers view their unpaid caregiving role as a “job” too.

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.”*

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*“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 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 adults<sup>7</sup>—is beyond the reach of most middle-class families today.

The high cost of care is an enormous financial and emotional worry for people 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.<sup>8</sup>

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*“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

*“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 care team 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.

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

— LEVINE, P. 105

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

*“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

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*“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

*“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 a range of public policies and supports for caregiving families. Family and friends also need to be proactive “help seekers” for themselves and for those for whom they care.

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*“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 require multiple approaches and strategies to meet the diverse support needs of family caregivers.

*“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 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

*“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.

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*“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 family caregivers, 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 families need public acknowledgment, family-friendly workplace environments, and affordable services and supports to assist them in their caregiving role and to help them maintain their own health and well-being.

*“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 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

Family caregivers are an invisible army of millions of American family members and friends. They are isolated from each other, undocumented in health care records, and transient in their care for aging relatives.

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The challenge ahead is to mobilize widespread support for social change to better sustain family caregivers—those who are the backbone of the LTSS system and key partners in health care—and who unselfishly take on the role and job of caregiver, experiencing its worries and hardships, as well as its profound meaning and intimacy.

These authors agree that much can be achieved by getting the American public talking about their caregiving experiences and expectations, acknowledging them, learning from one another, and working together to improve the care and quality of life for people with chronic illness or disability and those who care for them.

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### Endnotes

<sup>1</sup> 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 on the Issues 51 (Washington, DC: AARP, June 2011).

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

<sup>3</sup> 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.

<sup>4</sup> According to the National Consensus Project for Quality Palliative Care, “The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patient and family, optimizing function, helping with decision making, and providing opportunities for personal growth. As such, it can be delivered concurrently with life-prolonging care or as the main focus of care.” National Consensus Project for Quality Palliative Care (2009), *Clinical Practice Guidelines for Quality Palliative Care*, 2nd ed., <http://www.nationalconsensusproject.org>.

<sup>5</sup> The only time health care professionals cannot share medical information with family caregivers or others is when the patients says he or she does not want this information shared with others. [http://www.nextstepincare.org/uploads/File/NSIC\\_HIPAA\\_4.24.pdf](http://www.nextstepincare.org/uploads/File/NSIC_HIPAA_4.24.pdf).

<sup>6</sup> L. Feinberg, et al. Valuing the Invaluable.

<sup>7</sup> 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).

<sup>8</sup> 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](http://longtermcare.gov/LTC/Main_Site/Planning/Importance/Know.aspx).

Spotlight 1, February, 2012

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