

# Family Caregivers: Part of the Workforce, But Often Not Part of the Team

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*Shaping New York's Health Care:  
Information, Philanthropy, Policy*

**Mission:** United Hospital Fund works to build a more effective health care system for every New Yorker. An independent, nonprofit organization, we analyze public policy to inform decision-makers, find common ground among diverse stakeholders, and develop and support innovative programs that improve the quality, accessibility, affordability, and experience of patient care.

[www.uhfnyc.org](http://www.uhfnyc.org)



Created by UHF, Next Step in Care is designed to change health care practice by routinely identifying, acknowledging, training, and supporting family caregivers, especially at times of transitions in care. It provides practical advice and easy-to-use guides for both health care providers and family caregivers that focus on transitions between hospitals, rehabilitation facilities, nursing homes, and home. While New York is the primary focus of UHF and Next Step in Care's work, the impact and relevance are national and even international.

[www.nextstepincare.org](http://www.nextstepincare.org)

# Family Caregivers Are Us

- Broad definition includes relatives, partners, friends, and neighbors
- Provide or manage care of someone who needs assistance because of age, frailty, illness, or trauma
- Age range from children and teens to people over 80
- 60% women, 40% men
- About half are employed
- Numbers vary by definition but 2015 NAC/AARP survey found about 43.5 million Americans are caregivers
- If they were paid at modest rate the total would be \$475 Billion

# Ambiguous Role in Workforce

- Family caregivers do what needs to be done; no “scope of practice” defines their jobs
- Often called “informal” caregivers because they aren’t paid
- Sometimes called “volunteers” although many say that they have no choice
- Language matters: Taking care of “loved one” suggests caregivers are emotional, not objective, want special treatment
- Relationships to professionals and paraprofessionals such as home care aides often unclear and seldom discussed

# Family Caregivers: Home Alone and Poorly Trained (If At All)

- AARP PPI/UHF survey “Home Alone: Family Caregivers Providing Complex Chronic Care” (2012)
- Nearly half of all family caregivers perform complex medical/nursing tasks but few get adequate training in hospitals, doctors’ offices, or Eds
- Family caregivers also perform ADLs, IADLs, and care coordination.
- Subgroups of family caregivers (employed, spouses, caregivers of people with cognitive or behavioral problems) did these tasks at same rate as not employed caregivers
- Most family caregivers have little or no help at home

# Learning from “A Lady on the Phone”

- *Quote from Paul (caring for friend with multiple conditions):*  
“She had to get her medicine through a PICC line (peripherally inserted central catheter) and I had to clean it, put in the new medication, and repeat the process the next day. Then they changed the medication, and that meant the whole process had to be changed. A lady called to say, ‘You’ve done this before, and it’s the same thing.’ But it wasn’t. It was a much more complicated system. I was able to figure it out but I don’t think anyone else who wasn’t used to putting equipment together would have been able to do it. They should have sent someone to show me how to do it, not just leave it to a lady on the phone.”

Source: United Hospital Fund discussion group May 2015

# Family Caregivers: Always On Call and Often at Risk

- Chronic stress and depression
- Generally in worse health than noncaregiving peers
- Diminished immune response, leading to infections and less protection from vaccines
- Increased risk of heart disease
- Lower levels of self-care
- Increased mortality
- Women fare worse than men in terms of depression, physical health, and quality of life

# Family Caregivers and Care Coordination

- New jobs in hospitals, health plans, payers for “care coordinators,” “navigators,” “coaches”
- Different levels of training, responsibilities, supervision
- Role depends on who they work for
- Family caregivers have to coordinate the coordinators
- Family caregivers coordinate life
- Family caregivers make it possible for person to participate in community life—ordinary activities like shopping and attending religious services to major life events like weddings and graduations



A Campaign of



## Guides & Checklists

- For Family Caregivers
- For Health Care Providers
- *Para Cuidadores Familiares*
- 關於家庭照護者
- Для лиц, ответственных за медицинский уход
- Quality Improvement Surveys
- Links and Resources
- Terms and Definitions
- News
- About the Campaign
- About the United Hospital Fund

## Home Care



I'm caring for  
someone in a...

moving to...




Text size: A A A

**Next Step in Care** provides easy-to-use guides to help **family caregivers** and **health care providers** work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.

Transitions are moves between care settings, for example, hospital to home or rehab facility, or the start or end of home care agency services. Because transitions are often rushed, miscommunication and errors can occur.

**Next Step in Care** materials emphasize careful planning, clear communication, and ongoing care coordination.

### In the Media

Andrea Chalupa's [Huffington Post blog](#) explores family caregiver stress as a factor in the recent JetBlue flight attendant meltdown—featuring an essay by [Carol Levine](#); and a [Post-Journal column](#) about health care-related websites prominently features the Next Step in Care, calling it a "wonderful" resource.

### New Guide on Hospice and Palliative Care

The newest addition to the website is [Family Caregiver's Guide to Hospice and Palliative Care](#), available in English, Spanish, Chinese, and Russian, and designed to help family caregivers understand their options at a difficult time in

# Next Step in Care Guides, Tools, and Checklists for Family Caregivers

## For All Family Caregivers

Becoming a Family Caregiver  
HIPAA  
Personal Health Record  
Medication Management  
Advance Directives  
Urgent Care Centers  
Emergency Room Visits  
Doctor Visits  
Hospice and Palliative Care  
LGBT Caregiving  
Care Coordination  
What Do I Need as a Family Caregiver?  
Technology (organizers, sensors, and apps)

## Care Setting Specific

### ***Hospital Stay & Discharge***

Admission  
Hospitalists  
Surgery for Older Adults  
Hospital Discharge options and checklists  
Get a 7 days Post-Discharge Appointment

### ***Rehabilitation***

Short-Term and Long-Term

### ***Home Care***

Working with Home Health Aides  
Durable Medical Equipment  
Planner for Care at Home  
Discharge from Home Care

# Next Step in Care Guides, Tools, and Checklists for Providers

**HIPAA:** clarifies HIPAA rules re: sharing info with FC to reduce confusion and increase communication.

**Identifying and Assessing Family Caregivers:** primary FC; Availability and Willingness; Training Needs; Worries

**Medication Management:** Framework for talking to FCs about medication timing, administration, adherence, efficacy and side-effects; 6 videos created with CMS supplement the guide

***Reducing the Stress of Hospitalization for Patients with Dementia and their Family Caregivers:*** specific tips and insights for building positive working relationships with patients and FC

**Discharge Planning:** includes *Hospital Discharge Planning: First Steps with Family Caregivers* the provider's companion to *Leaving the Hospital and Going Where?* and Discharge Planning Elements for Hospital, Rehab, and Home Care settings

***Referring Patients and Family Caregivers to Community-Based Services:*** framework for making effective referrals, from needs assessment to follow-up, and resources

***A Professional Care Coordinator's Guide to Partnering with Family Caregivers:*** provides the professional care coordinator with tips, structure, and food for thought in working effectively together with family caregivers

***Project RED (Re-Engineered Discharge) Tool 7: Understanding and Enhancing the Role of Family Caregivers in the Re-Engineered Discharge:*** Specific to Project RED. This chapter includes

- Identifying the family caregiver,
- Assessing the family caregiver's needs,
- Integrating the family caregiver's needs into the after-hospital care plan,
- Sharing family caregiver information with the next setting of care, and
- Providing telephone reinforcement of the discharge plan.

# Some Difficult Questions

- What are professionals' responsibilities to people who are not their clients or patients but who provide essential services to them?
- Are we as a society expecting too much of family caregivers in general and certain caregivers in particular?
- Are there some medical/nursing tasks that untrained family caregivers should not be expected to do?
- Are some policies and practices placing patients and family caregivers at risk because of lack of training and support?
- How can we get past the myths of the “good old days” and move together into a more realistic and equitable future?

# Thank You

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