Getting on the Same Page: Hospital, Community, Caregiver Alliance

California Readmissions Summit: Driving Readmissions Down

October 10, 2013

Carol Levine

Director, Families and Health Care Project

United Hospital Fund

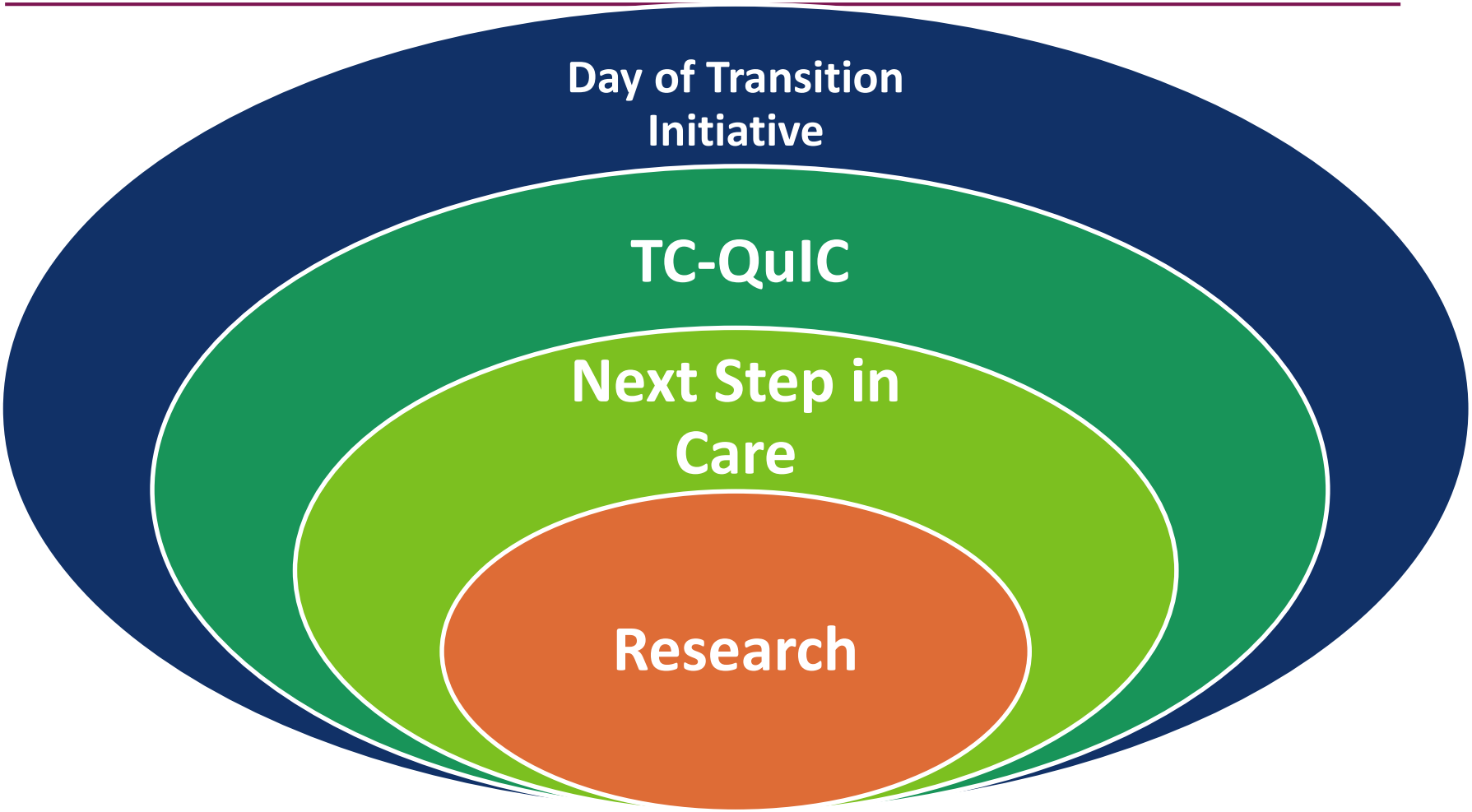
United Hospital Fund

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

Next Step in Care™

Family Caregivers & Health Care Professionals Working Together

In this presentation…



The idealized patient…and a reality check

Manages alone…

6 things to do when you leave the hospital

Last reviewed: June 2011

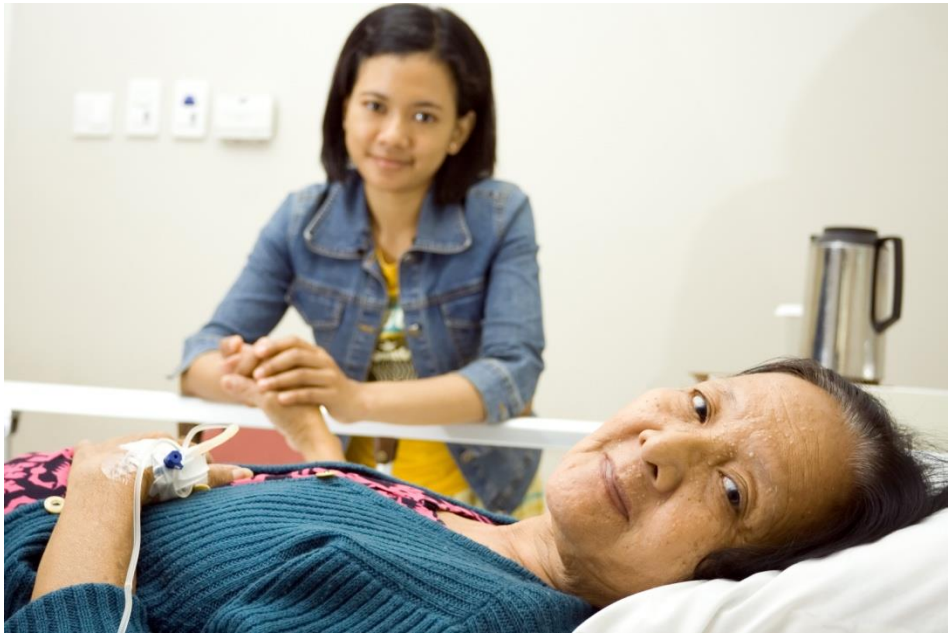
More than a third of hospital patients fail to get needed follow-up care once they get home, according to research from the Agency for Healthcare Research and Quality. To prevent that from happening to you, take these steps as you prepare for your hospital discharge:

1. See a discharge planner. You or your hospital helper should try to do this at least a day before you leave so your family, your doctor, or the hospital can arrange for monitoring or services you'll need at home.

2. Decide if you're ready to go home. Hospitals and insurance companies have strong financial incentives to discharge you as soon as possible. And for most patients, the sooner you get home the better. But if you don't feel ready, say so. You shouldn't go home if you feel disoriented, faint, or unsteady; have pain that's not controlled by oral medication; can't go to the bathroom unassisted; can't urinate or move your bowels; or can't keep food or drink down. If your doctor isn't able to extend your stay, appeal to the discharge planner, the hospital's patient advocate or, if available, a state appeals board.

Needs assistance

Who's missing?
The family caregiver



Day of Transition Initiative

- March 2013-spring 2014
- Purpose: to improve the patient and family caregiver experience of transitioning from one setting to another
- Method: "Closing the communication loop," then implementing changes based on that feedback from patients, family caregivers, and the next setting of care

Three New York hospitals and their chosen partners

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Self-examination and implementation of change

- Phase 1: Planning and Design
  - Fact-finding, analysis of data, creation of new protocols
  - Transition map
  - Chart review
  - Surveys of patients, family caregivers, and partner (intake and field nurses)
- Phase 2: Implementation (*starting now*)
  - Testing, with adjustments and new tests
  - Data collection, with new tests based on data
  - Assessment of redesign of day of transition

Fact-finding revealed areas for improvement

- Accurate medication reconciliation (especially OTCs), with someone to call with questions
- Family caregiver confusion and stress over specifics
  - Start of home health aide
  - Transportation: how/when are they going home?
- Confidence ≠ competence
  - Family caregivers left hospital reporting feelings of confidence regarding medication administration
  - Family caregivers did not feel prepared for ongoing management of those medications
  - Teach Back revealed errors with 80% of "confident" caregivers

"Patient perceptions and written documentation do not adequately reflect patient understanding of discharge care."

Horwitz, et al, "Quality of Discharge Practices and Patient Understanding ant an Academic Medical Center," *JAMA Internal Medicine*, 2013.

Plan

- Addressing the anxiety and safety issues of the day of transition
  - Anticipated Discharge Planning ("ADP"): assignment of what needs to happen prior to discharge
    - Transportation
    - Pharmacist/pharmacy tech available for education, resolving final issues
    - Face-to-Face Encounter documented for home care
    - Prescriptions, medical orders, labs, etc.

Plan

- Enhanced and earlier communication between hospital readmissions (PACT) team, floor staff, and VNSNY with delivery of improved information to patient and family caregiver
- Improved medication reconciliation, utilizing different shared tool and including community pharmacy, with multiple teaching methods and reinforcement

Plan

- Hospital utilizing new tool which assesses potential reasons for non-adherence to medication regimen, with results given to partner for immediate inclusion in care plan
- Discharge huddles with hospital team, patient, and family caregiver, possibly day before transition

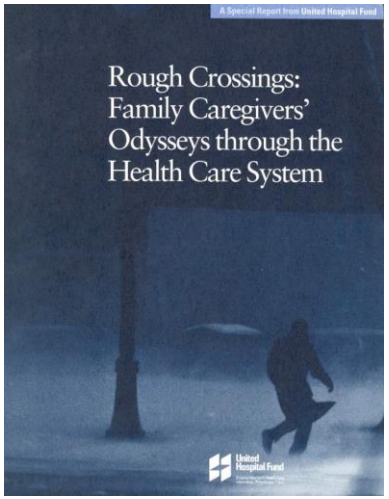
Common theme

Partnership is not easy.

- Shared patients, shared EMR, same administration, same system: still not partners
- Partnership appears to require face-to-face meetings between the hands-on staff, sharing of honest feedback regarding patient hand-off practices and needs, and continual communication

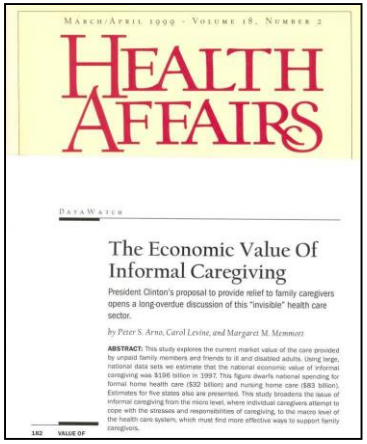
How did we get here?

Research: Listening to family caregivers



1998

Rough Crossings: Family Caregivers' Odysseys through the Health Care System
(UHF)

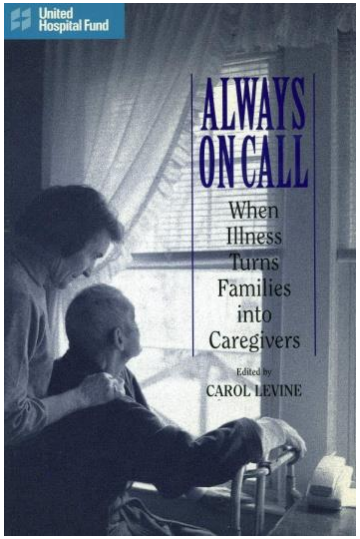


1999

"The Economic Value of Family Caregiving"
(co-authored with Peter Arno and Margaret Memmott)

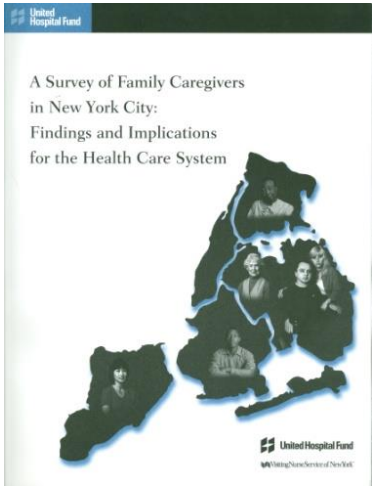
1999

Always on Call: When Illness Turns Families into Caregivers,1st ed.
(UHF)



2000

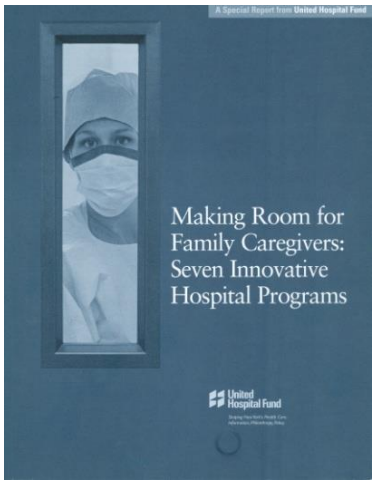
A Survey of Family Caregivers in New York City: Findings and Implications for the Health Care System
(Visiting Nurse Service of New York and UHF, with Harvard School of Public Health)

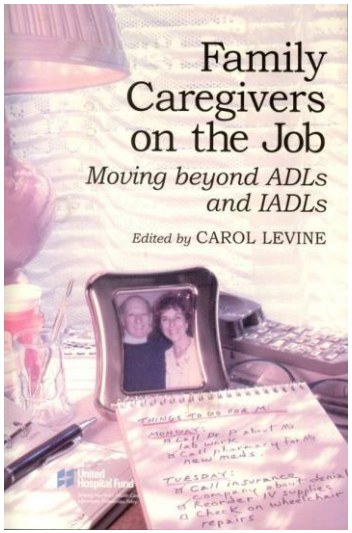


Research (con't)

2003

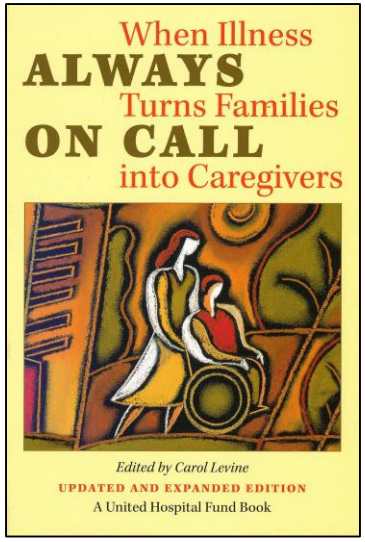
Making Room for Family Caregivers: Seven Innovative Hospital Programs
(UHF, grant initiative)





2004

Family Caregivers on the Job: Moving Beyond ADLs and IADLs
(UHF)

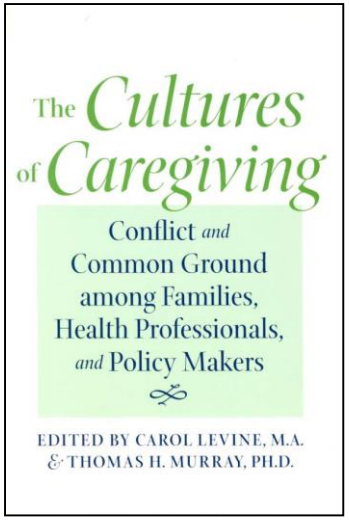


2004

Always on Call: When Illness Turns Families into Caregivers, 2nd ed.
(UHF, published by Vanderbilt University Press)

2004

The Cultures of Caregiving: Conflict and Common Ground Among Families, Health Professionals, and Policy Makers
(Co-edited by Thomas Murray, Hastings Center, published by Johns Hopkins University Press)



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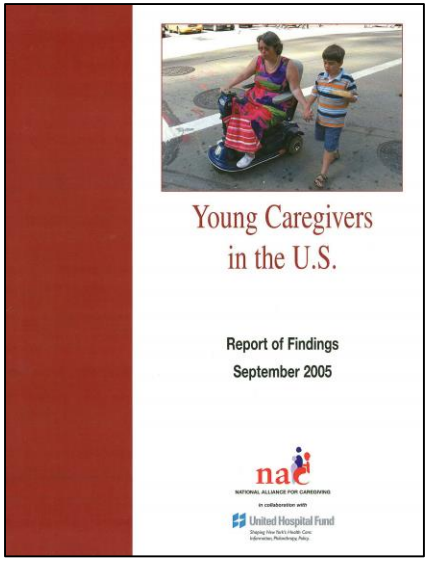
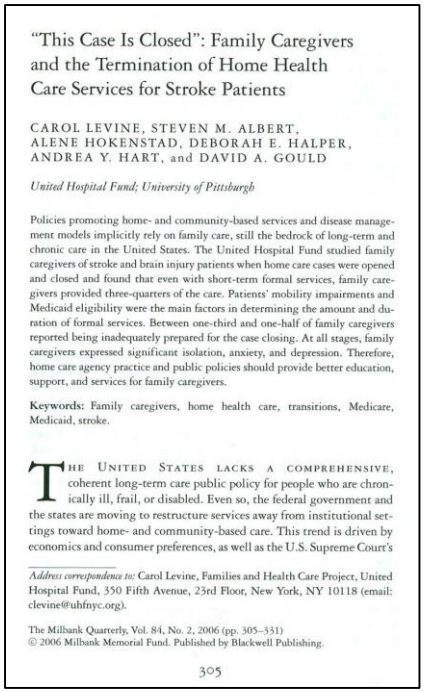
Research (con't)



2005

Young Caregivers in the U.S.: Findings from a National Survey
(National Alliance for Caregiving and UHF)



"This Case Is Closed": Family Caregivers and the Termination of Home Health Care Services for Stroke Patients

CAROL LEVINE, STEVEN M. ALBERT, ALENE HOKENSTAD, DEBORAH E. HALPER, ANDREA Y. HART, and DAVID A. GOULD

United Hospital Fund; University of Pittsburgh

Policies promoting home- and community-based services and disease management models implicitly rely on family care, still the bedrock of long-term and chronic care in the United States. The United Hospital Fund studied family caregivers of stroke and brain injury patients when home care cases were opened and closed and found that even with short-term formal services, family caregivers provided three-quarters of the care. Patients' mobility impairments and Medicaid eligibility were the main factors in determining the amount and duration of formal services. Between one-third and one-half of family caregivers reported being inadequately prepared for the case closing. At all stages, family caregivers expressed significant isolation, anxiety, and depression. Therefore, home care agency practice and public policies should provide better education, support, and services for family caregivers.

Keywords: Family caregivers, home health care, transitions, Medicare, Medicaid, stroke.

THE UNITED STATES LACKS A COMPREHENSIVE, coherent long-term care public policy for people who are chronically ill, frail, or disabled. Even so, the federal government and the states are moving to restructure services away from institutional settings toward home- and community-based care. This trend is driven by economics and consumer preferences, as well as the U.S. Supreme Court's

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The Milbank Quarterly, Vol. 84, No. 2, 2006 (pp. 305–331)

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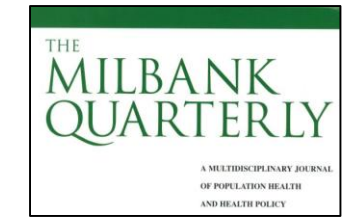

2006

"This Case Is Closed: Family Caregivers and the Termination of Home Health Care Services for Stroke Patients"

By Carol Levine, Deborah Halper, Ariella Peist, and David A. Gould

Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care

ABSTRACT Families are the bedrock of long-term care, but policymakers have traditionally considered them "informal" caregivers, as they are not part of the formal paid caregiving workforce. As chronic and long-term care systems have become more complex and as more demanding tasks have been shifted to families, this view is no longer sustainable. The care transition process offers a critical opportunity to treat family caregivers as important care partners. Enhancing their involvement, training, and support will contribute to reducing unnecessary rehospitalizations and improving patient outcomes. The contributions and experiences of family caregivers should be considered in gathering information to shape policies and practice; training health care professionals; developing programs; and reforming financing.

INFORMAL CAREGIVERS ARE "the backbone of the long-term care system in the U.S. today." Some variant of this statement, often using "bedrock," prefaces nearly every discussion of long-term care. But do family caregivers receive commensurate recognition in analyses of long-term care? Beyond the initial statement, the usual mention of family caregiving goes something like this: In the United States, an estimated thirty-four million family caregivers, the majority of them women, provide 75–80 percent of long-term care in the community; the estimated value of their unpaid labor is $375 billion a year—an unpaid contribution not calculated in the costs of long-term or health care.

Having given an obligatory nod in the direction of family caregivers, policy analysts rapidly move on to address other issues such as financing, workforce shortages, long-term care insurance, consumer-directed care, and home and community-based care alternatives to institutional care. Like the bedrock to which it is compared, unpaid family care is invaluable but only occasionally visible.

In its 2008 report *Retooling for an Aging America: Building the Health Care Workforce*, the Institute of Medicine (IOM) called for a new perspective on family caregivers: "The definition of the health care workforce must be expanded to include everyone involved in a patient's care: health care professionals, direct-care workers, informal caregivers (usually family and friends), and patients themselves. All of these individuals must have the essential data, knowledge, and tools to provide high-quality care." However, the committee noted, "Exactly when and how providers need to incorporate the family into the health care process is not yet well understood, but such incorporation is relevant across the full spectrum of institutional, ambulatory, and residential patient-care settings."

This paper provides a framework for collaboration with family caregivers by describing the complex roles family caregivers already play and their untapped potential to contribute to solving the problems of fragmentation, discontinuity, and poor-quality care. But, based on our experience, we also know that bringing family caregivers into the mainstream of policy and practice agendas is a daunting challenge that requires breaking through longstanding attitudinal, behavioral, financial, and professional barriers.

2010

"Bridging Troubled Waters: Family Caregivers, Transitions, And Long-Term Care"
(*Health Affairs*)

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What did we learn?

"We want to include you in this decision without letting you affect it."

Family caregivers are important to transitions (and readmissions)

Many transition plans assume a considerable amount of family care.

- The patients most at risk of readmission are often too sick, cognitively impaired, or otherwise unable to "self-manage."
- The best-laid transition plans will fall apart if one key partner—the family caregiver—cannot do the job.
- If family caregivers are not involved in planning, they may not understand what is expected of them.
- They also have no opportunity to have barriers accounted for in the care plan or to refuse.

What could the United Hospital Fund do?

Next Step in Care

Focus:

- Seriously and chronically ill patients whose family caregivers are significantly involved in their care
- Transitions to and from hospitals, nursing homes, and certified home health agencies

Goals:

- **Change provider practice** so that family caregivers are routinely included in transition care planning, implementation, and follow-up. Transform the abrupt admission/discharge processes into transitions in care
- **Provide information and tools to family caregivers** to enable them to manage transitions in cooperation with health care professionals

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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
- Videos
- Links and Resources

I'm caring for someone in a...

Select ...

moving to...

Select ...

Search

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

Action Agenda on Transitions Released

At a major conference, the United Hospital Fund launched an **agenda of ten action steps to improve transitions in care**. These steps lay the foundation for health care professionals to make family caregivers part of the care team, and for regulators, payers, and accrediting agencies to align financing and accreditation policies.

Medication Management Form

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Date of birth: _____

Pharmacy phone number: _____

Company phone number: _____

Prescribed By	Side Effects / Danger Signs

Over-the-Counter Med

- ❑ Allergy relief, antihistamines
- ❑ Antacids
- ❑ Aspirin / other relief for pain, headache, or fever
- ❑ Cold / cough medicines
- ❑ Diet pills
- ❑ Herbals, dietary supplements

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Formulario para el control de la medicación

Nombre del paciente: _____ Fecha de nacimiento: _____

Nombre de la farmacia local: _____ Teléfono de la farmacia: _____

Dirección de la farmacia local: _____

Nombre de la compañía de venta postal: _____ Teléfono de la compañía: _____

Nombre de la medicación marca o genérica	Dosis (mg, unidades, dosis del inhalador, gotas)	Cuando tomarla? ¿Cantidad de veces al día? ¿Por la mañana o por la tarde? ¿Con las comidas?	¿Por qué toma [illegible]?	Fecha de [illegible]	Fecha de [illegible]	Control requerido (por ejemplo:	Recetado por	Efectos Secundarios/

Medicaciones sin receta médica (marque todas las que su familiar

- ❑ Alivio de alergias, antihistamínico
- ❑ Antiácidos
- ❑ Aspirina / otras para alivio del dolor, dolores de cabeza o fiebre
- ❑ Medicinas para el re
- ❑ Pastillas para adelga
- ❑ Hierbas, suplement

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藥物管理表

病人姓名：_____ 生日：_____

本地藥房名稱：_____ 藥房電話：_____

本地藥房地址：_____

郵購公司名稱：_____ 公司電話：_____

藥物名稱 原廠或副廠	劑量 （單位：毫克、劑、滴）	何時服用？ 每天幾次？ 早上或晚上？ 吃飯時服用？	爲何服用？	開始日期	停止日期	需要觀察 （例如：每	離開的處方	副作用 / 危險徵兆

成藥（經常檢查您家人所服用的藥物）

- ❑ 抗過敏藥
- ❑ 制酸劑（胃藥）
- ❑ 阿斯匹靈 / 其他止痛藥、退燒藥
- ❑ 感冒藥 / 咳嗽藥
- ❑ 減肥藥
- ❑ 草本藥物、膳食補充品
- ❑ 瀉藥
- ❑ 安眠藥
- ❑ 維他命、

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Памятка по приему лекарств

ФИО пациента: _____ Дата рождения: _____

Название местной аптеки: _____ Номер телефона аптеки: _____

Адрес местной аптеки: _____

Название компании, торгующей по каталогам: _____ Номер телефона компании: _____

Название медицинского препарата Брэндовый или генерике	Доза (мг, единиц, впрыскиваний, капель)	Когда принимать? Раз в день? Утром или вечером? С приемом пищи?	Зачем принимать?	Дата начала приема	Дата окончания приема	Требуемое наблюдение (напр., лабораторные анализы каждые ____ недель)	Кто прописал	Побочные эффекты/ признаки опасности

Медицинские препараты, отпускаемые без рецепта (отметьте все, что ваш родственник принимает регулярно)

- ❑ Противоаллергенные, антигистаминные
- ❑ Антациды
- ❑ Аспирин /другие болеутоляющие, средства против головной боли или жаропонижающие
- ❑ Лекарства, принимаемые при простуде/кашле
- ❑ Диетические пилюли
- ❑ Травы, пищевые добавки
- ❑ Слабительные
- ❑ Лекарства от бессонницы
- ❑ Витамины, минералы
- ❑ Другое (перечислите ниже): _____

www.nextstepincare.org ©2010 United Hospital Fund Date this form was updated: _____ 1

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I'm caring for someone in a...
Hospital
moving to...
Rehab Facility

For Health Care Providers

Questions and Toolkit

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
- Videos
- Links and Resources

Search

Health care providers have many opportunities to improve transitions (and improve care for patients) by engaging and partnering with family caregivers. This website section comprises three parts:

Guides for Health Care Providers

Four Questions About Engaging Family Caregivers

A Toolkit for Working with Family Caregivers
(adapted from the Change Package developed for the **Transitions in Care-Quality Improvement Collaborative**)

- Terms and Definitions
- Quality Improvement Surveys
- News
- About the Campaign
- About the United Hospital Fund

Sign Up for Updates

Guides for Health Care Providers

In addition to the family caregiver guides and the materials in the Toolkit, Next Step in Care has specific guides for health care providers to help you understand the family caregiver perspective. These are:

- **HIPAA - Provider's Guide**
- **Assessing Family Caregivers' Needs - Provider's Guide**
- **Medication Management - Provider's Guide**
- **Reducing the Stress of Hospitalization for Patients with Dementia and Their Family Caregivers: A Provider's Guide**
- **Hospital Discharge Planning - First Steps with Family Caregivers**
- **Referring Patients and Family Caregivers to Community-Based Services**

Go to top

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Referring Patients and Family Caregivers to Community-Based Services: A Provider's Guide

This guide is intended to help health care providers and care team members make referrals to the different types of community-based services and supports that may be available to patients and family caregivers experiencing transitions in care. This may be the responsibility of the social service, discharge planning, or other departments.

Referral to community-based services is an important but often overlooked component of the discharge process. It can be a vital complement to a successful transition — as important as an updated medication list and a follow-up doctor's appointment. Many services that support the patient and family caregiver through those critical post-discharge weeks and beyond are available through community-based agencies. However, patients and family caregivers often do not know how to find them on their own. Making the connection to services, or encouraging the patient and family caregiver to connect on their own, may help people with illness and disability better manage day-to-day, live longer in the community, and possibly avoid a rehospitalization or delay a move to an

TC-QuIC at a glance

- Three-year (2010-2012) quality improvement initiative
- 45 multidisciplinary teams from hospitals, nursing home rehab programs, home care agencies, and hospices, almost all working in partnership (*example*: New York Methodist Hospital partnered with Center for Nursing and Rehabilitation)
- Change package based on *Next Step in Care* guides and other resources
- Data collection and analysis, using Model for Improvement
- Over 2200 family caregivers identified
- Over 200 staff members involved

<u>Teams that measured readmissions saw significant improvement</u>

TC-QuIC Strategies

- Early identification of the family caregiver
- Guided self-assessment of the caregiver's needs for training and support
- Inclusion of family caregiver in medication reconciliation
- Discussing options for post-discharge care
- Planning smooth day of discharge
- Following up with receiving agency and family caregiver (*starting point for Day of Transition Initiative*)

Engaging patients and family caregivers

- Starts with **engaged staff** willing to revisit attitudes and behavior to better meet patient and family's needs
- Requires **ability to meet patients and family caregivers where they are**, not where professionals think they should be
- Means **recognizing different levels of willingness and capacity** of patients and families to participate in care because of cognitive deficits, health literacy, or language differences, life experiences, or other factors
- Depends on **establishing a trusting relationship** in which no one is judged or blamed but is offered assistance to achieve goals

TC-QuIC Fundamentals

- Focus on family caregivers as “key learners” in transitions (Institute for Healthcare Improvement)
- Partnerships between agencies that share patients regularly
- Included transitions in addition to hospital to home
- Involved regular staff (nurses, social workers, case managers, QI specialists, pharmacists, physicians)
- Based on belief that transitional care is every professional’s responsibility, even if there is a designated coach or navigator to support patient and family

Family caregivers as a part of the readmissions picture

- Integration of family caregivers into existing transitions improvements
  - Identification of family caregivers
    - Different from next-of-kin, POA, family spokesperson, etc.
  - Post-transition follow-up targeted to family caregivers
  - Assessment of family caregiver needs contributes to realistic discharge plans
  - Can “do” RED, CTI, TCM, BOOST, INTERACT (Stop & Watch, advance care planning) with identified family caregivers

Transitions in Care-Quality Improvement Collaborative (TC-QuIC)

United Hospital Fund

A SPECIAL REPORT SUMMARY

Engaging Family Caregivers as Partners in Transitions

TC–QuIC: A Quality Improvement Collaborative

Carol Levine, Director, Families and Health Care Project
Deborah E. Halper, Vice President, Education and Program Initiatives
Jennifer L. Rutberg, Senior Program Manager, Families and Health Care Project
David A. Gould, Senior Vice President for Program

Highlights of a special report on a three-year United Hospital Fund initiative, involving 45 health care providers in engaging and supporting family caregivers as a core strategy for improving patient transitions between care settings.

What does it take to improve transitions in care for seriously or chronically ill persons? If there were a simple answer to that question, we would know it by now. Over the past two decades many different programs have been tested, with varying levels of success. What has been largely missing in all the efforts has been the active engagement and involvement of family caregivers, broadly defined, who are de facto care coordinators and are often responsible for performing complex medical/nursing tasks at home.

Building on 15 years of efforts to develop strong working partnerships between health care providers and family caregivers, the United Hospital Fund's Transitions in Care–Quality Improvement Collaborative, or TC–QuIC, identified and tested ways to fill that gap.

Over nearly three years, teams from 45 health care organizations—hospitals, home care agencies, nursing home rehab programs, and hospices—participated in one or both of two rounds of TC–QuIC. Their experiences can guide other organizations embarking on a similar path. This summary provides a brief overview of TC–QuIC. A comprehensive report, *Engaging Family Caregivers as Partners in Transitions*, available at http://www.uhfnyc.org, details what participants did, what they learned in the process, and the impact of their efforts.

United Hospital Fund

A SPECIAL REPORT FROM THE UNITED HOSPITAL FUND

Engaging Family Caregivers as Partners in Transitions

TC–QuIC: A Quality Improvement Collaborative

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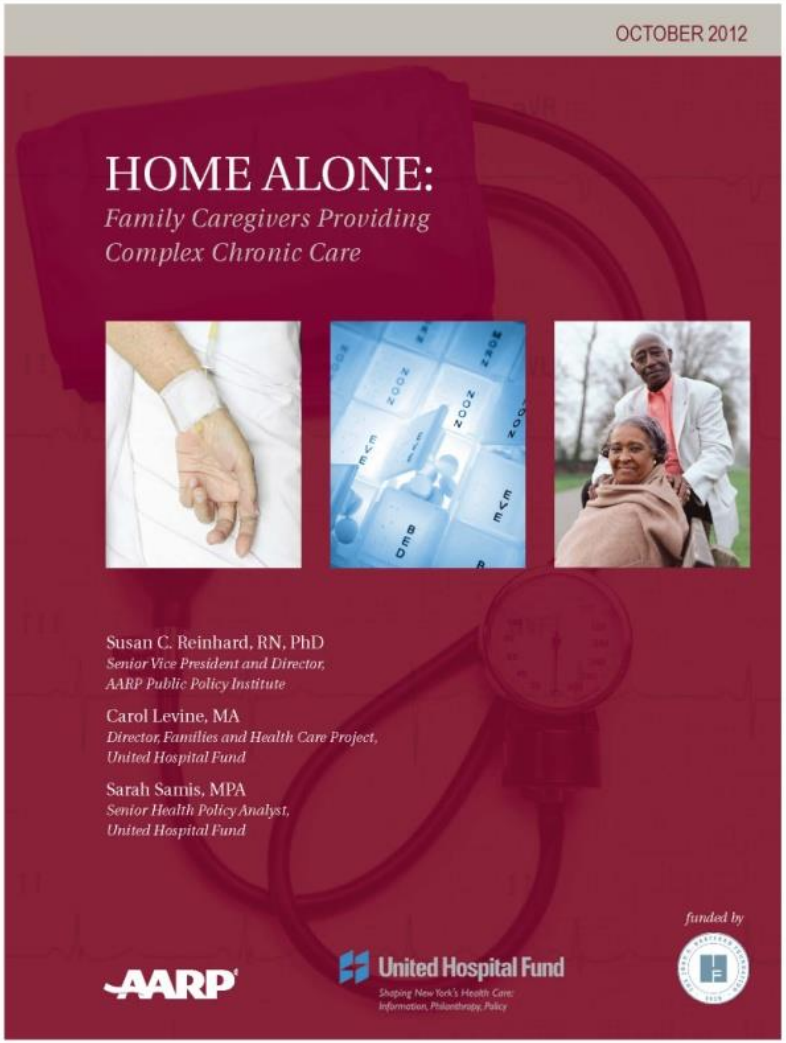
Home Alone: Families Providing Complex Chronic Care



United Hospital Fund
Shaping New York's Health Care:
Information, Philanthropy, Policy

Next Step in Care™
Family Caregivers & Health Care Professionals Working Together

Action Agenda

United Hospital Fund

ACTION AGENDA

Creating effective partnerships with family caregivers of chronically ill persons is mission-critical for health care providers, payers, and innovators. This United Hospital Fund ***Action Agenda*** sets forth ten action steps that can improve transitional care and contribute significantly to the transformation of the nation's health care.

Transitions in Care 2.0 An Action Agenda

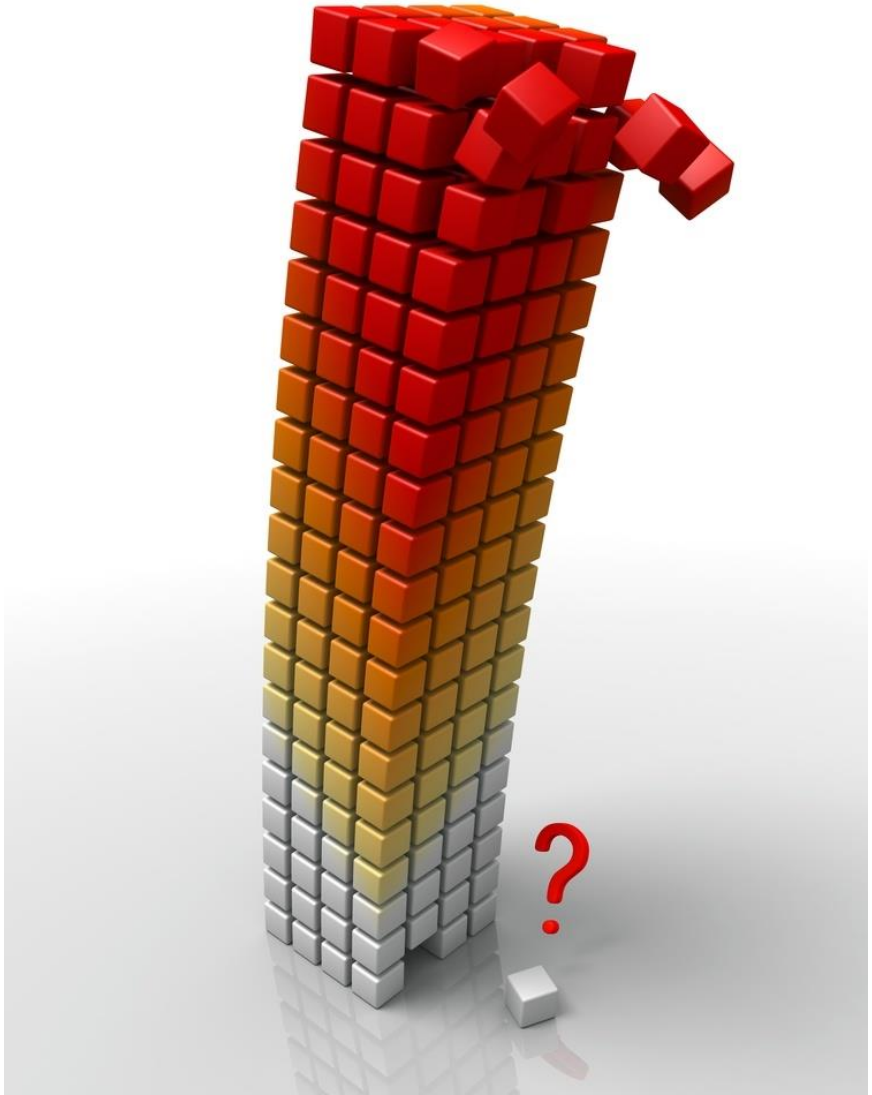
David A. Gould, Senior Vice President for Program
Carol Levine, Director, Families and Health Care Project

"I wasn't prepared!" reported family caregivers in 1997 when the United Hospital Fund asked about their experience taking a relative home from the hospital. In 2012, when family caregivers were asked, in a United Hospital Fund/AARP survey, who taught them to manage medications and do wound care, the typical response was similar: "I learned on my own." Much has changed in health care in 15 years, but family caregivers are still not prepared to manage care at home and are still not systematically included in critical transition discussions and plans.

This situation must change, and now is the time to do it. The United Hospital Fund's Transitions in Care 2.0 Action Agenda—based on more than 20 years of experience and study by the Fund and others—outlines steps that should be taken to improve transitions from one care setting to another for chronically ill adults and their family caregivers.

While family caregivers' contributions to long-term services and supports are now well recognized, much more attention must be focused on their vital role in the transitions between acute care and community care. A generation of patient-centered transitional care programs has demonstrated that they are acceptable to providers and patients, useful, and cost-effective. Further investments to integrate, train, and support family caregivers will yield greater returns in improving outcomes and reducing repeated transitions between acute and community care. Achieving the Institute for Healthcare Improvement's Triple Aim of better health, better care experiences, and lower costs can be advanced by implementing this agenda.

Remember: Take away the family caregiver and the structure falls down



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Thank you!

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