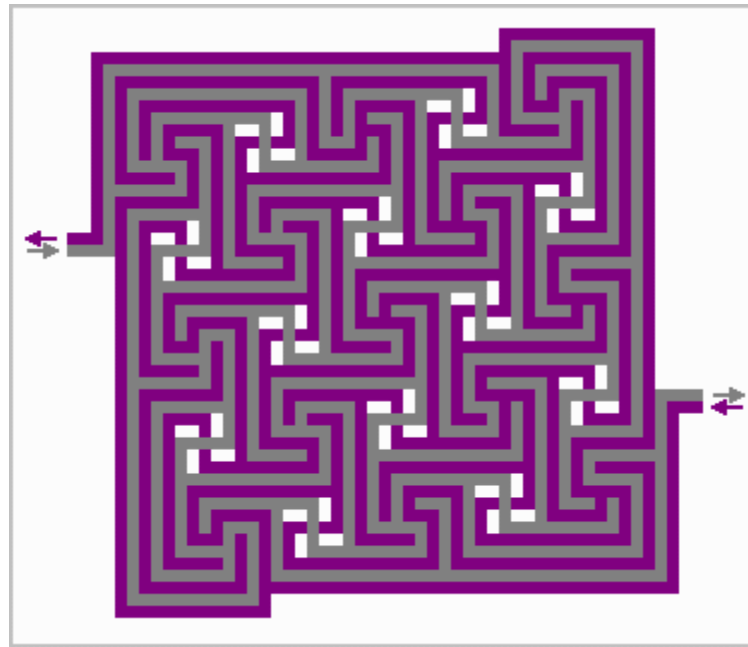


Transitions in Care: What Patients and Families Need

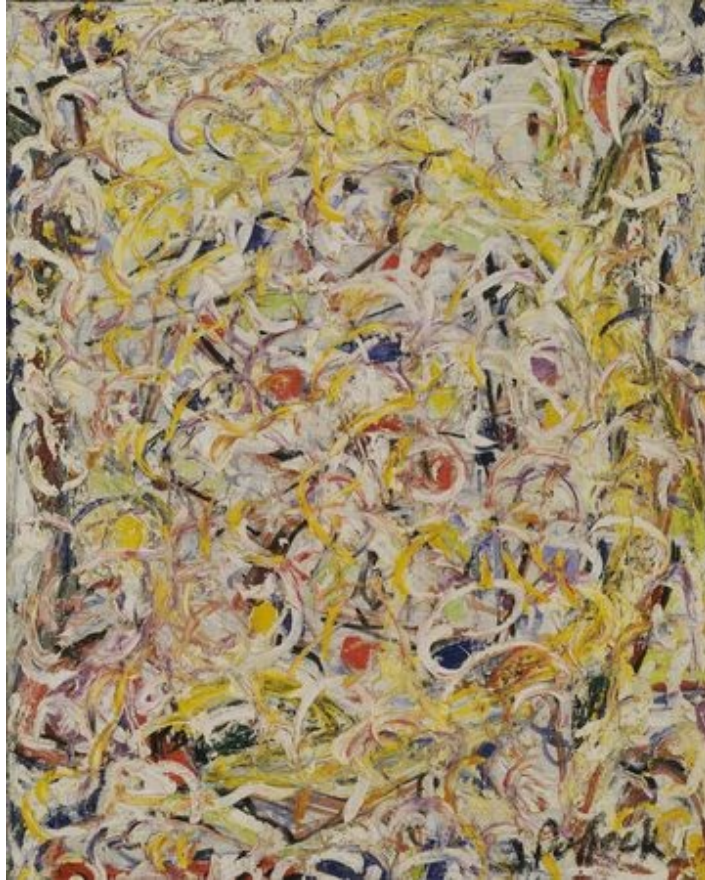
Carol Levine
Director, Families and
Health Care Project
United Hospital Fund

Massachusetts Care Transitions Seminar
Massachusetts Health Data Consortium
Westborough, MA
April 29, 2009

A Journey Through the Health Care System ca. 1990



A Family Caregiver's Journey Through the Health Care System ca. 2009



What Patients Need in Transitions

- Knowing who is in charge of the transition
- Being part of the plan
- Understanding the plan and what it means
- Understanding follow-up instructions
- Knowing whom to call with questions

What Patients Need in Transitions

Patients most at risk in transitions

- Older and sicker
- More chronic conditions
- Cognitive impairments
- Multiple medications
- Language or literacy problems

These patients are not able to “self-manage”

They need someone to provide or manage their care, advocate on their behalf

That person is usually a family caregiver

Who is a Family Caregiver?

- Someone who provides or manages the care of a family member, friend, partner, or other person who has a disability or chronic and serious illness.
- Who Counts as Family?
 - “Family” should be interpreted broadly.
 - Spouses and adult children most likely relatives to take on care but others may be involved.
 - Family members may not be related by blood or marriage but are “fictive kin” or “families of choice.”

Why family caregivers matter

- Family caregivers—over 34 million Americans of all ages, including children--provide most of the care to elderly, disabled, and chronically ill individuals
- They provide care over years...and years...and years
- They are (largely) unpaid
- If paid at a modest rate, their labor would add an additional \$375 billion every year to the health care system's costs (AARP estimate)
- And people wonder why family caregivers don't leap to identify themselves as caregivers!

What do family caregivers do?

All or some of the following:

- Medication management, including pain medications
- Symptom control
- Operation of medical equipment
- Record keeping
- Personal care
- Emotional support
- Financial and legal management
- Nutrition
- Mobility and transportation
- Communication with health care professionals
- Household management
- Companionship

**And Care Coordination of medical, social, and all other services
Not to mention jobs, children, other responsibilities....**

Transitions in Care: A Critical Need for Coordination

- Chronically ill patients move frequently from one setting to another
- Rush to discharge → gaps in communication → medication and other errors
- Unnecessary hospitalizations and rehospitalizations → increased costs and poor outcomes
- Little information, involvement, and training for family caregivers
- Culture Shock
 - Each profession and setting has its own language, norms, and unspoken rules, all confusing to family caregivers.
 - In each setting, family roles are different and are seldom explained.

Transitions in Care: Why Coordination is so Complicated

- Crossing sectors made up of silos made up of subsilos, made up of individuals with rigidly defined roles
- Professionals have difficulty making connections with other professionals
- Not enough advance notice to plan carefully
- Not enough information to plan carefully
- Not enough resources and options
- Many unknowns and some unknowables

Transitions in Care Settings: The Case of Mrs. Jones

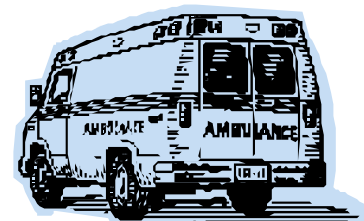
This is Mrs. Jones.
She is an 81-year-old widow.
She lives alone and manages
quite independently.



This is her daughter Louise.
She lives nearby and helps her
mother manage her medications
and financial affairs.



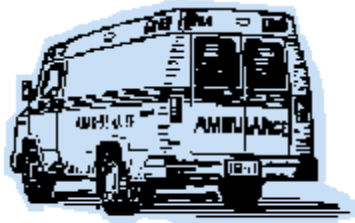
One day on her daily walk
Mrs. Jones falls and breaks her hip.



Mrs. Jones' Transitions in Care



HOME CARE



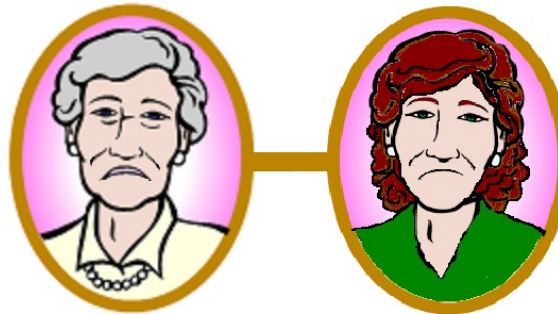
EMERGENCY ROOM



INTENSIVE CARE



REHAB at a SNF



SURGERY



HOSPITAL FLOOR



REHAB at a SNF



HOSPITAL FLOOR

What (Many) Family Caregivers Don't Understand and Should: A Short List

- That they are family caregivers, not just spouses, daughters, or sons
- How the health care “system” works, particularly home care and rehab
- What policy and insurance terms mean
- Who makes reimbursement decisions and on what basis
- The difference between Medicare and Medicaid
- How to appeal a hospital or rehab unit discharge
- The beneficiary’s rights to be offered a choice of home care agency or nursing home
- How to find the services that they are supposed to coordinate
- How best to coordinate the services they do find

Professional Care Managers and Family Caregivers

- Professional CMs not routinely available
- Not many CMs know the whole spectrum of patient need or community resources
- Most don't focus on family caregiver needs
- Facility-based CMs focus on discharge
- Insurance-based CMs have to balance patient needs with resource allocation
- Deal with most difficult cases (homeless, no family, complex medical or behavioral situation)
- Privately paid CMs - an option for some but not majority



Focus:

- Seriously and chronically ill patients whose family caregivers are significantly involved in their care
- Admissions and discharges in hospitals, nursing homes, and Certified Home Health Care Agencies

Goals:

- Change provider practice so that family caregivers are routinely included in transition care planning, implementation, and follow-up
- Provide information and tools to family caregivers to enable them to manage transitions in cooperation with professionals

Next Step in Care Values: 7Cs

Changes in practice should be grounded in values that guide all interactions with family caregivers and patients. Organizations that sign on to campaign will agree that these values are consistent with their mission:

- Communication
- Cultural competence
- Consideration
- Courtesy
- Collaboration
- Coordination
- Continuity

Next Step In Care Guides and Checklists

- Different materials reflect the specific transition experience to and from each setting (hospital, rehab, and home care)
- Accurate, simple, readable, task-oriented, and realistic
- Introduces caregivers to their roles and responsibilities
- Assists staff in facilitating a realistic and sustainable plan of care
- All guides and checklists are free and downloadable on www.nextstepincare.org
- Family caregiver guides in English and Spanish

www.nextstepincare.org

The screenshot shows a Windows Internet Explorer browser window displaying the homepage of www.nextstepincare.org. The browser's address bar shows the URL, and the page title is "UHF Next Step in Care | :: Next Step In Care Homepage". The website features a navigation menu on the left with options like "Search", "Text size", and "Guides & Checklists". The main content area includes a header with the logo "Next Step in Care" and the tagline "Family Caregivers & Health Care Professionals Working Together". Below the header, there is a large image of three people (two women and one man) in a clinical setting. To the right of this image, there is a section titled "I'm caring for someone in a..." with two dropdown menus: "Hospital" and "Rehab Facility". Below this, there is a blue arrow button. The bottom section of the page has a purple background with the text: "Next Step in Care provides information and advice to help **family caregivers** and **health care providers** plan safe and smooth transitions for patients. Transitions occur when patients move from one care setting to another, for example, from a hospital to home or rehab facility, or when home care agency services start and end. Patient transitions are often complicated, rushed, and beset by errors or misunderstandings." To the right of this text is a small image of two women, one adjusting the other's collar. The browser's taskbar at the bottom shows the Start button, several application icons, and the system tray with the time 12:04 PM.

UHF Next Step in Care | :: Next Step In Care Homepage - Windows Internet Explorer

http://www.nextstepincare.org/ Live Search

File Edit View Favorites Tools Help

UHF Next Step in Care | :: Next Step In Care Homepage

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

A United Hospital Fund Campaign

Search

Text size: A A A

Guides & Checklists

- ▶ For Family Caregivers
- ▶ «Para Cuidadores Familiares»
- ▶ For Health Care Providers
- ▶ Links and Resources
- ▶ Terms and Definitions
- ▶ News

Hospital

Rehab

I'm caring for someone in a...

Hospital

moving to...

Rehab Facility

Next Step in Care provides information and advice to help **family caregivers** and **health care providers** plan safe and smooth transitions for patients.

Transitions occur when patients move from one care setting to another, for example, from a hospital to home or rehab facility, or when home care agency services start and end. Patient transitions are often complicated, rushed, and beset by errors or misunderstandings.

Internet 100% 12:04 PM

Next Step In Care Guides and Checklists

Partial List

Admission

- *HIPAA: Questions and Answers for Family Caregivers*
- *Your Family Member's Personal Health Record*
- *Medication Management Form*
- *A Family Caregiver's Guide to Advance Directives*

Planning for Discharge

- *The Next Step in Care: What Do I Need as a Family Caregiver?*
- *Hospital-to-Home Discharge Guide*

Discharge

- *Family Caregivers' Guide to Medication Management*
- *Going Home: What You Need to Know*

Next Steps

- *A Guide to the ER*
- *When the Next Step Is Home Care: A Family Caregiver's Guide*
- *When the Next Step Is Rehab: A Family Caregiver's Guide*



Medication Management Form

Patient name: _____ Date of birth: _____
 Local pharmacy name: _____ Pharmacy phone number: _____
 Local pharmacy address: _____
 Mail order company name: _____ Company phone number: _____

Name of Medication Brand or Generic	Dosage (mg, units, puffs, drops)	When to take it? Times per day? AM or PM? With meals?	Why take it?	Start Date	Stop Date	Monitoring Required (e.g. lab test every _____ weeks)	Prescribed By	Side Effects / Danger Signs

Over-the-Counter Medications (check all that your family member uses regularly)

- | | | | |
|---|---|---|---|
| <input type="checkbox"/> Allergy relief, antihistamines | <input type="checkbox"/> Cold / cough medicines | <input type="checkbox"/> Laxatives | <input type="checkbox"/> Other (list below):

_____ |
| <input type="checkbox"/> Antacids | <input type="checkbox"/> Diet pills | <input type="checkbox"/> Sleeping pills | |
| <input type="checkbox"/> Aspirin / other relief for pain,
headache, or fever | <input type="checkbox"/> Herbals, dietary supplements | <input type="checkbox"/> Vitamins, minerals | |

Name and Contact Information for Agencies Providing Care to Your Family Member

It's important to have contact information for all agencies and people involved in your family member's care. This is very helpful in an emergency.

Name of home care agency:	() _____ : _____
Team providing services:	
Team leader or supervisor:	
Team leader or supervisor telephone number in case of emergency:	() _____ : _____
Other emergency telephone number	() _____ : _____
Person coordinating your family member's care plan and phone number:	
Are other agencies also providing services (such as home health aides)?	<input type="checkbox"/> Yes <input type="checkbox"/> No
If yes, name of agency:	() _____ : _____

Services in this Care Plan

Home care can include many different types of services. Make sure you know what these services are and who will provide them. You can check the boxes next to those who will be involved in your family member's care.

- | | |
|--|--|
| <input type="checkbox"/> Home health aide | <input type="checkbox"/> Occupational therapist (OT) |
| <input type="checkbox"/> Nurse | <input type="checkbox"/> Speech therapist |
| <input type="checkbox"/> Physical therapist (PT) | <input type="checkbox"/> Social Worker |
| <input type="checkbox"/> Other: | |

Home Care Agency Services

The home care agency may send one or more people to help in your family member's care. Services can be from professionals (nurses, physical therapists, occupational therapists, or speech therapists) and paraprofessionals (home health aides). It is important to know what kind of service each person provides. Keep in mind that services may not always be provided by the same person. Talk with the home care agency nurse or case coordinator and check those services (below) that your family member will get and who will provide these services.

Home Health Aide. Services may include:

Personal Care

- | | | |
|-----------------------------------|---|---|
| <input type="checkbox"/> Bathing | <input type="checkbox"/> Brushing teeth | <input type="checkbox"/> Changing diapers |
| <input type="checkbox"/> Dressing | <input type="checkbox"/> Nail care | <input type="checkbox"/> Toileting |

Nutrition

- | | |
|----------------------------------|--|
| <input type="checkbox"/> Cooking | <input type="checkbox"/> Assist with feeding |
|----------------------------------|--|

Household Chores and Escort

- | | | |
|---|--|--|
| <input type="checkbox"/> Clean | <input type="checkbox"/> Patient's laundry | <input type="checkbox"/> Go with patient to other location |
| <input type="checkbox"/> Grocery shopping | <input type="checkbox"/> Go with patient to doctor or clinic | |

Vital Signs

- | | | |
|--|--------------------------------------|---|
| <input type="checkbox"/> Check temperature | <input type="checkbox"/> Check pulse | <input type="checkbox"/> Measure blood pressure |
|--|--------------------------------------|---|

Activities

- | | | |
|----------------------------------|---|---|
| <input type="checkbox"/> Walking | <input type="checkbox"/> Transfers (such as moving from bed to chair) | <input type="checkbox"/> Exercises (simple range of motion) |
|----------------------------------|---|---|

Other services the aide may provide

- | | | |
|---|--|---|
| <input type="checkbox"/> Medications: assist or remind | <input type="checkbox"/> Assist with nebulizer | <input type="checkbox"/> Assist with tube feeding |
| <input type="checkbox"/> Assist with dressing change for wound care | <input type="checkbox"/> Ostomy care | <input type="checkbox"/> Other: _____ |

Care Schedule for the week of: _____

Monday		Tuesday		Wednesday	
Service or Activity	Time	Service or Activity	Time	Service or Activity	Time
<input type="checkbox"/> Home Health Aide		<input type="checkbox"/> Home Health Aide		<input type="checkbox"/> Home Health Aide	
<input type="checkbox"/> Nurse		<input type="checkbox"/> Nurse		<input type="checkbox"/> Nurse	
<input type="checkbox"/> Occupational Therapist		<input type="checkbox"/> Occupational Therapist		<input type="checkbox"/> Occupational Therapist	
<input type="checkbox"/> Physical Therapist		<input type="checkbox"/> Physical Therapist		<input type="checkbox"/> Physical Therapist	
<input type="checkbox"/> Speech Therapist		<input type="checkbox"/> Speech Therapist		<input type="checkbox"/> Speech Therapist	
<input type="checkbox"/> Doctor's Appointment		<input type="checkbox"/> Doctor's Appointment		<input type="checkbox"/> Doctor's Appointment	
<input type="checkbox"/> Deliveries		<input type="checkbox"/> Deliveries		<input type="checkbox"/> Deliveries	
<input type="checkbox"/> Other		<input type="checkbox"/> Other		<input type="checkbox"/> Other	
Notes and Questions:		Notes and Questions:		Notes and Questions:	

Provider Guides

- Guide to HIPAA
- Guide to Caregiver Needs Assessment
- Medication Management Guide



Assessing Family Caregivers: A Guide for Health Care Providers

As a health care professional, you assess patients all the time. But you generally do not assess a patient's family caregiver, except to identify that person as a "resource" or "informal support" when developing a discharge plan. In this traditional view, the family caregiver, who is not a client or a beneficiary and not an official part of the health care team, is typically outside the realm of professional responsibility.

Like so much of health care today, that view is changing. Increasingly professionals "hand off" very sick or disabled patients to family caregivers after a hospital stay, a short-term nursing home stay, or an episode of home care services. In these transitions, especially when the patient is elderly or chronically ill, the patients' continued health and well-being depends on a family caregiver. That person must be willing and able to handle the patient's complex health, financial, legal, and social needs. Sometimes these tasks are temporary, while the patient recovers; in the case of elderly or seriously ill patients, the job can continue for months or years.

Caregiver assessment is a tool to help identify strengths and limitations and to develop a realistic plan for the next stage of care. The goal is twofold: (1) to ensure that the patient's health and well-being are maintained and enhanced; and (2) to ensure that the caregiver's capacities and needs are considered and addressed in a care plan.

This guide is an introduction to caregiver assessment in hospitals, nursing homes, and home health agencies. Although these settings are different, the guide gives some basic information and suggestions. These are the questions we address:

- Who is a family caregiver?
- What is caregiver assessment and why is it important?
- Who should do it, when, and how?
- What should it cover?
- How should the assessment be used?

Implementation Steps

Collaboratives

- Teams from hospitals, nursing homes, home care agencies working together (New York City area)
- Selected problems
- Data collection and evaluation

Community agency outreach

Conferences

Webinars

Dissemination of results

Thank you!

www.nextstepincare.org

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