

Improving Transitions of Care by Involving Family Caregivers

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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 or not be related by blood or marriage but are “fictive kin” or “families of choice.”

What do family caregivers do?

All or some of the following:

- Symptom control
- Medication management, including pain medications
- 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....

Caregiver mental health

- Caregivers show high levels of depression
 - Between 40-70% have clinically significant symptoms
 - Symptoms increase as care recipient's condition declines
 - Placing care recipient in nursing home does not necessarily lessen anxiety and depression
 - Increase in mental health problems for caregivers who provide 36 hours or more a week
- Caregivers suffer from high levels of stress
 - Feel angry, drained, guilty, helpless, isolated
 - Different sources of stress

Caregiver physical health

- Caregivers are in worse health than noncaregiving peers
- Increased risk of heart disease
- Immune system deficiencies
- Sleep deprivation
- Joint and muscle problems
- Lower levels of self-care
- Increased mortality – the ultimate price

Caregiver financial health

- Half of all caregivers employed full- or part-time
- 70% reported impact of caregiving on employment
 - 2/3 went in late, left early, took time off
 - 20% took a leave of absence

Result:

Short-term impact on finances

Long-term impact on retirement and long-term care

Which caregivers are most vulnerable?

- Older caregivers
- Poor caregivers
- Caregivers with chronic health problems
- Caregivers with language or health literacy problems
- Caregivers taking care of more than one person
- But all caregivers may be vulnerable in different ways, such as financially and emotionally

Caregiving rewards

- New skills
- Appreciation/love of care recipient
- Obligation/duty fulfilled
- Spiritual growth
- Rewards are self-defined; can't be forced

What's different now: “Outsourcing” of medical care

- Families have always taken care of their ill and elderly members but never with so much complicated care and so many responsibilities in a daunting service delivery and economic environment
- “The invisible contract: shifting care from the hospital to the home”
 - Briany Dow and John McDonald, 2007

What's different now:

Multiple chronic diseases

- Aging population suffers from multiple chronic diseases (CHF, COPD, arthritis, diabetes, as well as cancer, dementia, others)
- Multiple medications with side effects
- Fragmented health care system
- Lack of care coordination, especially in transitions

Why family caregivers are important to transitions

- Many transition plans assume a considerable amount of family care
 - If family is not involved in planning, they may not understand this assumption
- To provide care, family needs ongoing training and support
- Best-laid transition plans will fall apart if one key partner—the family—cannot fulfill professional expectations
- No one can absorb all the information and instructions given at discharge without follow-up

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.



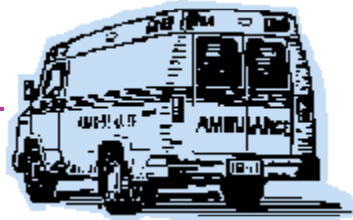
One day on her daily walk
Mrs. Jones falls and breaks her hip.



Mrs. Jones' Transitions in Care



HOME CARE



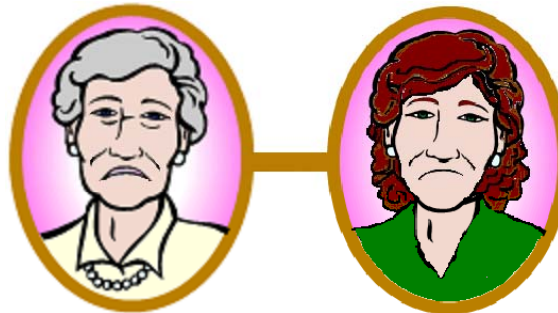
EMERGENCY ROOM



INTENSIVE CARE



REHAB at a SNF



SURGERY



HOSPITAL FLOOR



REHAB at a SNF



HOSPITAL FLOOR

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 Care 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 professionals

Major activities

- Inclusion in Western and Central New York Transition in Care collaborative
- UHF Transitions in Care-Quality Improvement Collaborative (TC-QuIC) –25 health care providers working in partnerships across care settings to improve transitions
- Work with community agencies to train staff to use Next Step in Care materials before a crisis occurs
- Direct outreach to caregivers through Next Step in Care website – www.nextstepincare.org
- 19 family caregiver guides –free, downloadable, in English, Spanish, Chinese, and Russian



Hospital Rehab



I'm caring for someone in a...

moving to...

A United Hospital Fund Campaign

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Guides & Checklists

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

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.

Selected Topics

- What Do I Need as a Family Caregiver? (caregiver needs assessment)
- Medication Management
- Going Home: What You Need to Know (discharge checklist)
- A Family Caregiver's Planner for Care at Home
- Guides to specific settings: ER, home care, rehab

Assessing Family Caregivers' Needs

From the Next Step in Care guide for providers:

- Definition: “A systematic process of gathering information that describes a caregiving situation and identifies the particular problems, needs, resources, and strengths of the family caregiver.”
- Approaches issues from the caregiver’s perspective
- Focuses on what caregiver might need
- Seeks to maintain caregiver’s own health and well-being
- NOT a quick judgment based on appearances or stereotypes

About Helping Your Family Member

As a family caregiver, you might be responsible for the help your family member needs at home. Here is a list of many of the things that may need to be done. For each item, check one of the following: I am able to help *without* training, I would be able to help *with* training, or I am unable to help. If your family member will not need help with one or more of the items, just skip them and go on to the rest of the list.

| What Needs to Be Done | I am able to help <i>WITHOUT</i> training | I am able to help <i>WITH</i> training | I am unable to help |
|--------------------------------------------------------------------------------------------------------|-------------------------------------------|----------------------------------------|--------------------------|
| Bathing (washing in the shower, bath, or sink) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Dressing (getting dressed and undressed) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Eating | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Personal hygiene (such as brushing teeth) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Grooming (such as washing hair and cutting nails) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Toileting (going to the bathroom or changing diapers) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Transfer (such as moving from the bed to a chair) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Mobility (includes walking) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Medication (ordering medications, organizing them, and giving all medications as prescribed) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Managing symptoms (such as pain or nausea) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Equipment (such as oxygen, IV, or infusion) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Coordinating the patient's care (includes talking with doctors, nurses, and other health care workers) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Making and keeping appointments | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Driving or helping with transportation (such as car, bus, or taxi) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Household chores (such as shopping, cooking, and doing laundry) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Taking care of finances (includes banking and paying bills) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Next Step in Care: What Do I Need as a Family Caregiver?



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 |
|----------------------------------------|----------------------------------------|-------------------------------------------------------------------|--------------|---------------|--------------|----------------------------------------------------------------|---------------|--------------------------------|
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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 | _____ |

Work in progress

- Family caregiver guide to hospice and palliative care
- Providers' guide to recognizing dementia in health care settings
- Reports from the Transitions in Care-Quality Improvement Collaborative
- Reports from the field

Thank you!

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