

Making the Transition to Hospice: What Family Caregivers Want and Need to Know

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Six Questions

- π Who is a family caregiver and what does she or he do?
- π What is a transition?
- π How can family caregivers' needs be assessed?
- π When and where can the transition to hospice be introduced?
- π What are key points for a family meeting?
- π What information about hospice and palliative care do family caregivers need?

Next Step in Care

Focus:

- π **Seriously and chronically ill patients whose family caregivers are significantly involved in their care**
- π **Transitions to and from hospitals, nursing homes, and Certified Home Health Care Agencies**

Goals:

- π **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
- π **Provide information and tools to family caregivers** to enable them to manage transitions in cooperation with professionals



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



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.



Three major activities

- π Transitions in Care-Quality Improvement Collaborative (TC-QuIC)—25 health care providers working in partnerships across care settings to improve transitions
- π Work with community agencies to train staff to use Next Step in Care materials before a crisis occurs
- π Direct outreach to caregivers through Next Step in Care website—www.nextstepincare.org

Who is a Family Caregiver?

- π 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.
- π 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.”

I'm not a caregiver!

- π Many family members don't self-identify as caregivers.
- π They may fear losing their status as daughter, son, spouse, or partner.
- π They may also fear losing their identity by becoming engulfed in caregiving (not an unrealistic fear).
- π “Family caregiver” – two words
 - √ “Family” is who you are
 - √ “Caregiver” is what you do

What do family caregivers do?

All or some of the following:

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

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

What's different now: Multiple chronic diseases

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

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

π 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

π “The invisible contract: shifting care from the hospital to the home”

- Briony Dow and John McDonald, 2007

Caregiver mental health

- π 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

- π Caregivers suffer from high levels of stress
 - Feel angry, drained, guilty, helpless, isolated
 - Different sources of stress

Caregiver physical health

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

Caregiver financial health

- π Half of all caregivers employed full- or part-time
- π 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?

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

Caregiving rewards

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

What is a transition in care?

- θ **A move from one care setting to another**
 - ✓ Hospital to rehab
 - ✓ Rehab to home
 - ✓ Rehab to hospital
 - ✓ Opening and closing a home care agency case
 - ✓ Decision to enter hospice care
- π **More than an admission or discharge**
- π **Not completed until patient is safely under the care of another prepared provider, who may be a family caregiver**

Transitions in Care: What's the Problem?

- π Chronically ill patients move frequently between settings
- π Rush to discharge → gaps in communication → medication and other errors
- π Unnecessary hospitalizations and rehospitalizations → increased costs and poor outcomes
- π Little information, involvement, and training
- π 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.

What do family caregivers need in the transition to hospice?

- π Assessment of their strengths and limitations
- π Validation for their concerns
- π Help from trained, compassionate professionals
- π Exploration of patient preferences
- π Explanation of surrogate decision-making
- π Affirmation of non-abandonment
 - Curtis, Engelberg et al, 2005; Azoulay, 2005

Assessing Family Caregivers' Needs

From the Next Step in Care guide for providers:

- π **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.”
- π Approaches issues from the caregiver’s perspective
- π Focuses on what caregiver might need
- π Seeks to maintain caregiver’s own health and well-being
- π NOT a quick judgment based on appearances or stereotypes

Caregiver Needs Assessment

- π No standardized assessments
- π Two suggestions:
- π Next Step in Care “What Do I Need as a Caregiver?”
- π “Brief Assessment Scale for Caregivers of the Medically Ill”

–Glajchen, M. et al. 2005

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



What Do I Need?

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 WITHOUT training	I am able to help WITH 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	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

BASC

Brief Assessment Scale for Caregivers (BASC) of the Medically Ill

Please check off to what extent you have had any of the following feelings in the past month because of taking care of _____.

Because of _____'s illness, how much have you:	Not at all	A little	Some	A lot
1. Worried about _____ even when you are not with him/her.				
2. Been depressed because of _____'s illness.				
3. Been upset about not having enough time for yourself because of caring for _____.				
4. Been overwhelmed by the responsibility of caring for _____.				

Please rate your distress during this past month:	Not at all distressed	A little distress	Some distress	A lot of distress	Does not apply
5. Distress over seeing _____ in so much pain or discomfort.					
6. Distress at not having enough time to do your job, other responsibilities and chores.					
7. Distress about making decisions about hospitalizing _____.					
8. Distress over talking about what medical procedures _____ would want or would not want if his/her heart or breathing were to stop.					
9. Distress of seeing how much _____'s illness has changed your relationship.					
10. Distress at having strained relationships with other family members over taking care of _____.					

Please rate whether you agree or disagree with each of these statements as it applies to you in your care of _____ this month:	Agree a lot	Agree a little	Disagree a little	Disagree a lot	Does not apply
11. Taking care of _____ has drawn the two of us closer together.					
12. Taking care of _____ has brought meaning to my life.					
13. Taking care of _____ has drawn other members of our family closer together.					
14. Taking care of _____ makes me feel good about myself.					

Glajchen, M., Kornblith, A., Homel, P., Fraidin, L., Mauskop, A., Portenoy, R.K. (2005). Development of a Brief Assessment Scale for Caregivers of the Medically Ill. *Journal of Pain and Symptom Management*, 29, no. 3: pp 245-254.

Introducing Hospice as an Option

- π By the time hospice is an option, family caregivers have probably gone through many transitions
- π Transitions not generally positive experiences
- π Family caregivers approach hospice with misinformation, many concerns, and perhaps lack of trust

Patient and Family Barriers to Enrolling in Hospice

- π Patient and/or family not ready for hospice
- π Misconception that hospice is for the last hours to days of life
- π Family caregiver unable/unwilling to take on care responsibilities
- π Hoping for other treatment options from doctor
- π Unwillingness to acknowledge patient is dying
- π Family disagreement

–Vig, Starks, Taylor et al., 2010

Provider Barriers to Enrolling in Hospice

- π Focus on what *isn't* provided by hospice
- π Overlooking patient concerns about continuity of care after enrollment
- π Overlooking caregivers' concerns about losing contact with home care team and primary care physician
- π Reluctance or refusal by PCP for hospice referral
- π Uneven training for hospice intake professionals
- π Variability in rules among different hospice

programs



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

–Vig, Starks, Taylor et al., 2010



Introducing Hospice: The Emergency Room as an Option

π **ER presents unrealized opportunity for end-of-life discussions**

π **Challenges include:**

- decision making by new physician
- incomplete history available
- problem-focused assessment
- aggressive therapy
- lack of privacy
- cultural barriers

♣ – Glajchen, Lawson, Todd, 2010

Introducing Hospice: Home Care as an Option

- π Caregivers report high unmet transitional care needs, especially information and access to services
- π Communication gaps common as cases are handed off to new home care team
- π Fragmentation in care common as patients decline
- π Discussions about prognosis and hospice are left to the primary care physician

Introducing Hospice: Discharge Planning as an Option

- π Patients discharged quicker and sicker
- π Little time to educate family caregivers about home care, follow-up, care options
- π Post-discharge period extremely stressful for caregivers
- π Missed opportunity to introduce hospice
–Bowles, Naylor, Foust 2002

Introducing Hospice: The Family Meeting as an Option

- π Valuable clinical tool for:
- ✓ communicating medical information
 - ✓ delineating the goals of care
 - ✓ facilitating decision-making
 - ✓ paying attention to patient preferences
 - ✓ safe setting in which to process emotions
 - ✓ private, controlled environment to introduce hospice

–Azoulay, 2005; Boyle, Miller, 2005

Introducing Hospice: The Family Meeting as an Option

π Common pitfalls

- ✓ Excluding the patient
- ✓ Truth-telling and truth-withholding
- ✓ Significant family conflict
- ✓ Giving pathophysiology lectures
- ✓ Offering reassurance prematurely

Can the Family Meeting improve caregivers' well-being?

- π Ideal forum for eliciting caregiver concerns, providing clear information about treatment, facilitating end-of-life care decisions, avoiding inappropriate treatment
- π Reduces unmet caregivers' needs
- π Increases family satisfaction in the ICU
- π Promotes a safe setting for caregivers to process emotions and receive validation for their concerns

- ❖ Hudson et al., BMC Palliative Care, 2008, 7(12)
- ❖ Azoulay, Am J Respir Crit Care Med, 2005, 171:803-4
- ❖ Gueguen, et al., Palliat Support Care, 2009, 7(2), 171-9

Can Specialist Level Palliative Care improve caregivers' well-being?

- π Caregivers' QoL is influenced by patient's stage of illness and goals of care
- π Psychological distress level similar for both dyad members
- π Specialist level palliative care assoc with:
 - √ Improved symptom management for patients
 - √ Short-term outcome: meeting caregivers' needs
 - √ Long-term outcomes: promoting bereavement and preventing pathological grief

- ♣ Abernathy et al., Supp Care in Cancer, 2008
- ♣ McMillan et al., Cancer, 2006

Can Hospice care improve caregivers' well-being?

- π Multisite study: 332 pt-caregiver dyads, EOL discussions led to lower rates of ventilation, resuscitation, ICU admission, earlier hospice referral
- π Earlier, longer hospice enrollment is associated with less caregiver depression and higher satisfaction
- π Recent meta-analysis of randomized trials: home hospice deaths were associated with less psychiatric illness and PTSD in bereaved caregivers compared with ICU and hospital deaths

- ♣ Bradley, Prigerson, Am J Psychiatry, 2004 161(12):2257-62
- ♣ Northouse et al., CA Cancer J Clin, 2010, 60: 317-339
- ♣ Wright, Zang, Ray, JAMA, 2008, 300(14):1665–1673

Bereaved Caregivers Reflect on Last Place of Care

- π **After death study compared bereaved caregivers' satisfaction with care received in hospital, home care, hospice home care, and nursing home settings**
- π **High rates of unmet needs in**
 - √ symptom management
 - √ physician communication about medical decision making
 - √ emotional support
 - √ respectful treatment of dying family member
- π **Caregivers of patients who died in hospice home care reported**
 - √ higher satisfaction,
 - √ fewer concerns with care
 - √ fewer unmet needs

–Teno, Clarridge, Casey, et al., 2004

JACOB FELLOW HOSPICE AND DIVIC HAVE formed Metropolitan Jewish Health System

- π Largest Jewish hospice program in the region
- π 13% growth in patient volume over the last 2 months
- π Still in the process of transitioning from two programs into one
 - √ Inpatient care
 - √ Home hospice
 - √ Home-based palliative care
 - √ Pediatric care
 - √ Different care settings
 - √ Culturally specific end of life care
 - √ MD's and RN's board certified in HPM
- π **Potential for large scale caregiver programs in clinical, educational and research realms**

Next Step in Care Guide to Hospice and Palliative Care

Explicitly addresses:

- ✓ Differences and similarities between hospice and palliative care
- ✓ Requirements for hospice admission
- ✓ First days of hospice care
- ✓ Disenrollment from hospice
- ✓ Family caregiver's responsibilities

Available in English, Spanish, Chinese, and Russian
Free and downloadable at www.nextstepincare.org



Family
Caregiver
Guide

Family Caregiver's Guide to Hospice and Palliative Care

If you have been a family caregiver for a while, you probably have been through a lot of transitions. Maybe your family member was in and out of the hospital several times. Perhaps he or she spent a few weeks in a rehabilitation unit or received home care services. Or perhaps he or she is now a resident in a long-term care facility. In each of these transitions, you had to meet new health care professionals, learn more about your family member's health, and adjust to new caregiving tasks and routines.



Even though you have been through transitions before, this one may be harder.

Now you are coming to a new transition. Maybe your family member's health is getting worse. Perhaps the treatments intended to prolong his or her life are not working or causing a lot of pain and suffering. You may have a lot of questions and concerns about what to do. You may also be dealing with many feelings as your family member faces a serious and life-threatening illness, or is dying.

When you are thinking about whether your family member's current care is appropriate for his or her condition, here are some questions to ask:

- ▶ What is the prognosis—the expected course—of my family member's illness?
- ▶ What are the goals for care? For instance, is the goal to cure the disease or comfort measures to provide comfort and improve the quality of my family member's life?

Hospice and palliative care: A comparison

	Palliative Care	Hospice Care
Goals	To assess and treat the patient's pain and other physical, psychosocial, and spiritual problems.	To keep the patient comfortable, as free as possible from pain and symptoms, and allow him or her to maintain a good quality of life for the time remaining. Hospice accepts death as an inevitable outcome for a patient with a terminal (end-stage) illness.
Patients	Palliative care accepts patients who have complicated or advanced medical disease. There is no time limit in terms of life expectancy –patients may or may not be dying. Patients can get treatments intended to cure. They also can participate in research studies.	Hospice only accepts patients who are near the "end of life" (meaning they have a terminal illness) and are likely to die within 6 months.
Where care occurs	Palliative care is usually given in hospitals. Sometimes it takes place at nursing homes or assisted living facilities. Palliative care at home is possible but not readily available.	Most hospice care happens at home, although it can also be given in other settings as well, such as in-patient hospices and nursing homes.
Who provides the care	Palliative care is a medical subspecialty. This means that doctors and nurses who practice palliative care have extra training about ways to manage symptoms.	Hospice care is often led by nurses under the direction of a doctor. Hospice care may require a lot of time and effort from the family. Hospice doctors and nurses may also have special training.
Paying for services	Palliative care is paid for by the patient's health insurance, just like other medical care. There is no special insurance for palliative care at home.	Hospice is a Medicare (federally funded) program. There are strict rules about patients it will accept. Many private health insurance plans pay for hospice under Medicare rules. A patient who chooses the Medicare hospice benefit agrees to give up treatments meant to cure disease. This is in return for other types of support and supplies. Because of this,

Thank you!

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