



Hospital Discharge Planning: Helping Family Caregivers Through the Process

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Discharge planning is a hard job.

You have many interests to juggle, requirements to meet, and people to consult. In the past several years, the job has become even harder. Hospital stays have become shorter and patients older and sicker. Coordination of care has become more complex. While an increasing number of facilities and levels of care are available, public and private insurance have made cost containment a high priority, limiting discharge options. Hospital staff assigned to discharge planning have been cut, making the caseload for each remaining discharge planner more demanding. Yet appropriate discharge planning remains essential to the orderly functioning of the hospital, the ongoing care of patients, and the well-being of family caregivers.

This guide is a companion to a booklet for family caregivers. Together they are intended to make discharge planning a little smoother by informing family caregivers of what to expect and by giving you, the discharge planner, some insights about the family's perspective. Many of you are already aware of these concerns. But because discharge planners come from a variety of disciplines, and have

varying levels of experience, many others will find these tips a useful addition to practice routines.

Involving family members was originally a major goal of hospital discharge planning, with specially trained social workers managing the process. In recent years, however, as hospitals emphasized rapid discharge of patients, consultation with families received low priority. Now family involvement has regained importance, for several reasons.

Many hospital patients are discharged before they are fully recovered, and must rely on family to take care of them at home. Many patients and family caregivers have become more experienced at advocating for themselves and their relatives, and are more likely to ask questions about the process. And the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has revised its standard on continuity of care, providing new institutional impetus for involving family members in discharge planning.

The intent of the JCAHO standard is to ensure that patient and family are informed of the care process, especially when post-discharge care is anticipated.

For your information: JCAHO standard CC.6.1.1 calls for patients to be “informed in a timely manner of the need for planning for discharge or transfer to another organization or level of care.” The intent of the standard is to ensure that “the organization is responsible for keeping the patient and the patient’s family informed of the care process, especially when the organization anticipates some level of care continuing after discharge. These discussions begin as early as possible in the care process, continue through it, and include the anticipated time of discharge. Patient and family education and continuity of care are related functions. This relationship is clear in the discharge-planning process, which includes giving the patient and family information about:

- The conditions that may result in transfer to another organization or level of care;
- Alternatives to transfer, if any;
- The clinical basis for discharge; and
- The anticipated need for continued care following discharge.”

Scoring is based on the following question: “Is the information listed in the intent given to patients, and, when appropriate, their families on a timely basis before discharge?” Possible scores are: Yes (1); With a few minor exceptions (2); Not consistently (3); Rarely (4); No (5). How would your hospital rate on this scoring?

What Family Caregivers Identify as Problems

In focus groups and interviews, family members consistently report that discharge from the hospital was a traumatic experience, and that they did not feel prepared. Naturally, the discharge plans that go smoothly do not often get acknowledged. Nevertheless, these are the sorts of problems families encounter:

- Family members do not understand the discharge planning process, and learn about the plan only on the day of discharge.
- Family members do not understand the financial implications of discharge, and do not know what their relative's insurance coverage will pay for. They may expect much more than they are likely to receive.
- Family members feel that they are presented with a discharge plan that has been developed without their input. They have not had an opportunity to discuss all the options. They may feel that too much is being expected of them without any consideration of their other responsibilities.

Many health care providers say that discharge planning should begin on admission. This is a good idea in theory but is not always practical.

- Family members do not understand that their relative (or the caregiver, on the relative's behalf) has the right to appeal a discharge decision, and do not know what the process is for making an appeal.
- Family members do not receive referrals to community-based or government agencies that may be helpful to them or to their relative.

How Can You Help?

Some of these problems are beyond the discharge planner's capacity to solve. But many are relatively simple to manage. Here are some factors to keep in mind.

TIMING IS CRUCIAL

The point at which a discharge planner enters the picture can determine how well the process moves along. Many health care providers say that discharge planning should begin on the day of admission. This is a good idea in theory but, clearly, is not always practical. Certainly discharge planning for a patient

admitted for elective surgery, with a fairly predictable course of recovery and home or nursing-home care needs, can be started very early in the hospital stay, or even before admission.

For family members dealing with a crisis — their relative in the ICU, for example — that process is more problematic, however. Although some of these caregivers may find discussions of the future comforting, more often they are unready to think about discharge, and may even interpret the planner's approach as premature or inappropriate. While you may not be able to develop a solid plan at that point, you can get to know the family and lay the groundwork for meaningful discussions later on, when the patient's condition is stable.

The people with the closest caregiving ties to the patient may be partners or friends. Lack of legal “family” status should not bar their inclusion.

EACH FAMILY IS DIFFERENT

As you know, each family has its own history, structure, and values. Its network usually includes some community ties — religious congregations, informal neighborhood links, social and other organizations. Knowing a little bit about these ties helps the planner identify potential sources of assistance.

Asking about the makeup of the patient's family, who has been helping the patient and in what ways, and who will be involved in care after the hospital stay tells the family or other caregivers that you are aware of their needs as well as the patient's, and are not making assumptions about anyone's role.

While most family caregivers are indeed spouses, adult children, or other close relatives, in many cases other people — friends, partners, distant relatives — are those with the closest emotional and caregiving ties to the patient. Lack of legal status as "family" should not be a bar to including them in the discussions. (Regardless of who claims the role of caregiver, discharge planners should seek the patient's assent, if she is able to communicate).

Similarly, while most family caregivers are women, men are becoming more involved in family care. Women may have multiple family and work responsibilities and be unable to devote significant time to caregiving. Discharge planning should be gender-neutral.

Family caregivers also have different levels of capacity, willingness, and resources to become involved in the discharge plan. If you ask about family members' own health problems, you may uncover a serious obstacle to the plan. A family caregiver with limited mobility cannot do all the tasks that are necessary. A family caregiver who lives far away but has come for the hospital stay is not going to be available post-discharge. While the discharge planner focuses on the patient in the hospital, the family must think of everyone's needs and the demands on their limited resources.

Not everyone can master complex caregiving tasks. In these cases, home care assistance and supervision are essential.

If the patient's care requires the ability to manage complex medication regimens and operate equipment, the family caregiver must be able to learn how to do these tasks. Not everyone has mastered or can learn these skills. In these cases, home care assistance and supervision are essential.

Sometimes these potential problems are left for the home care agency to solve. The hospital discharge planner should at least be on the alert for special problems that must be addressed at the next level of care.

THE APPEALS PROCESS

Many families are not aware that they can appeal a discharge decision if they feel their relative is not well enough to go home or to a subacute level of care. Patients have legal rights, and they and their caregivers must be informed about them. Hospitals are required to give every Medicare patient or family caregiver a copy of the statement "An Important Message from Medicare" about appealing decisions, and to make sure that they understand the process. Most cases will never reach the appeals level, but families should know about it anyway.

It's the law: On behalf of a relative, family members can appeal any discharge decision if they feel the patient is not well enough to go home. The statement “An Important Message from Medicare,” which the hospital must give Medicare patients and their family caregivers, spells out those patients’ right to all needed hospital care and post-discharge follow-up. The hospital must also give a written notice explaining the discharge, a “Hospital-Issued Notice of Non-coverage,” or HINN. The HINN will include a phone number for a local Peer Review Organization (PRO) or other organization that reviews contested cases. Hospitals cannot force family caregivers to take patients home or pay for continued care before the PRO makes a decision. Other types of insurance provide similar appeals processes.

Family members appreciate referrals to agencies that can provide further assistance, including support for the caregiver.

COMMUNITY REFERRALS

Discharge planning, however skillfully implemented, cannot answer all of a family caregiver's questions or provide for every future possibility. Family members will appreciate referrals to community-based or government agencies that can provide further assistance, both with direct patient care and with support for caregivers themselves.

A folder of information, similar to the admissions packet, is a valuable asset in the discharge process. It can include brochures from various local organizations providing meals, transportation, respite, support groups, or other services to patients and family caregivers, making it a valuable ongoing resource. Family members may not use it right away, but they can refer to it as needed later on; point out to them that it includes referrals to services for caregivers as well as for the patient.

Working with Family Caregivers: A Checklist

Even with the best of discharge plans, you may find yourself having to mediate between family caregivers and the professional care team. A checklist, far from being a “cookie-cutter” approach, helps ensure that patients’ and caregivers’ unique situations and needs are addressed. Here are some elements essential to such a list.*

DISCUSSION

Prior to planning, engage both health care professionals and family caregivers — and the patient, if appropriate — in discussing:

- The patient’s condition, and any changes that may have occurred as a result of treatment at the facility;
- Any likely symptoms, problems, or changes that may occur when the patient is at home;
- The patient’s care plan, the caregiver’s needs, and any adjustments that must be made to meet these needs;
- The potential impact of caregiving on the caregiver, including warning signs of stress and techniques for reducing stress.

PLANNING

With patient consent, if possible, work with health care professionals and family caregivers prior to discharge to:

- Arrange for an in-hospital assessment to determine Medicare or other insurance eligibility for home care services, such as visiting nurses and home care aides;
- Set up home care services for which the patient is eligible and others for which the patient/family will pay;
- Ready the home by arranging for equipment rentals and home modifications;
- Provide a 24-hour phone number the caregiver can call to speak with a health care professional;
- Organize transportation home for the patient;
- Schedule a follow-up appointment.

* Adapted from C. Levine, *Rough Crossings: Family Caregivers' Odysseys through the Health Care System* (New York: United Hospital Fund of New York City, 1998), p. 35.

TRAINING

Ensure that family caregivers receive adequate information and training before discharge, including:

- A written medication list with specific instructions on medication dosages and the duration of the regimen, and information about possible side effects;
- Teaching and practice of techniques such as bed-to-chair transfers, care procedures, use and monitoring of equipment, recognition of symptoms, and other elements of patient care.

REFERRALS

Work with health care professionals, caregivers, and patients to explore available support services before discharge, including:

- Community sources of social support for caregivers and patients;
- Community-based agencies that provide services such as transportation, equipment maintenance, respite care, home care, and volunteer services;
- Information resources such as books, pamphlets, videos, and websites.

For More Information

Administration on Aging

www.aoa.gov/caregivers

Caregiver resources from the Administration on Aging
(also see Eldercare Locator below)

Caregiving.com

www.caregiving.com

Online support groups and numerous articles
on caregiving

Care Planner

www2.careplanner.org

Online decision support tool for seniors, individuals
with physical impairments, and their caregivers

Children of Aging Parents

800-227-7294

www.caps4caregivers.org

Information, referrals, and support for caregivers
of the elderly and chronically ill

Eldercare Locator

800-677-1116

www.eldercare.gov

Help with locating aging services in every community
throughout the United States

Family Caregiver Alliance

800-445-8106

www.caregiver.org

Information on caregiving, and online support groups;
California-focused

continued

Healthfinder

www.healthfinder.gov

Free Internet guide to consumer health information from the U.S. Department of Health and Human Services

Medicare.gov

800-MEDICARE

www.medicare.gov

The official U.S. government site for people with Medicare

National Alliance for Caregiving

www.caregiving.org

Support for family caregivers and the professionals who serve them

National Association of Professional Geriatric Care Managers

520-881-8008

www.caremanager.org

Information on geriatric care management, and a free online care manager search tool

National Family Caregivers Association

800-896-3650

www.nfcacares.org

Support for those who care for chronically ill, aged, or disabled loved ones

Society for Social Work Leadership in Health Care

866-237-9542

www.sswlhc.org

Dedicated to promoting the principles of social work within the health care system

United Hospital Fund

212-494-0700

www.uhfnyc.org

Publisher of *Always on Call: When Illness Turns Families into Caregivers*

Established in 1996, the National Alliance for Caregiving is a nonprofit coalition of national organizations that focuses on issues of family caregiving. The Alliance was created to conduct research, do policy analysis, develop national programs, and increase public awareness of family caregiving issues.

The United Hospital Fund is a health services research and philanthropic organization whose mission is to shape positive change in health care for the people of New York. Since 1996, the Fund's Families and Health Care Project has been combining analysis with targeted philanthropy to find ways to support family caregivers.

MetLife Foundation, established in 1976 by MetLife, has supported several initiatives related to caregiving issues, including an educational video for caregivers and families of persons with Alzheimer's disease and the distribution of a brochure, *Resources for Caregivers*, to area agencies on aging. MetLife Foundation (www.metlife.org) supports health, education, civic, and cultural programs throughout the United States.



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United Hospital Fund

*Shaping New York's Health Care:
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