A Family Caregiver's Guide to Hospital Discharge Planning

What Is It?

Who Does It?

When Should It Happen?

What Will Insurance Pay For?

What Else Should You Know?

A Publication of the National Alliance for Caregiving and the United Hospital Fund of New York

Funded by **MetLife Foundation**

A Family Caregiver's Guide to Hospital Discharge Planning was written by Gail Gibson Hunt, executive director of the National Alliance for Caregiving, and Carol Levine, director of the United Hospital Fund's Families and Health Care Project. This brochure may be copied and used if attributed to its publishers; it may not be republished without prior written permission.

The authors gratefully acknowledge the contributions of the Society for Social Work Leadership in Health Care in preparing this brochure.

This brochure is available online at www.caregiving.org and www.uhfnyc.org.

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.

Your relative is going to the hospital. Perhaps she is already a patient. (To keep the language simple, in this booklet the patient is sometimes referred to as "she" and sometimes as "he.")

This is a difficult time for both of you. Whether your relative stays in the hospital for a few days or for much longer, it will be easier if you know what to expect.

Note: This booklet was written for family members, but if you are the patient it has important information for you as well.

The hospital will give you lots of information about what to bring and what to leave home, when visitors are allowed, and how the television and phone work. Within a short time, you will learn much more. Whether your relative is admitted through the Emergency Department or the treatment was planned, you will figure out hospital routines, learn who to ask for updates on your relative's condition, and maybe even discover which elevators are least crowded.

As important as it is to know what to expect when your relative enters the hospital, it is just as essential to know what happens when he is ready to leave. This booklet is a guide to

the discharge planning process. Because you will continue to be involved in your relative's care, you need to know about what happens next. You will still be the patient's spouse, partner, child, grandchild, other relative, or friend. Because you have already or will be taking on some additional responsibilities, you are the patient's family caregiver.

A definition: A family caregiver is a person who helps someone who is ill, disabled, or elderly. "Family" includes both relatives and friends. Help may be direct care, household help, financial assistance, management of other services, emotional support, and many other responsibilities.

This booklet will help you get started. To make the discharge process go smoothly, keep these three "Bs" in mind:

Be realistic.
Be persistent.
Be prepared.

What Is Discharge Planning?

Sometimes it seems as though discharge from the hospital happens all at once, and in a hurry. But discharge planning is a process, not a single event. Medicare defines discharge planning this way: "A process used to decide what a patient needs for a smooth move from one level of care to another." As a result of that

process, the discharge plan may be to send your relative to her own home or someone else's, a rehabilitation facility, a nursing home, or some other place outside the hospital.

Discharge from a hospital does not mean that your relative is fully recovered. It simply means that a physician has determined that her condition is stable and that she does not need hospital-level care. If you disagree, you can appeal the decision (how to do that is discussed on page 5).

Who Does It?

Only a physician can authorize a hospital discharge. However, many other people are involved in working out the details of the discharge plan. As the patient's family caregiver, you are—or should be—one of the most important. You alone have essential information about and understanding of the patient's home situation, as well as about your own caregiving capabilities. Make sure you are involved from the outset.

Of the professionals involved in your relative's discharge, the discharge planner is your primary contact. The discharge planner may be a nurse, a social worker, an administrator, or have some other title. It is important for you to know who this person is and to understand what she can do — as well as what is beyond her control. If the discharge planner does not come to see you and your relative early in the

hospital stay, find out who is in charge of your relative's discharge and ask for an appointment.

The discharge planner is responsible for making sure that the plan for your relative's discharge is, to use Medicare's language, "safe and adequate." This means that your relative should be going to a place that does not present immediate dangers to her health and well-being, and that realistic plans have been made for appropriate follow-up care. Medicare does not specifically define "safe" and "adequate," so you and the discharge planner have to interpret what it means in your relative's case.

Tip: Keep a special notebook with all the names and phone numbers of people who are involved in your relative's hospital care and discharge plan. You can also write instructions and referrals you will need later. A notebook with pockets is especially handy for keeping business cards and information sheets.

On behalf of your relative, you can appeal any discharge decision if you feel that she is not well enough to go home. If your relative is a Medicare patient, her rights are spelled out in the statement "An Important Message from Medicare," which the hospital must provide to you. This statement explains that she has the right to get all of the hospital care that she

needs, and any needed follow-up care after leaving the hospital. The hospital must give you a written notice, a "Hospital-Issued Notice of Non-coverage," or HINN. This will have the phone number of a local Peer Review Organization (PRO) or other organization that will review the case if you appeal the discharge decision.

If you do decide to appeal, you must do so as soon as you receive the HINN. The PRO will then consult with both you and the patient's physician; until the PRO makes its decision, the hospital cannot force you to take your relative home or pay for continuing care. There are similar appeals processes for other types of insurance.

Discharge planning is a short-term plan to get your relative out of the hospital. It is not a blueprint for the future. Your relative's condition may improve or worsen over time. You may or may not be able to sustain the intense level of caregiving that is required at the outset. Even though no one can predict what the needs will be four weeks, or four months, from discharge, it is important for you to think about the long term as much as possible. You may be able to build into the immediate plan services that will be important in the long run.

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When Should It Happen?

Many health care providers say that discharge planning should begin on the day of admission. This is a good idea in theory, but it is not always practical. If your relative's admission was planned — for example, for surgery — the doctor undoubtedly gave you some idea of how long the hospital stay would be. In these cases, discharge planning can begin even before admission. But if the hospital stay was unplanned — an accident, stroke, sudden illness — you may not have any idea of how long he will be in the hospital or what his condition will be. Still, it is a good idea to start thinking about the options as soon as the outcome becomes a little clearer.

Try to avoid making major decisions under pressure. Most of the time, you can work out an acceptable arrangement with your relative and the discharge planner. Sometimes, however, there are disagreements. Your relative may want to go home as quickly as possible. The hospital may need the bed. As the family caregiver, you may have to balance your relative's preferences and the hospital's needs against the hard realities of the situation.

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Some advice: Your relative may have unrealistic expectations about what she can do on her own. Ask a nurse or doctor to evaluate your relative and then to explain to you and to her what she will be able to do and what will not be possible. This assessment will help you determine how much care will be needed immediately after discharge, and for the first weeks.

What Will Insurance Pay For?

Most people — whether as patients, family caregivers, or health care professionals — do not have a good idea of what medical insurance (assuming the patient has some) will pay for until the need arises. Family members and patients are often shocked to find that insurance will not pay for many services and items needed at home that are routinely paid for in the hospital. Unless your relative has specific long-term care insurance (and very few people do at this point), many home care needs, especially home care aides or attendants, will not be covered at all or beyond an initial short-term period.

Even though your primary concern is your relative's health, it makes sense to begin as soon as possible to investigate what follow-up care will be paid for and what your relative or you will have to pay out of pocket. The discharge planner or a social worker can help you get started. It may also be useful to talk to others who have been in the same situation.

Some short-term home care — say, for a few weeks or a month — may be covered, but even that is not guaranteed. The hospital discharge planner may not be able to give you all the information you need about home care benefits, because coverage will depend on your relative's progress at home and other factors. The discharge planner can refer you to home care agencies and other community resources.

Even though the financial picture may seem very discouraging, you should not give up trying. There are many ways to make the case that the care your relative needs is "medically necessary," or that she is continuing to make progress (a requirement for continuing physical or occupational therapy). You may be able to justify the need for durable medical equipment, such as a special hospital bed and mattress at home.

A caution: If someone tells you "Medicare" – or another insurance – "won't pay for it," don't stop there. Check it out yourself through your State Health Insurance Assistance Program (the phone number is in the back of the "Medicare and You" handbook), the Medicare Rights Center (212-869-3850, or online at www.medicarerights.org), or another independent source.

Tip: Keep written records of every conversation about financial matters, whom you spoke to, what they said, and when they said it. Insurance coverage decisions are often flexible. You may need to document interpretations you have been given by different people. This is a task that another family member may be willing to take on.

What Should I Be Doing While My Relative Is in the Hospital?

Of course your primary concern is your relative's condition and making sure that he is getting the best care possible. But you should also be thinking about the next steps. This may be particularly difficult if this is the first time he has been seriously ill or hospitalized. Try to talk with someone in the hospital about your concerns. A social worker is the most logical choice, but you can also speak to a nurse, doctor, patient advocate, or chaplain.

Here is where the first "B" comes in. Be realistic. You want to do whatever is best for your relative, but you also must consider all your other obligations. You may be able to take some time off from work, but not quit your job. You may be able to provide some care, but not all of it. You may have health problems of your own that prevent you from doing some kinds of care. Your other family responsibilities may limit your availability.

Sometimes health care providers assume that the relative who has been a faithful companion in the hospital will be available full time for future care. If that is not the case, you need to say so – firmly and consistently. A discharge plan that is based on faulty assumptions or incomplete information is not going to work.

Tip: With the help of an experienced health care provider or family caregiver, make a list of all the tasks that will have to be done when your relative leaves the hospital. Then make a list of all those that you can do. The third list should be people and services that can provide the care that you cannot do alone.

You can also begin to learn some of the techniques that are important for your relative's care. Because hospital staff do not have much extra time for training, they may not offer to teach you what you need to know until the day of discharge. At that point it is hard to learn, especially if equipment is involved.

Watch. Ask questions. Practice, with supervision if possible. Even if you are not going to provide all the care yourself, it is important that you understand how it should be done so that you can instruct or supervise others.

Don't be afraid to say that you are not able or do not want to do certain tasks, such as personal hygiene or wound care. Remember that you are a family member, not a professional. You should

not have to do anything that interferes with maintaining your special relationship with your family member.

What Are the Choices?

Ideally a discharge plan should be based on a careful review of all the options. That may not always happen, especially since hospital stays have become so brief. For example, the discharge plan may involve sending the patient home with in-home physical therapy and some assistance with personal care. An alternative, if the patient meets certain medical criteria, might be a short-term stay in a nursing home, where he would get more intensive physical therapy and would have some extra time to recover from a stroke or surgery.

As another example, the discharge plan might be to send your relative to a nursing home that has a bed available. But the nursing home may be far away or one that you do not believe provides excellent care. Exploring other nursing home possibilities, even if there is a wait, may be a better option for the patient and for you.

Sometimes discharge planners do not have all the information you want about all the nursing homes, rehabilitation facilities, or home care agencies in your area. They may work mainly with certain facilities or agencies. If you want to look at other choices, you may have to do some research on your own. This can certainly be a big job, but it is also one that another family member or friend can begin.

This is where the second "B" becomes important. Be persistent. Don't settle for a plan that you have doubts about. Ask questions. Get information. Review the options. Then make an informed decision.

Take Care of Yourself

While you are busy making all the arrangements for a smooth discharge process for your relative, don't forget that you should try to take care of yourself as well. You probably have been spending a lot of time at the hospital. You may not have been sleeping well or eating regular meals. Maybe you are worrying about all the things that you have not had time to do at home or at your job. All this takes a toll on your own health and well-being. It can make a difficult time even harder.

Try to find a little time to unwind. Even a few hours doing something you enjoy or talking to a trusted friend or family member will help. Ask the discharge planner or social worker about resources in the community you can turn to when the hospital stay is over. If your employer has an Employee Assistance Program, call to get referrals. There are support groups of many kinds, counselors familiar with caregiving stresses, and many different kinds of practical, emotional, and even financial help.

The Basics of a Discharge Plan

The third "B" is "Be prepared." Here are some helpful suggestions on how discharge planners, family members, and others involved in the process of planning a discharge to home should work together.*

DISCUSSION

At the very outset of discharge planning, health care professionals, family caregivers, and the patient (if appropriate) should discuss the following:

- **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; warning signs of stress; techniques for reducing stress.**

* 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.

PLANNING

Prior to discharge, health care professionals should work with family caregivers – with patient consent, if appropriate – to:

- Arrange for an in-hospital assessment to determine Medicare or 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;
- Get the home ready by arranging for equipment rental and home modification;
- 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.

TRAINING

Before discharge, health care professionals should provide family caregivers with applicable training, including:

- A written medication list with specific instructions on medication dosages and how long they should be taken, 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

Before discharge, health care professionals, caregivers, and patients should explore available support services, 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.

Of course, you may have other concerns and questions as well. Write them down as you think of them. Again, remember the first "Be": Be realistic. Many family caregivers find that their relative's care is harder after a hospital stay, because there are many new tasks and worries. Make sure you have someone else with you or to call on until you feel comfortable with the new situation. And don't be afraid to speak up – to the doctor, the home care agency, your family – if you feel unsure. In most cases it takes a while to settle in, so don't expect everything to be the same as before. But help will not be available unless you ask for it. Be persistent.

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

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

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

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Funded by

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