



Fact Sheet:

Hospital Discharge Planning: A Guide for Families and Caregivers

A trip to the hospital can be an intimidating event for patients and their families. As a caregiver, you are focused completely on your family member's medical treatment, and so is the hospital staff. You might not be giving much thought to what happens when your relative leaves the hospital.

Yet, the way this transition is handled—whether the discharge is to home, a rehabilitation ("rehab") facility, or a nursing home—is critical to the health and well-being of your loved one. Studies have found that improvements in hospital discharge planning can dramatically improve the outcome for patients as they move to the next level of care.

Patients, family caregivers and healthcare providers all play roles in maintaining a patient's health after discharge. And although it's a significant part of the overall care plan, there is a surprising lack of consistency in both the process and quality of discharge planning across the healthcare system.

This fact sheet will look at the keys to a successful transition from hospital to home, explain some important elements, offer suggestions for improving the process, and provide caregivers with checklists to help ensure the best care for a loved one. If you are a caregiver, you play an essential role in

this discharge process: you are the advocate for the patient and for yourself.

What is discharge planning?

Medicare says discharge planning is "A process used to decide what a patient needs for a smooth move from one level of care to another." Only a doctor can authorize a patient's release from the hospital, but the actual process of discharge planning can be completed by a social worker, nurse, case manager or other person. Ideally, and especially for the most complicated medical conditions, discharge planning is done with a team approach.

In general, the basics of a discharge plan are:

Evaluation of the patient by qualified personnel

- **Discussion** with the patient or his representative
- **Planning** for homecoming or transfer to another care facility
- **Determining** if caregiver training or other support is needed
- **Referrals** to home care agency and/or appropriate support organizations in the community
- **Arranging** for follow-up appointments or tests.

The discussion needs to include the physical condition of your family member both before and after hospitalization; details of the types of care that will be needed; and whether discharge will be to a facility or home. It also should include information on whether the patient's condition is likely to improve; what activities he or she might need help with; information on medications and diet; what extra equipment might be needed, such as a wheelchair, commode, or oxygen; who will handle meal preparation, transportation and chores; and possibly referral to home care services.

Why is good discharge planning so important?

Effective discharge planning can decrease the chances that your relative is readmitted to the hospital, help in recovery, ensure medications are prescribed and given correctly, and adequately prepare you to take over your loved one's care.

Not all hospitals are successful in this. Although both the American Medical Association and the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) offer recommendations for discharge planning, there is no universally utilized system in US hospitals. Additionally, patients are released from hospitals "quicker and sicker" than in the past, making it even more critical to arrange for good care after release.

Studies have shown that as many as 40 percent of patients over 65 had medication errors after leaving the hospital, and 18 percent of Medicare patients discharged from a hospital are

readmitted within 30 days. This is not good for the patient, not good for the hospital, and not good for the financing agency, whether it's Medicare, private insurance, or your own funds. On the other hand, research has shown that excellent planning and good follow-up can improve patients' health, reduce readmissions and decrease healthcare costs.

Even simple measures help immensely. For example, you should have a telephone number(s) accessible 24 hours a day including weekends, for care information. A follow-up appointment to see the doctor should be arranged before your loved one leaves the hospital. Since errors with medications are frequent and potentially dangerous, a thorough review of all medications should be an essential part of discharge planning. Medications need to be "reconciled," that is, the pre-hospitalization medications compared with the post-discharge list to see that there are no duplications, omissions or harmful side effects.

Under the best of circumstances, the discharge planner should begin his or her evaluation when the patient is admitted to the hospital.

The caregiver's role in the discharge process

The discharge staff will not be familiar with all aspects of your relative's situation. As caregiver, you are the "expert" in your loved one's history. While you may not be a medical expert, if you've been a caregiver for a long time, you certainly know a lot about the patient and about your own abilities to provide care and a safe home setting.

The discharge planners should discuss with you your willingness and ability to provide care. You may have physical, financial or other limitations that affect your caregiving capabilities. You may have other obligations such as a job or childcare that impact the time you have available. *It is extremely important to tell hospital discharge staff about those limitations.*

Some of the care your loved one needs might be quite complicated. It is essential that you get any training you need in special care techniques, such as wound, feeding tube or catheter care, procedures for a ventilator, or transferring someone from bed to chair.

If your loved one has memory problems caused by Alzheimer's disease, stroke, or another disorder, discharge planning becomes more complicated, and you will need to be a part of all discharge discussions. You may need to remind the staff about special care and communication techniques needed by your loved one. Even without impaired memory, older people often have hearing or vision problems or are disoriented when they are in the hospital so that these conversations are difficult to comprehend. They need your help.

If you or your family member are more comfortable speaking in a language other than English, an interpreter is needed for this discussion on discharge. Written materials must be provided in your language as well. Studies have shown that numerous, and sometimes dangerous, errors can be made in home care when language is not taken into account at discharge.

Because people are in a hurry to leave the hospital or facility, it's easy to forget what to ask. We suggest you keep the questions on pages 5-6 with you, and request that the discharge planner take the time to review them with you.

Getting help at home

Listed below are common care responsibilities you may be handling for your family member after he or she returns home:

- **Personal care:** bathing, eating, dressing, toileting
- **Household care:** cooking, cleaning, laundry, shopping
- **Healthcare:** medication management, physician's appointments, physical therapy, wound treatment, injections, medical equipment and techniques
- **Emotional care:** companionship, meaningful activities, conversation.

Community organizations can help with services such as transportation, meals, support groups, counseling, and possibly a break from your care responsibilities to allow you to rest and take care of yourself. Finding those services can take some time and several phone calls. The discharge planner should be familiar with these community supports, but if not, your local senior center or a private case manager might be helpful. (See the *Resources* section at the end of this fact sheet.) Family and friends also might assist you with home care.

If you need to hire paid in-home help, you have some decisions to make. Unfortunately, these hiring decisions are often made in a hurry during hospital discharge. You might be handed a list of agencies, with instructions to decide which to use—but often without further information. This is another good reason discharge planning should start early—as caregiver, you'll have time to research your options while your loved one is cared for in the hospital.

Think about both your needs as a caregiver and the needs of the person you are caring for, including language and cultural background.

You have a choice between hiring an individual directly or going through a home care or home health care agency. Part of that decision may be affected by whether the help will be "medically necessary" i.e., prescribed by the doctor, and therefore paid for by Medicare, Medicaid or other insurance. In that case, they will most likely determine the agency you use. In making your decisions, consider the following: home care agencies take care of all the paperwork for taxes and salary, substitutes will be available if the worker is sick, and you may have access to a broader range of skills. On the other hand, there may be a more personal relationship if you hire an individual directly, and the cost is likely to be lower. In either case, try to get recommendations for hiring from acquaintances, nurses, social workers and others familiar with your situation.

Discharge to a facility

If the patient is being discharged to a rehab facility or nursing home, effective

transition planning should ensure continuity of care, clarify the current state of the patient's health and capabilities, review medications, and help you select the facility to which your loved one is to be released.

Too often, however, choosing a facility can be a source of stress for families. You may have very little time and little information on which to base your decision. You might simply be given a list of facilities, and asked to choose one. To help, a private geriatric care manager (for whom you will pay an hourly fee) or a social worker can offer much needed advice and support. There are also online sources of information (see the *Resources* section of this fact sheet) that rate nursing homes, for example.

Convenience is a factor—you need to be able to easily get to the facility—but the quality of care is very important, and you may have to sacrifice your convenience for the sake of better care. The list of questions on pages 5-6 will give you direction as you start your search for a facility.

Paying for care after discharge

You might not be aware that insurance, including Medicare, does not pay for all services after a patient has been discharged from the hospital. However, if something is determined by the doctor to be "medically necessary" you may be able to get coverage for certain skilled care or equipment. You will need to check directly with the hospital, your insurer or Medicare to find out what might be covered and what you will have to pay for. Keep careful records of your conversations.

What if you feel it's too early for discharge?

If you don't agree that your loved one is ready for discharge, *you have the right to appeal the decision*. Your first step is to talk with the physician and discharge planner and express your reservations. If that isn't enough, you will need to contact Medicare, Medicaid or your insurance company. Formal appeals are handled through designated *Quality Improvement Organizations* (see the *Resources* section). You should know that if the QIO rules against you, you will be required to pay for the additional hospital care. The hospital must let you know the steps to take to get the case reviewed.

Improving the system

As we have mentioned throughout this fact sheet, discharge planning is an inconsistent process, which varies from hospital to hospital. Who does it, when it's done, how it's done, what kind of follow-up is mandated, and whether caregivers are assessed for their ability to provide care and included as respected members of the discussion are all elements that differ from setting to setting.

In general, hospitals make money only when beds are occupied, so in many cases, discharge and transitional care planning become "orphan" services that produce no revenue. Despite its benefits, which clearly increase the well-being of patients and caregivers, discharge/transition planning is often not given the attention it deserves, and indeed, ineffectual planning often serves to add to patients' and caregivers' stress.

Discussions among experts on improving transitional care and discharge planning have centered on improvements that emphasize education and training, preventive care and including caregivers as members of the healthcare team. Some studies have revealed that surprisingly simple steps can help. For example, sending the summary of care to the patient's regular doctor increases the likelihood of effective follow-up care. Likewise, telephone calls from knowledgeable professionals to patients and caregivers within two days after discharge help anticipate problems and improve care at home.

Broader recommended changes in practice and policy include:

- Formally recognize the role families and other unpaid caregivers play include them as part of the healthcare team, and assess their capabilities and willingness to provide care.
- Coordinate care across sites, from hospital to facility to home. Improve communication between hospital and community-based services.
- Develop better educational materials, available in multiple languages, to help patients and caregivers navigate care systems and understand the types of assistance that might be available to them, both during and after a hospital stay.
- Improve training for healthcare staff, including ways to respond to language, culture and literacy differences.

- Simplify and expand eligibility for public programs. Make transitional care a Medicare benefit; change reimbursement policies to cover more home-based care in addition to institutional care. Reward hospitals and physicians that improve patient well-being and reduce readmissions to hospitals.

Conclusion

Multiple studies have explored the importance of effective discharge planning and transitional care, and have highlighted the very real benefits in improved patient outcomes and lower rehospitalization rates. Several pilot programs have illustrated those benefits, but until healthcare financing systems are changed to support such innovations in care, they will remain unavailable to many people. Caregivers, patients and advocates are continuing their efforts to alter our healthcare system to make discharge planning a priority. With our graying population, these changes are ever more necessary.

Some Basic Questions for Caregivers to Ask

Questions about the illness:

- What is it and what can I expect?
- What should I watch out for?
- Will we get home care and will a nurse or therapist come to our home to work with my relative? Who pays for this service?
- How do I get advice about care, danger signs, a phone number

for someone to talk to, and follow-up medical appointments?

- Have I been given information either verbally or in writing that I understand and can refer to?
- Do we need special instructions because my relative has Alzheimer's or memory loss?

What kind of care is needed?

- Bathing
- Dressing
- Eating (are there diet restrictions, e.g., soft foods only? Certain foods not allowed?)
- Personal Hygiene
- Grooming
- Toileting
- Transfer (moving from bed to chair)
- Mobility (includes walking)
- Medications
- Managing symptoms (e.g., pain or nausea)
- Special equipment
- Coordinating the patient's medical care
- Transportation
- Household chores
- Taking care of finances

Questions when my relative is being discharged to the home:*

- Is the home clean, comfortable and safe, adequately heated/cooled, with space for any extra equipment?

- Are there stairs?
- Will we need a ramp, handrails, grab bars?
- Are hazards such as area rugs and electric cords out of the way?
- Will we need equipment such as hospital bed, shower chair, commode, or an oxygen tank? Where do I get this equipment?
- Who pays for these items?
- Will we need supplies such as adult diapers, disposable gloves, or skin care items? Where do I get these items?
- Will insurance/Medicare/Medicaid pay for these?
- Do I need to hire additional help?

Questions about training:

- Are there special care techniques I need to learn for such things as changing dressings, helping someone swallow a pill, giving injections, using special equipment?
- Have I been trained in transfer skills and preventing falls?
- Do I know how to turn someone in bed so he or she doesn't get bedsores?
- Who will train me?
- When will they train me?
- Can I begin the training in the hospital?

Questions when discharge is to a rehab facility or nursing home:

- How long is my relative expected to remain in the facility?

- Who will select the facility?
- Have I checked online resources such as www.Medicare.gov for ratings?
- Is the facility clean, well kept, quiet, a comfortable temperature?
- Does the facility have experience working with families of my culture/language?
- Does the staff speak our language?
- Is the food culturally appropriate?
- Is the building safe (smoke detectors, sprinkler system, marked exits)?
- Is the location convenient? Do I have transportation to get there?

For longer stays:

- How many staff are on duty at any given time?
- What is the staff turnover rate?
- Is there a social worker?
- Do residents have safe access to the outdoors?
- Are there special facilities/programs for dementia patients?
- Are there means for families to interact with staff?
- Is the staff welcoming to families?

Questions about medications:

- Why is this medicine prescribed? How does it work? How long will the medicine have to be taken?

- How will we know that the medicine is effective?
- Will this medicine interact with other medications, such as prescription and nonprescription? Or herbal preparations that my relative is taking now?
- Should this medicine be taken with food? Are there any foods or beverages to avoid?
- Can this medicine be chewed, crushed, dissolved, or mixed with other medicines?
- What possible problems might I experience with the medicine? At what point should I report these problems?
- Will the insurance program pay for this medicine? Is there a less expensive alternative?
- Does the pharmacy provide special services such as home delivery, online refills or medication review and counseling?

Questions about follow-up care:*

- What health professionals will my family member need to see?
- Have these appointments been made? If not, whom should I call to make these appointments?
- Where will the appointment be? In an office, at home, somewhere else?
- What transportation arrangements need to be made?
- How will our regular doctor learn what happened in the hospital or rehab facility?

- Whom can I call with treatment questions? Is someone available 24 hours a day and on weekends?

Questions about finding help in the community:

- What agencies are available to help me with transportation or meals?
- What is adult day care and how do I find out about it?
- What public benefits is my relative eligible for, such as In-Home Supportive Services or VA services?
- Where do I start to look for such care?

Questions about my needs as a caregiver:*

- Will someone come to my home to do an assessment to see if we need home modifications?
- What services will help me care for myself?
- Does my family member require help at night and if so, how will I get enough sleep?
- Are there things that are scary or uncomfortable for me to do, e.g., changing a diaper?
- What medical conditions and limitations do I have that make providing this care difficult?
- Where can I find counseling and support groups?
- How can I get a leave from my job to provide care?

- How can I get a respite (break) from care responsibilities to take care of my own healthcare and other needs?

** Adapted with permission from www.nextstepincare.org, United Hospital Fund.*

References

Next Step in Care. United Hospital Fund.
www.nextstepincare.org

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"Studies Suggest Ways to Improve the Hospital Discharge Process to Reduce Postdischarge Adverse Events and Rehospitalizations," December 2007, Patient Safety Network

"E.R. Patients Often Left Confused After Visits," Laurie Tarkan, New York Times, Sept. 16, 2008

"Tip Sheet for Beneficiaries-Hospital Discharge Planning," Center for Medicare Advocacy,
www.medicareadvocacy.org

Medicare: "Planning for Your Discharge" – Publication 11376

Medicare: "Compare Care — Home Health Brochure" — Publication 11070

Medicare: "Guide to Nursing Home Compare"

"A Simple Plan – Discharge Planning Improves the Odds," Jane Erwin, Nurseweek, June 28, 1999.

"Safety As You Go from Hospital to Home," National Patient Safety Foundation, www.npsf.org

"From Hospital to Home: Improving Transitional Care for Older Adults," Health Research in Action, University of California, Berkeley,
www.uchealthaction.org

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

Southern Caregiver Resource Center offers free support services to caregivers of adults with chronic and disabling conditions in San Diego and Imperial counties. Services include information and referral, needs assessments, care planning, family consultation, case management, individual counseling, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance

235 Montgomery Street, Suite 950
San Francisco, CA 94103
(415) 434-3388; (800) 445-8106
Web site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues, provides assistance in the development of public and private programs for caregivers, and assists caregivers nationwide in locating resources in their communities.

Family Care Navigator

Developed by Family Caregiver Alliance, a comprehensive online guide for caregivers to locate services and programs in all 50 states. Includes Frequently Asked Questions and glossary.

Next Step in Care

United Hospital Fund
Comprehensive information and advice to help family caregivers and healthcare providers plan transitions for patients. Spanish translations available.
www.nextstepincare.org

Medicare

(800) MEDICARE
www.medicare.gov

Medicare's Nursing Home Compare

www.medicare.gov/nursinghomecompare

Medicare Rights Center

www.medicarerights.org

Center for Medicare Advocacy

"Hospital Discharge Planning"
www.medcareadvocacy.org

The American Health Quality Association

www.ahqa.org

Eldercare Locator

(800) 677-1116
www.eldercare.gov

Aging Life Care Association (formerly National Association of Geriatric Care Managers)

(520) 881-8008
www.aginglifecare.org

Fact Sheets

Caregivers Guide to Medications & Aging

Hiring In-Home Help

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