

# Transitions in Care: Navigating the Health Care Maze

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Caregivers of individuals with a chronic illness experience increased stress during episodes of acute illness, which may require a transition from one care setting to another. Often, important health care decisions need to be made in a short period of time. There are a few guiding principles that apply to these likely occurrences. The following information can help guide you through the process.

- **Know your loved one's health insurance policy.** Take time to understand the insurance coverage. You don't want any last-minute surprises. For example, many older Americans are not aware that Medicare does not cover the full cost of a hospital stay and other necessary care. Find out if your loved one qualifies for medical assistance and, if not, look into options for secondary insurance. Understand prescription coverage and copays for medication. Some insurance companies have case management programs to help navigate patients through chronic illness. Contact your loved one's insurance company to determine if this option is available.
- **Write it down.** Use a caregiving journal to keep a detailed record of all aspects of your loved one's care.
  - Include the names of all health care providers.
  - Keep a list of current medications and side effects.
  - When speaking with hospital staff and community agencies, write down names, phone numbers, dates, and what was said. Make sure that you are receiving information from the treatment team in the language with which you are most comfortable.
- **Talk about the tough stuff.** By the time someone needs a caregiver, onset of a life-threatening illness is likely. It is important to talk about care plans and medical decisions well in advance. It's especially helpful to discuss advance directives and a financial power of attorney so that if a crisis happens, the care recipient's wishes are clear and you are able to uphold them.
- **Develop and maintain a good relationship with your loved one's primary care provider.** He or she can be instrumental in partnering with the hospital team if an admission is needed.
- **Start your involvement from day one of any hospitalization.** If you are the caregiver of someone who has been admitted to the hospital, start getting involved in your loved one's care from the time of admission. Introduce yourself to the health care team, and share your loved one's care plan that was in place prior to being hospitalized. Be clear about any aspects of care that you are worried about or those where additional help may be needed.
- **Know your health care team.** If the hospital is an academic medical center, such as Johns Hopkins Bayview or The Johns Hopkins Hospital, your loved one will be cared for by a

team of health professionals. Members of this team often include an attending physician, fellow, resident physician, nurse practitioner or physician assistant, and medical student. Your loved one also may be cared for by a nurse, certified nursing assistant, and – if necessary – physical, occupational, or speech therapists.

It can be quite difficult and confusing to keep track of everyone who is caring for your loved one. We encourage you to speak up and let your team know if you are unclear about what the plan of care is or uncertain about who will be involved providing that care.

Once your loved one is ready to transition from the hospital, a team of professionals will help coordinate additional care. The team, composed of a social worker, nurse case manager, and case assistant, is trained to help families through the difficult care decisions that arise at discharge from a hospital and to help them plan accordingly when there is a change in a patient's functional abilities. They will refer you to community resources, such as nursing homes and rehabilitation centers, home care services, medical equipment providers, and transportation services. The team also may be able to help with financial and legal concerns. It may be helpful to meet with this team early in the admission to start planning together.

- **Be firm, but flexible.** *Be firm.* Speak up if you feel that a plan is not meeting your needs. You have the right to say no to a hospital discharge plan if you feel it is premature or if you are not prepared to manage the necessary care at home. If someone tells you that a particular service is not covered or available, take the time to see if the decision can be negotiated or formally appealed to an insurer.

*Be flexible.* You may not always find the perfect solution to a problem. Be willing to consider an alternate plan or choice other than your preferred one. Recognize that often some services will require out-of-pocket payments. If you are unable to afford necessary care for your loved one, ask your treatment team to link you with a hospital financial counselor.

