

## When Your Loved One Is Hospitalized

Caregivers know all too well the feelings of helplessness that accompany their role of caring for a loved one with a chronic illness. When a hospitalization is involved, it is not uncommon to feel as though you have lost all control. There are steps you can take to ease the stress of a hospitalization and to ensure that you remain a part of the health care team should a hospital stay take place.

Most patients enter the hospital today as the result of a serious complication of a chronic illness or a life-threatening acute event. Because your loved one is likely to be seriously ill, there may be a great deal of uncertainty involved with his/her prognosis. Your loved one may experience a significant decline in function, and you may be forced to make crucial decisions without his/her input. By being proactive now, prior to any hospitalization, you will ensure that you and your loved one have a voice when it counts the most.

### The Papers You Need

Having the proper legal documents in place is critical if you want to ensure that your loved one will receive the type of care they want and need. The following list outlines the basic documents we all should have.

- *Durable Power of Attorney for Health Care*. A durable power of attorney for health care, also known as a health care agent or proxy, is an individual you have appointed to make decisions about your medical care if you become unconscious or can no longer speak for yourself. A health care agent can be assigned as part of the advance directive form.
- *Advance Medical Directive*. An advance directive informs your physician and family members what kind of care you wish to receive in the event that you can no longer make your own medical decisions.
- *Living Will*. A living will is a type of advance directive that outlines what kind of medical treatment you want in certain situations. It only comes into effect if you are diagnosed with a terminal illness and have less than six months to live, or if you are in a persistent vegetative state. A living will does not, however, allow you to name someone to make decisions on your behalf.
- *Do-Not-Resuscitate Order*. A do-not-resuscitate order (DNR) is a signed order directing that no cardiopulmonary resuscitative efforts (efforts to restart the heart after it has stopped) are to be undertaken in the event that your heart stops beating or you stop breathing. A DNR

can be part of your advance directive. Does your loved one want resuscitation to occur regardless of circumstances? What are his/her feelings about ventilators and other life-sustaining equipment? If the decision is made that cardiopulmonary resuscitation is not what your loved one desires, than a DNR order must be written by your physician.

Advance directives, living wills, and durable power of attorney forms are all simple documents to complete and samples may be obtained through your local hospital, your attorney, or your state's attorney general's office. Your physician may also have copies of some of these documents. Signed copies should be given to your family physician. The documents must also be placed in the hospital chart each time your loved one is hospitalized.

### **Information You Need to Provide to Hospital Personnel**

In addition to having the vital documents mentioned above, you can facilitate your loved one's transition to the hospital by providing the health care team with the following information:

- The patient's medical history, in writing;
- A list of the patient's allergies;
- A list of current medications and dosages;
- A list of all physicians and consultants who are caring for your loved one, along with phone numbers.

Providing this information immediately upon admission to the hospital can save crucial hours and improve communication. Often the hospitalization begins in the emergency room. The above information will ensure that in the busy emergency room setting, your loved one's care is facilitated and physicians familiar with his/her case are involved from the start.

### **The Health Care Team**

As a family caregiver, you are a part of the health care team, which also includes the attending physician, the hospital nurses, and a hospital social worker or case manager. Each of these individuals, including you, has a role in the hospitalization. Stand up for your role on the team. The other members of the health care team need your input in order to evaluate, educate, prognosticate, advise, and treat your loved one. Here are four things you should do upon arrival at the hospital.

1. Find out the name of the attending physician of record for your loved one. This is the individual who will be coordinating the care throughout his/her hospital stay. This

physician will be the primary doctor on the case. The attending physician will be in communication with the other consulting physicians and know their recommendations. Sometimes it is necessary to talk to a consultant about a specific issue, but often the attending physician can summarize the entire treatment plan. Make sure you understand and agree with that plan. Don't hesitate to continue to ask questions until you feel comfortable with the answers. You may find it helpful to keep a running list of questions that you wish to discuss each time you see the physician.

2. The first time you speak with the attending physician, make sure to find out the best way to get in touch with him/her. Who will initiate the phone contact? At what number can the physician be reached and what times are best to call? Make sure the face sheet in your loved one's hospital chart contains your name and your correct phone numbers.
3. Get to know the nurses who are caring for your loved one. They can answer your day-to-day questions and are an excellent source of information and support. Don't be afraid to ask the nurses about any new procedures or changes in your loved one's course of treatment. They are the natural starting point for questions, and will direct you to the attending physician when necessary. This will cut down on any frustration you might feel at not being able to reach your attending physician every time you have a new issue to discuss. Realize that the change of shifts is a very busy time for the nurses, so find out when they shifts occur and try to hold your questions until the nurse coming on duty has received his/her report.
4. As soon as you are able, speak to a hospital social worker or case manager, who will help you with any discharge planning issues. In a sense the discharge process begins at the time of admission in terms of you finding out everything you need to know. This includes what follow-up is necessary after you leave the hospital; who will be providing home health care, if necessary; what home health equipment you might need; and who will be paying for these additional expenses including any special transportation services. Make sure you obtain the numbers of all home health companies providing goods and services and the names and numbers of companies that will deliver the equipment. A hospitalization may be the transition to a nursing home or hospice setting. The hospital social worker or case manager should help you make a smooth transition and can provide support for you, the caregiver, as well as for the patient.

## **Maintaining Some Control**

Medicine is full of “lesser of the evils” choices, and at no time is this truer than when a chronically ill patient is hospitalized. The goal of hospitalization in these cases is often symptom management, with the understanding that the underlying problem cannot be fixed. The focus in the hospital will be on palliation and management rather than cure. It is important for you, as the primary caregiver, to keep this in mind, and to strive to understand the risks and benefits of any proposed course of treatment. It is also your role to make clear to everyone in the health care team what your loved one’s wishes are regarding short-and long-term treatment. By being more proactive in your communication, you will not only simplify everyone’s jobs, you will maintain some degree of control. At no time is your role as caregiver more important than when you speak on behalf of the person you love. ■

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