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Hospitalization

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Roger C. Bone Award Recipient for National Leadership in End-of-Life Care

There's no place like home ... especially when you have been to the hospital many times. Most people with a serious illness want to stay at home. Family members and other caregivers play an important role in helping patients recognize and treat symptoms to prevent a crisis and to avoid unwanted or unnecessary hospitalizations.

Here are eight things that may help you keep yourself or your loved one at home: a logbook, an information sheet, a scale, routine medications, stand-by medications, a plan, other people to help, and courage. But, do remember, even with the best of care and unlimited resources not everyone can be kept at home.

A logbook: By keeping track of basic information, you will be able to provide your health care team with accurate reports – either over the phone or during visits. Don't make this complicated. A simple spiral-bound notebook will do just fine. Get into the habit of recording daily weights, symptoms (like pain, trouble breathing, and swelling), medication changes, and activities.

The key point: Write down things that are important because nobody can remember all that is involved with helping to take care of another.

An information sheet: Write down important names and phone numbers and post it in a very visible location. Here is a sample list, including for a hospice if one is involved:

Name of general doctor: _____

Phone number: _____

Pager/after-hours: _____

Name of specialty doctor: _____

Phone number: _____

Pager/after-hours: _____

Name of hospice: _____

Hospice phone number: _____

Name of hospice team: _____

Name of hospice nurse: _____

Name of hospice social worker: _____

Name of hospice chaplain: _____

Call a member of your health care team when there is a new symptom like unusual weight gain, difficulty breathing, confusion, nausea, vomiting, or any other distressing symptom.

A scale to record weights: This is especially relevant for certain conditions. Heart failure, for example, means that the heart is losing its ability to pump blood effectively. Fluid may back up in the lungs and the feet. In other words, the body becomes congested. By weighing your loved one daily, you may be able to prevent a hospitalization.

Key point: Call your health care team if there is a weight gain of two pounds or more in one day or five pounds or more in one week.

Routine medications: Keep a list of all medications in your logbook. If your loved one takes more than three medications a day, use a pillbox that stores medications for a week. Get rid of medications that are no longer being used and keep all routine medications together in the same area of the house.

Key point: Keep an accurate account of all medications and call your health care team if medications are running out or a dose is missed.

Stand-by medications: Keep a second list of medications in your logbook. List these medications along with the symptoms they treat. These are stand-by medications and should be used **as needed** for symptoms like weight gain, pain, and shortness of breath. Confirm with your health care team that the list is accurate.

Key point: Know what medications to use when symptoms arise. Always call your health care team if you are not sure.

Keep Communicating: Your loved one's condition will change over time as the disease runs its course. Along the way, be sure to talk with your loved one and their health care team about what changes in the disease mean in terms of your loved one's wishes and goals. Starting this conversation with your loved one can be difficult, but it is necessary. "I know this is a hard subject to talk about, but I want to honor your wishes. How do you want to spend your last days? Do you want to remain at home? Are there any financial affairs/wills that we need to settle? What about funeral and burial plans?"

Others: Don't do it alone. Being a caregiver can be physically, emotionally and spiritually draining. Having someone come in for a few hours can give you the time away you need to do chores or get some time for yourself. Join a support group. And be realistic: one day, even with the help of others, the time may come when you will no longer be able to care for your loved one at home – that is OK.

Courage: It is important to say good-bye. Sometimes this is done with words and at other times it is expressed by our actions. Quiet times and simple gestures of affection can reflect the uniqueness of the moment, your love, and concern. Putting our feelings into words may be painful and tearful, but this can help your loved one say what needs to be said and this can provide closure and peace.