Understanding and Enhancing Role of Caregivers

Below is an excerpt from a tool developed by the United Hospital Fund (UHF) in collaboration with Project Re-Engineered Discharge (RED). Authors: Carol Levine and Jennifer Rutberg, United Hospital Fund; Brian Jack, MD, and Ramon Cancino, MD, Project RED.

Understanding and Enhancing the Role of Caregivers in Discharge Planning

Caregivers are a critical element in the success of the After Nursing Home Care Plan (ACP). Caregivers can be family members related by birth, marriage or commitment and/or they can be those who take on responsibilities for providing various kinds of assistance to the patient.

Identifying the caregiver—or caregivers, if there is more than one—is an important first step.

If caregivers are not involved in planning, they may not understand what is expected of them. They also have no opportunity to discuss problems or issues in the ACP or to express their unwillingness or inability to participate in some or all aspects of care.

Five Steps to Integrating Caregivers into the ACP

Step 1: Identify the Caregiver

Important considerations:

- Establish appropriate time during patient's stay when caregiver will be identified.
- Establish which care team member will identify caregiver and the role of caregiver in patient's care.
- Determine where information will be recorded in patient's record so entire care team is aware of patient's caregiver(s).

Step 2: Assessing the Caregiver's Needs

A caregiver needs assessment is a tool to help identify strengths and limitations and to develop a realistic plan for the next stage of care. The goal is two-fold:

1. Ensure that the patient's health and well-being are maintained and enhanced; and
2. Ensure that the caregiver's capacities and needs are considered and addressed in the ACP.

For a guided self-assessment of the caregiver's needs, developed by United Hospital Fund, see Next Step in Care's "What Do You Need as a Family Caregiver?" (http://nextstepincare.org/Provider_Home/What_Do_I_Need/).

The results of the needs assessment should include:

- Availability, other responsibilities, and relevant health status of the caregiver.
- Breakdown by task of what the caregiver feels he/she currently does, could do with training, and cannot do.
- Overarching concerns and questions. Deep-seated worries about the caregiving situation may hamper a caregiver from engaging in education and discharge planning.
- Perception of the patient's health and functional status.
- Values and preferences about caregiving ("do it all myself," "can't deal with needles or incontinence," "I can't take Mom to my home because there just isn't room for another person").
- Impact of caregiving on emotional status, finances, and other family members.
- Community resources used by the patient or the caregiver, or resources they are interested in accessing.

Step 3: Integrating the Caregiver's Needs into the ACP

Given the patient's care needs and the assessed abilities of the caregiver, realistic discharge options can be developed in the areas of:

- Medications
- Post-discharge appointments
- Training

The caregivers should receive a copy of the ACP.

Step 4: Share Caregiver Information with the Next Setting of Care

Transmitting the ACP to the post-discharge clinician is an essential part of transition work. Sharing the information gathered about the caregiver is also important; this allows the clinician to understand the role of the caregiver in care and the caregiver's other responsibilities which could impact care.

Step 5: Provide Telephone Reinforcement of the ACP

Post-discharge telephone calls should be directed to the people responsible for each part of the ACP. That may require phone calls to both the patient and to a caregiver, or even to multiple caregivers, depending on the patient's situation. The sections of the ACP in which each person participates should be the focus of the call.

The best After Nursing Home Care Plan may fall apart if one key partner—the caregiver—cannot do the job.