

Choosing Home Healthcare Assistance

Families facing HD are typically very self-reliant. Care is often provided at home during the progression of the disease and frequently by one family member. As symptoms worsen, the task of caregiving may become overwhelming. Obtaining professional home care assistance may improve the quality of life for both the caregiver and the patient. Caregivers cannot expect themselves to be cheerful and supportive all the time, while tending to the demanding physical and emotional needs of a person with HD. Respite is needed for the caregiver to "refuel" emotionally and physically.

After the decision is made to obtain assistance, the question becomes "What level of service is needed?" Caregiving assistance takes many forms. It may be as simple as employing a cleaning or laundry service. A housekeeper may be hired to cook meals a few days a week. Consistent relief from even a few tasks may help the caregiver get "out from under."

Due to the long-term nature of this disease, the support services a caregiver needs will change over time. Custodial tasks such as bathing, toileting, dressing and feeding may become difficult to manage because of the patient's size or behavior. A home health aide or certified nurse assistant can come into the home to provide personal care and assistance. These workers may be hired through an agency or directly by the caregiver.

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Home healthcare agencies recruit, train and supervise home health aides. Medicare may pay for services provided through a home healthcare agency, if a physician orders these services. To be eligible for services under Medicare, a patient must need skilled nursing assistance or physical, speech and/or occupational therapy. Home healthcare workers are a supplement to this care and are usually scheduled for three hours a day, several days a week. Talking to the patient's doctor or a social worker is the first step.

QUESTIONS TO ASK A HOME HEALTHCARE AGENCY

- How are employees screened?
- Who supervises the workers?
- What type of training do the aides receive?
- Who will come when the worker is ill or on vacation?
- Are there limitations on tasks or times of service?
- Can the worker be replaced if the caregiver or patient dislikes the aide?

Once the aide has been hired, it is important that they be made aware, in

words and in writing, of the patient's needs and routine. Accepting a new person into the household may initially be difficult for the HD patient, so it is critical that the aide understand the patient's likes, dislikes, personality and behavior patterns and that they follow the expected routine carefully. It is also imperative to assess the personality of the aide and the way they interact with the patient. The aide is being hired to support the caregiver and reduce the level of stress in the household. The caregiver will need to spend time with the aide until an acceptable relationship is established. If the aide cannot work well with the patient, or the caregiver, they should be replaced. Getting assistance with caregiving is a challenge. Paperwork and bureaucracy can be frustrating. At first, caregivers may feel that the effort causes more problems than it solves. But a system of professional support, once it is in place, can give a caretaker precious time for their families, their work and themselves.

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