

Stages of Caregiving



**Del Mar Caregiver
Resource Center**

Supporting Caregivers through their Journey

How does a person prepare for caregiving? In a culture that celebrates youth, self-sufficiency and productivity, caregiving is not something commonly thought of or understood. Most often people caring for a relative, or friend living with a chronic illness do not identify themselves as caregivers. Caregivers of persons with neurological conditions shoulder more responsibilities than other caregivers. (National Alliance for Caregiving, 2017). Assistance with Activities of Daily Living (ADL) are greater for these caregivers. They serve as patient advocates guiding their loved one through complex health and human services systems, making sure the treatments and services they need are received. As the person receiving care enters the late stage of their illness, caregivers may perform medical/nursing tasks with little or no training. Medical/nursing tasks include readings of vitals, administering injections, tube feedings, catheter, ostomy and respiratory care.

Caregivers experience unique experiences and challenges across three stages. Understanding caregiving from a stage approach recognizes that caregivers advance through stages alongside stages of disease progression experienced by persons with neurological disorders.

Beginning Stage Characteristics of Caregiving

After a diagnosis of a neurological condition, caregivers and their loved one enter a period of uncertainty. Relationships begin to transition from being familial husband-wife, mother-daughter, to caregiver and care-receiver. Thoughts about what lies ahead overwhelm both parties leaving families at a loss for what to expect. Most prominent in the early stage of caregiving is the need for disease specific knowledge and information about community services.

In the beginning stage of caregiving, the care-receiver may exhibit minimal symptoms or limitations to performing self-care, still able to perform their own care. At this stage the care-receiver may retain a level of independence. Shared fears and uncertainty about the future can affect self-image and identity for both caregiver and care-receiver.

During this stage of caregiving attention is devoted to gathering information and learning about disease(s), symptoms, treatments and prognosis. Readiness to receive information and support may be difficult and can vary within the family due to issues of stigma, fear and worry.

Middle Stage Characteristics of Caregiving

In the middle stage of caregiving, care-receivers require more assistance with chores and personal care. Assistance may be required for shopping, housekeeping, management of finances, food preparation, taking medications and transportation. As the person's condition advances, increased assistance with personal care such as bathing, grooming and dressing develop. The care-receiver may begin to develop behavior problems during the middle stage of their condition. Problems with wandering and getting lost is a risk for persons experiencing memory loss and confusion. Behavior problems such as anxiety, depression, agitation, hallucinations and delusion may develop with some conditions.

Care needs during this stage increase the amount of time spent providing care and may result in higher levels of stress and fatigue. The need for supportive services from family, friends and professionals becomes more important. Caregivers may benefit from learning how to manage behavioral issues and counseling support to talk about issues around loss of intimacy and connectedness with their loved one and feelings of isolation.

Late Stage Characteristics of Caregiving

Families may begin to entertain thoughts about moving their loved one into a care facility during the late stage of caregiving. As medical conditions progress, care-receivers may lose the ability to walk, feed or toilet themselves. Individuals may become bedridden, requiring medical tasks such as administering injections, monitoring respiratory equipment, tube feedings, catheter and ostomy care.

During this stage caregivers begin to think more consciously about end of life. Complications associated with anticipatory grief may develop. Heightened emotional distress and physical exhaustion can impact a caregiver's coping skills and resilience. During this stage caregivers may begin to question their ability to continue providing care. Needs for professional assistance is greatest during this stage.

No caregiver should be left alone. Becoming familiar with the stages of caregiving helps prepare for the future. Preparing for the future includes putting together a network of care. For assistance and to prevent isolation reach out.

For information about caregiver services, call:

Del Mar Caregiver Resource Center | 1-800-624-8304

This paper was prepared by Sam Trevino, MSW, LCSW, Health Services Manager for Health Projects Center (HPC). HPC is a nonprofit organization that administers the Del Mar Caregiver Resources. For more information about HPC please visit www.hpcn.org