

From the Desk of
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Neurodegenerative Disorders and End of Life Care



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Introduction

Neurodegenerative disorders are chronic, incurable, and progressive diseases that ultimately end in the death of the individual. These illnesses present themselves and progress in a multitude of ways depending on the type of neurodegenerative condition and the individual him- or herself. Regardless, each disease will present challenges for the person, family and caregivers, especially towards the end of life. Such challenges include the variability of disease progression, physical and cognitive decline, and management of symptoms, especially pain.

All neurodegenerative disorders share a common pathological cause, marked by progressive neuronal loss. Such loss can be caused by neurovascular changes, changes in blood-brain barrier permeability and cerebrovascular fluid flow, and neurotoxic substances such as oxidative stresses or amyloid protein and genetic predisposition. Another characteristic shared by these disorders is the "long goodbye" experienced by everyone involved in the person's care. As these diseases progress, identity is lost, autonomy diminishes, independence disappears to the point in which death claims the person's body and soul. Quality of life and comfort become central themes in care, not only for the patient, but for their family as well.

A Brief Review of Common Neurodegenerative Disorders

Millions of Americans are affected by neurodegenerative disorders. Over 5 million are diagnosed with Alzheimer's and 500,000 are currently diagnosed with Parkinson's disease. These are by far the most common types. Worldwide, over 1 billion people are diagnosed and suffer from these illnesses. Other neurodegenerative disorders include Motor Neuron Disease, Huntington Disease, Multiple Sclerosis, Stroke, and Amyotrophic Lateral

Sclerosis or ALS. There are many others including HIV, Creutzfeldt-Jakob Disease, Frontotemporal Dementia (Pick's), and traumatic brain or spinal injury.

The diagnosis of a neurodegenerative disease is the beginning of a life-changing journey. One's world can literally be turned upside-down. Diagnosis is only the start of a long, progressive course towards the gradual loss of dignity, individuality and life itself. There will be many burdens experienced by the person, family and caregivers. Non-curative interventions including symptom control, comfort, and measures to enhance quality of life will be delivered by skilled staff in care facilities and by hospice professionals. Preventing and relieving suffering, assessing and treating pain, and assessing the individual's physical, psychosocial and spiritual needs will all be critical in the care of an individual diagnosed with a neurodegenerative disorder. Of great importance will be following through on the wishes of that individual during their care and at the end of their life. Hospice can be a very important and effective approach in delivering the right kind of care when it is needed most.

Managing End of Life Care

The needs of individuals with neurodegenerative disorders will vary according to many variables including to diagnosis, stage of the disease, variability or progression, and the individual him- or herself. Some needs will be very common while others may be more specific, especially towards the end of life. For instance, some individuals will receive an early diagnosis and start treatments and care quickly, while others will be diagnosed later in the disease progress, and unfortunately not receive the care necessary to manage symptoms and improve quality of life.

Disease progression is important and can determine the type and intensity of care. A disease may have an acute onset leading to either death or recovery, in the instance of a stroke. On the other hand, the progression may be prolonged with deterioration over a long time, as in cases of Parkinson's or Huntington disease. Or, in the case of Multiple Sclerosis, needs will vary as the disease fluctuates across time. Regardless of disease progression, they all end in gradual deterioration and death.

Treating both physical and cognitive decline are important aspects of end of life care. Many changes may develop towards the end of each illness including mood changes, communication

difficulties, confusion, or more complicated neuropsychiatric conditions such as:

- Dementia due to Alzheimer's, Parkinson's (Lewy body dementia), frontotemporal disorder and Multiple Sclerosis
- Severe cognitive changes due to Huntington's disease
- Depression and cognitive change due to Multiple Sclerosis
- Hallucinations, neuropsychiatric decline, agitation and confusion due to Parkinson's Disease
- Behavioral and mood changes, impulsivity, and loss of judgment due to any of the neurodegenerative disorders

This, unfortunately, is a short list of possible psychiatric complications that can arise with any neurodegenerative condition. Any of these can affect not only how care is delivered throughout the course of the disease, but particularly at the end of life. They can interfere with how care is planned and cause distress to family and caregivers. Each of these changes chip at the person- personality, independence, dignity and autonomy. They can indeed complicate an already complex clinical condition and make matters worse for everyone involved.

Identifying when an individual with neurodegenerative disorders requires hospice is crucial because it enables the beginning of clinically appropriate and necessary care to manage symptoms and promote quality of life. Talking with the person and their loved ones is a necessary first step. Organizing care around the interdisciplinary team is also important. There may be individuals who are reluctant to bring up hospice, but the complexities involved in end of life care are plenty and should be handled by those who are best prepared to deliver it.

Final Words

Neurodegenerative disorders already affect millions of people in the U.S. and roughly 1 billion around the world. These numbers are expected to rise, particularly in the U.S., due mainly to the increase in life expectancy and the massive Baby Boom Generation. These conditions carry heavy burdens for everyone. The specific disorder, rate of progression, cognitive and physical deterioration, neuropsychiatric symptoms, communication problems, loss of independence and eventual death all require the appropriate type of care delivered by well-prepared and compassionate hospice professionals.