



Managing Huntington's Disease in LTC

Wednesday, August 14 2024

An inherited, incurable illness, Huntington's Disease causes progressive deterioration "of an individual's ability to "reason, walk, and talk," says the Huntington's Disease Society of America. "The symptoms of HD are sometimes described as having ALS, Parkinson's and Alzheimer's - simultaneously," they add. Problems with swallowing, eating, speaking, and walking, along with cognitive changes and psychiatric disorders, often lead to admission to a skilled nursing facility. What do clinical teams need to know to manage Huntington's disease?

Ongoing decline

Medications are available to help manage the symptoms of Huntington's disease. But treatments can't prevent the physical, mental and behavioral decline associated with the condition, explains Dr. Steven Posar, CEO and CMO of GuideStar Eldercare.

Patients living with Huntington's have active insight into their own disease process until they reach the point of dementia, he says. Apathy is not a common symptom. Thus, an observation of apathy is considered depression, unless proven otherwise.

Huntington's symptoms arise because of degeneration of nerve cells in the brain. Damage to the frontal lobes creates conditions of increased impulsivity, increased irritability, poor judgement, social interaction deficits, and emotional lability. This damage makes individuals susceptible to triggers that will "launch" a person into angry outbursts or psychotic behaviors.

LTC admission – identify triggers

When an individual with Huntington's is admitted to a skilled nursing facility, it's helpful

to get to know them quickly and build an individualized list of "triggers". By carefully avoiding triggers, you can often avoid launching a person into angry or psychotic conditions. Dr. Posar advises:

- Obtain an inventory of reported pet peeves from the resident as soon as possible.
- Get a list of observed triggers from staff.
- Consult the psychology team to identify observed or mentioned triggers.

How to manage outbursts

What happens if a resident is triggered and "launches"? Here are four steps:

- Immediately remove the resident from the trigger, if possible.
- Place the resident in a quiet environment with minimal stimulation.
- Always do so with support. Never leave the resident alone.
- Try a distraction, such as TV, music, or a walk. Go outside if possible.

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Behavioral reinforcement matters too, says Dr. Posar. It is OK to reinforce positive behaviors, but it is never OK to reward negative behaviors.

Absence of triggers

What if you notice behavior ramping up when there is no observable trigger? Unexplained behavioral changes can point to other conditions such as pseudobulbar affect or seizures. Pseudobulbar affect is involuntary emotional expression that may exhibit as uncontrolled laughing or crying. Neurological evaluation is key when clinical changes arise, so that appropriate medications can be initiated.

Medications for Huntington's disease

Medication management is a cornerstone of symptomatic management for Huntington's, and it's easy to get it wrong. Some of Dr. Posar's guiding principles are:

- Remove any medications that could become "pharmacologic triggers" and any that could impair movement, e.g., anticholinergics and adrenergics.

- Consider drugs for mood stabilization, such as selective serotonin reuptake inhibitors (SSRIs) or valproic acid (VPA).
- Consider anxiolytic (anti-anxiety) drugs. Examples are propranolol or benzodiazepines.
- For pseudobulbar affect, consider Nuedexta.
- For complex partial seizures, consider Keppra.

Drugs that can help address psychosis or agitation include Zyprexa, Haldol, or rarely—Clozaril or Thorazine.

Huntington's disease can be difficult to live with—and manage. Thus, clinical strategies matter. An understanding of neurologically-driven symptoms and attention to best practices can make a difference. With extensive specialized experience in Huntington's care, Dr. Posar and the GuideStar team are here to help ease the suffering of your residents with Huntington's disease while promoting their safety, functionality, and dignity.

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