



PARKINSON'S DISEASE IN LONG-TERM-CARE SETTINGS

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Dealing with patients who have significant medical disorders can be difficult. In long-term care, the amount of time spent by staff can be overwhelming. This overview encompasses the unique aspects of caring for residents with end-stage Parkinson's disease and identifying when hospice is appropriate.

Understanding Parkinson's Disease

Parkinson's Disease (usually abbreviated PD) is a neurological disorder, which can cause difficulty with movement. The disease is chronic and progressive and eventually, can lead to death. Currently, there are nearly one million people in the U.S. living with Parkinson's disease. In patients with Parkinson's disease, the dopamine-producing cells begin to die and the normal amount of dopamine that is produced in the brain decreases. The brain slows messages to the body on how and when to move, which can affect a person's ability to begin and control normal movements.

Causes of Parkinson's Disease

The cause is unknown and there is no cure. However, there are treatment options including medications and surgery to minimize the symptoms and improve quality of life. Many scientific experts have identified aging as an important factor that contributes to the onset of Parkinson's disease and people over the age of 60 have a two to four percent risk of developing the disease, compared to one to two percent in the general population.

However, we are all aware of the award-winning actor, Michael J. Fox, who was diagnosed at the young age of 30. Familial tendencies include a small percentage of the population and family history has not been determined as a clear role. However, scientists have determined that the combination of genetic and environmental factors increases a person's risk of developing the disease. Epidemiological studies have demonstrated that people with an affected first-degree relative (such as a parent or sibling) have a two- to three-fold increased risk of developing Parkinson's disease, as compared to the general population.

In regard to environmental aspects, scientists have also suggested that the disease may result from exposure to environmental injury or toxins, which in combination with genetics can increase the risk of the disease. Some of the identified environmental factors include well water, herbicides and pesticides commonly used by people who reside in rural areas. Therefore, it has been determined that people who live, or have lived, in rural areas may have an increased risk of developing the disease. Another known factor is the synthetic narcotic agent called MPTP (1-methyl 4-phenyl 1, 2, 3, 6-tetrahydropyridine), which, if injected, is known to cause immediate and permanent Parkinsonism.

SYMPTOMS OF PARKINSON'S DISEASE

Primary Motor Symptoms

Although symptoms can vary from person to person, some of the most common primary motor symptoms are:

- Impaired balance and coordination
- Tremors of the jaw, face, arms, hands and legs
- Stiffness and rigidity of the limbs and trunk
- Slowness of movement (Bradykinesia)

Typically, the diagnosis of Parkinson's disease is determined upon the presence of one or more of these primary motor symptoms. Resting tremors are the most common symptom in patients with Parkinson's disease. In fact, about 70% of people with Parkinson's will exhibit a slight tremor of the hand or foot in the early stages in the disease's progression. The tremors are more pronounced when the patient is in a relaxed state and the person's muscles are relaxed. This tremor can spread to the other side of the body as the disease progresses, but it will remain most pronounced on the original side of occurrence. Tremors are easily identified and can be worrisome for the patient. In regard to the care of patients residing in a long-term-care facility, the acuity of the patient increases as the disease progresses. The patient may become a fall risk due to the impaired balance and affected gait. It may become more difficult to provide personal care due to the rigidity of the limbs and trunk. Adjusting the care to meet the needs of the patient is crucial and may require several care planning conferences throughout the progression of the disease.

There are other secondary and non-motor symptoms that can affect people with Parkinson's disease. These symptoms are more pronounced and can be more difficult to treat. Patients with these symptoms may also experience more discomfort and impaired life style.

Secondary Motor Symptoms

Secondary motor symptoms can affect people with Parkinson's disease, but not every Parkinson's patient will experience all of these. Some may experience very few, others may experience nearly all of them. The more symptoms, obviously the more debilitating the disease can be. The secondary motor symptoms include:

- Loss of facial expression
- Fatigue
- Slurred speech or softness of the tone of the voice
- Difficulty swallowing, which can lead to choking and possible aspiration
- Tendency to lean forward, stooped posture
- Drooling
- Impaired fine motor coordination and dexterity
- Impaired gross motor coordination
- Sexual dysfunction
- Small, cramped handwriting (Micrographia)

Non-Motor Symptoms

Parkinson's disease can also cause non-motor symptoms. These symptoms can be very difficult to control and can impact the patient and their family. Some of the most common non-motor symptoms seen in patients with Parkinson's disease include:

- Loss of energy
- Constipation
- Cognitive changes
- Pain
- Anxiety
- Compulsive behaviors including gambling, and sexual behaviors
- Skin problems
- Depression
- Urinary problems
- Memory difficulty and slowed thinking
- Fear

In regard to caring for a patient with non-motor symptoms, the facility staff may need to perform thorough skin assessments due to the risk of skin impairment; assessments for pain more frequently; offer emotional support to minimize anxiety; and adjust toileting schedules due to urinary problems and the risk for constipation.

TREATMENT OPTIONS

Medications

Although there is no known cure for Parkinson's disease, the treatment goal is to alleviate or minimize most of the distressing symptoms. Levodopa combined with carbidopa (Sinemet) is the most commonly used drug for the treatment of Parkinson's disease. The reason that the drugs are used in combination is that the drug carbidopa delays the conversion of the levodopa into dopamine until it reaches the brain. The nerve cells use levodopa to make dopamine and replenish the brain's diminished supply. Although Levodopa helps a reported three-quarters of Parkinson's patients, not everyone responds positively to the drug. The drug helps minimize the symptoms of rigidity and bradykinesia, but does not seem to reduce resting tremors. In patients that experience relief from tremors, typically the tremors are only marginally reduced. Balance and other symptoms may not be alleviated at all. There are many other drugs on the market including bromocriptine, ropinirole and pramipexole, which mimic the role of dopamine in the brain, which causes neurons to react as if the brain was producing natural dopamine.

In May 2006, the FDA approved rasagiline to be used in conjunction with levodopa for patients with advanced Parkinson's disease. It can also be used as a single-drug treatment for early Parkinson's disease. The drugs have minimal to almost no effect in end-stage Parkinson's disease cases.

Surgical

A therapy called deep brain stimulation (DBS) has now been approved by the U.S. Food and Drug Administration. Electrodes are implanted into the brain of the Parkinson's patient and the electrodes are connected to a small electrical device called a pulse generator. The pulse generator can be programmed externally to decrease dyskinesias, which are common side effects of the levodopa drug therapy. The DBS also helps to minimize or alleviate symptoms and reduce gait problems, tremors and the slowness of movements, which typically respond poorly to the traditional carbidopa/levodopa drug combination. The signal of the DBS can be adjusted as an outpatient procedure. This procedure does not cause brain tissue destruction, which commonly occurred with the older types of Parkinson's surgery. As with any surgical procedure, there are risks involved with this therapy. The risks include, but are not limited to, confusion, bleeding and infection. Rarely, significant bleeding into the brain can occur, which may mimic stroke-like symptoms including unilateral sided weakness. Therefore, the patient will need to determine if the symptoms are severe enough to accept the risks of the procedure. Currently, the procedure is used only in patients with moderately severe to severe Parkinson's disease, who experience poorly controlled symptoms through medications.

Determining a Prognosis

Determining a prognosis in a Parkinson's patient can be difficult. However, Parkinson's disease is an approved diagnosis for hospice. Parkinson's disease itself is not a "fatal" disease, but the complications associated with the disease can, and do, cause death. Parkinson's patients may experience pneumonia, which is the number one cause of death in many hospice patients. Choking, infections and falls are common with this disease, which can also contribute to the patient's death. The progression of symptoms in Parkinson's disease can take 20 years or more, but more often than not, the life expectancy of a Parkinson's patient is much shorter. Commonly used tools for determining prognosis include the Hoehn and Yahr scale. Another tool, which is much more complex, is the Unified Parkinson's Disease Rating Scale (UPDRS). Along with a hospice evaluation, these tools can help determine if a patient qualifies for hospice care.

Quality of Life

Although caring for a patient with the diagnosis of Parkinson's disease can be difficult, treatment options are available. Medications, surgery and hospice at end-stage can provide relief for those suffering from this debilitating disease. Ensuring the patient is comfortable, their dignity remains intact, and their quality of life is optimal is paramount when caring for these patients. Providing excellent care for Parkinson's disease patients can be done, for patients in early stages of the disease to those at the end of life. Facility staff is usually the first to notice changes in the patient's condition, and when appropriate, offer treatment options, including hospice to the patient and patient's family. Once the disease has reached the final stage, palliative care may be necessary to ensure adequate comfort and additional support for the family.

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