

Parkinson's Disease and End of Life Care



Bella Care
HOSPICE
Because Every Life is Beautiful

MARCH 2019



Introduction

Parkinson's disease is a progressive neurodegenerative disorder that affects movement due to the impairment of dopamine-producing neurons in the part of the brain known as the *substantia nigra*, which is Latin for "black substance". Dopamine is responsible for movement, emotions and the perception of both pleasure and pain. The disease develops gradually with almost no noticeable symptoms except for a very slight tremor in one hand. Although hand tremors are the most well-known symptoms of Parkinson's, the disorder also causes slowing of movement and muscle stiffness. Symptoms will continue to develop over the years and will vary slightly from person-to-person, but most likely lead to severe disability.

Facts

Parkinson's disease generally occurs after age 60 and increases in incidence with advanced age, and is the second most common neurodegenerative disorder, after Alzheimer's disease. There are also cases of people being diagnosed much earlier. The average length of life for an individual diagnosed with Parkinson's disease is between 10-15 years. According to The Centers for Disease Control and Prevention (CDC) it is the 14th leading cause of death in the United States. It affects more men than women with men having a 50% greater risk of developing the disease than women. Unfortunately, the cause is still unknown, but science is leaning towards heredity or the use of certain chemicals in the environment, such as pesticides. While there is no cure, medications are available but are mainly used to treat symptoms. At this time, medications cannot slow the progress of the disease.

Symptoms

Individuals diagnosed with Parkinson's disease may experience continued tremors of the hands, sometimes referred to as "pill rolling". A condition called bradykinesia or slowness of movements, may also be experienced by most people with

Parkinson's. Gait and balance problems as well as rigidity of limbs are to be expected. These types of symptoms are known as movement-related or "motor" symptoms. Non-motor symptoms of Parkinson's include depression, apathy, sleep disturbance, constipation, loss of sense of smell and cognitive impairment. Other common symptoms include swallowing and speech problems, complication of bowel and bladder function, decreased socialization, and anxiety.

Stages

Typical patterns of Parkinson's disease have been divided into 5 stages. During Stage One, symptoms are very mild and do not interfere with activities of daily living. Slight changes in walking, posture, and facial expression start to occur. Stage Two is characterized by a worsening of symptoms, especially motor symptoms on both sides of the body. Daily tasks become more difficult. During Stage Three, which is considered "mid-stage", slowness of movements and loss of balance become apparent, both of which contribute to an increased risk for falls. Symptoms become severe and limiting in Stage Four. The individual will require assistance with ADLs, walking, and living alone becomes dangerous. Finally, during Stage Five, the disease is advanced and debilitating. The individual will find it impossible to stand or walk and some will become bedridden. It is during this stage that hallucinations and delusions occur. Care around the clock becomes necessary.

Managing End of Life Care

Because Parkinson's disease has no cure, most care will be palliative in nature until the point where hospice will be required. The goals of care are to help the individual maintain as much independence as possible, manage motor and non-motor symptoms, and ultimately improve quality of life at every stage of the disease. Care will also be holistic, which focuses on all needs of the individual including physical, emotional, psychosocial and spiritual.

Near the end of life, individuals will need help dealing with feelings of depression and anxiety. They may need to express frustration concerning their limited abilities, restricted activities and social isolation. Feelings of loss and fear may also need attention. One issue in particular seems to be common with most neurodegenerative disorders – guilt. The individual may feel like a burden to their family and friends, physically, emotionally and financially.

Pain management is a special area that needs a great deal of attention during end of life care. Some studies report that much pain associated with Parkinson's disease goes under-

or untreated. These same studies also indicate that the pain from Parkinson's can be as severe and debilitating as that experienced by people with amyotrophic lateral sclerosis (ALS). Both palliative care and hospice must be aware of signs and symptoms, both verbal and non-verbal, of the individual's pain and suffering and manage it as best as possible.

Pressure ulcers may be a physical problem associated with lack of mobility and being restricted to bed and should be assessed regularly. Pressure ulcers are likely to develop over a bony prominence, but if contractures of limbs have developed due to immobility and the altered body shape associated with Parkinson's disease, pressure ulcers may develop in more unusual areas of the body.

Physical problems must be addressed during end of life care, such as pain, immobility, breathlessness, anorexia, and constipation. Psychological and emotional issues will need intervention including depression, anxiety, fear, guilt and uncertainty. Other issues such as spiritual beliefs, religiosity, the meaning of life, suffering, and why this has happened must be addressed. Difficult decisions will need to be made such as withdrawal of Parkinson's drugs due to lack of effectiveness and increased sensitivity to negative side effects such as hallucinations and delusions.

The family may have many needs that can be addressed by hospice. They will need time to come to terms with what is happening to their loved one. Many decisions will be made concerning management and treatment of symptoms, DNR, advanced directives, and withdrawal of medications. None of these areas are easy to address, so hospice professionals will need to be sensitive and aware of what families need and what they wish to talk about.

Final Words

Parkinson's disease is a progressively devastating neurodegenerative disorder that begins with almost unnoticeable tremors in one hand and leads to complete disability and eventual death. It can be said that no one dies of Parkinson's, but they instead die *with* Parkinson's and all of the complications that come with the disorder. Although medications such as L-dopa, Sinemet, Cogentin, Requip and others are available, they only help to treat symptoms of the disease, and do nothing to slow or stop the progression of it. Since there is no cure, both palliative care and eventually hospice services will be required throughout most stages of Parkinson's. Towards the end of life, there are only three things that may mean the most to both the individual and family: some level of independence, symptom management, and quality of life and death.