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# Hospice Medical Memo

A quarterly newsletter for physicians

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## Palliative and Hospice Care of Advanced Parkinson's Disease by Garry Snipes, MD

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*Fred is a 78 year old man who has had Parkinson's Disease for the last ten years. His initial symptoms were tremor and mild bradykinesia, but his disease state is now characterized by severe generalized rigidity and painful dystonias. Fred is non-ambulatory since a hip fracture six months ago, has mild dementia, and is dependent in all ADLs. He has had a 5% weight loss in the last 4 months due to poor oral intake and esophageal phase dysphasia, but has not had aspiration pneumonia. Fred and his family are considering a PEG tube at the suggestion of his neurologist. Fred's primary care physician has suggested hospice care.*

As our population ages and the management of cardiovascular disease and cancer improves, more people are living to an age when they may develop advanced neurodegenerative diseases such as Parkinson's Disease (PD) and "Parkinson's plus" syndromes. The inexorable but prolonged course and host of

symptoms associated with PD and other similar conditions make them a significant source of suffering. These diseases respond well to palliative care and hospice services as an adjunct to traditional disease-oriented medical care.

There is very little data to guide prognosis in PD. Characteristics that tend to indicate more rapid progression include rigid-predominant motor symptoms, onset at an older age, presence of cognitive impairment, and depression. **The Hoehn and Yahr staging system** provides a simple way to follow the progression of the disease and determine appropriate interventions to maximize quality of life:

- Stage I-(mild or early disease): Symptoms affect one side of the body only
- Stage II-Bilateral involvement, but posture remains normal
- Stage III-(moderate disease): Bilateral symptoms; mild imbalance during walking and

standing; person remains independent

- Stage IV-(advanced disease): Disabling instability while walking or standing. Substantial help required. **(Consider palliative care services)**
- Stage V-Severe, fully developed disease; non-ambulatory; restricted to bed or chair. **(May be appropriate for hospice care in later phase of Stage V.)**

Patients in Stage IV and V are generally at a point where disease modifying therapy is less effective, and palliation of symptoms is an appropriate priority. Even at these stages, optimal management of the motor symptoms with skillful balancing of risk versus benefit of anti-Parkinsonian therapy is an integral part of effective palliation. The advance stages of PD almost inevitably result in substantial secondary life-threatening complications such as complicated bacterial infections and malnutrition. Hospice care can be of significant



Hospice patient Helen Williams with husband, Buddy

benefit at this time.

### **Symptom management in advanced disease**

Certain symptoms of advanced disease in PD require a different approach than in other conditions. Some of these symptoms, such as pain, are not generally considered to be a part of PD, and may not be considered by clinicians unless specifically elicited from patients and families. Selected examples follow:

#### ***Pain***

Pain in PD generally is due to musculoskeletal causes related to rigidity, Bradykinesia and postural disturbance; painful dystonias (muscle spasms); or central pain due to altered nociception from the basal ganglia. Dystonias may be either due to the disease itself

## Who to call at Hospice of the Carolina Foothills

- Jean Eckert  
Executive Director
- Garry Snipes, MD  
Medical Director
- Sharon Maddox, RN, MPH  
Director of Patient Care Services
- Wendy McEntire, CMSW, LMSW  
Director of Bereavement Services
- Doug Brooks, RN  
Admissions Coordinator
- Meg Hoke, LMSW  
Palliative Care Program  
Coordinator
- Maureen Murphy  
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### ...Advanced Parkinson's Disease, *continued*

or to dopaminergic therapy and require skillful manipulation of levodopa itself as well as adjunctive use of dopamine agonists. Focal dystonia may respond to botulinum toxin injections. Traditional anti-spasmodics such as baclofen or benzodiazepines tend to be less effective and also have an unfavorable side effect profile in the elderly.

Musculoskeletal pain typically responds to NSAIDs, non-opioid analgesics or opioids if necessary. Physical therapy or massage therapy may be helpful if available. For central pain, judicious use of gabapentin may augment pain control.

### **Dysphagia**

Dysphagia is one of the hallmarks of advanced disease and is the precursor to what are commonly the fatal complications of PD: aspiration pneumonia, malnutrition and dehydration. Speech pathology can assist in characterizing the problem and offering suggestions to alleviate it. In patients with dysphagia that significantly impacts quality of life but with a reasonable prognosis otherwise, PEG tube feedings may be palliative although there are no studies demonstrating the impact of this intervention

in PD. Problems related to feeding and hydration are some of the most disturbing to families. This is one of the situations where a compassionate and detailed discussion of risk versus benefit and goals of care with all concerned parties is necessary to arrive at the best decision for the patient.

### **Depression**

Depression occurs in up to 40% of patients with PD, and is a negative prognostic factor, particularly if untreated. Depression also magnifies the disability associated with the disease condition. Diagnosis can be difficult due to overlap of symptoms of PD and depression. The Geriatric or Beck Depression Scales are useful in making the diagnosis. SSRI type antidepressants titrated to effect are the treatment of choice.

### **Hospice and Parkinson's Disease**

The requirement for physicians to certify a prognosis of six months or less of life expectancy is a special barrier to hospice care for conditions such as PD since prognosis is variable, and depends to a great extent on the occurrence of unpredictable acute complications such as aspiration or invasive infections. When patients reach mid- to late-Stage V on the Hoehn and Yahr scale, it is reasonable for the physician to consider hospice care.

The strengths of hospice care provided by the interdisciplinary team of attending physician, nurse, nursing assistant, social worker, chaplain and volunteers are congruent with the needs for excellent symptom management, caregiver support and assistance with decision making/advance care planning. Excellent symptom management is best accomplished with frequent observation, skillful application of medical measures and attentiveness to side effects. Caregiver fatigue, depression and burnout are common with a condition as prolonged and devastating as PD. Decision-making in PD can be very difficult, particularly when a patient is seriously debilitated physically but remains cognitively well-functioning.

Hospice of the Carolina Foothills staff are very familiar with the end-of-life care needs of patients with neurodegenerative disease of all types. We would be happy to assess and work with any patient you have with advanced PD and can offer assistance through our Palliative Care program if the patient is not yet hospice appropriate.

### **References**

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