Hidden Parkinson’s: Facing Challenging Complexity With Diminishing Capacity

i.e., *How to Stay Afloat!*

Diane G. Cook

Parkinson’s Patient
Person with Parkinson’s (PWP)

Parkinson’s is a complex, multi-system disorder!

- Insomnia
- Lightheadedness
- Visual dysfunction
- Runny nose
- Loss of sense of smell
- Body temperature regulation
- Stooped posture
- Pain
- Loss of arm swing
- Restless leg syndrome
- Itching
- Dry eyes
- Memory problems
- Slowed cognitive speed
- Stiffness of movement
- Impaired gait
Complex Multi-Symptom Disorder = Complex Multi-Faceted Support System!

- Neuropsychologist
- Movement Disorder Specialist
- Physical Therapist
- National Voice & Speech Center
- Vestibular Specialist
- PD Exercise Class
- Massage
- Sleep Doc

Carolyn & Paul
- Power Plate
- Holistic Neuro
- Nutritionist

Personal Support Network
- Meditation
- Husband
- Family
- Friends
- Colleagues

Health Club
- Support Groups
- Trainer

UC Med School

PCP
- Kinesis
- Zumba
- Pilates
- Dermatologist
- Vision Care Specialist
- Gastroenterologist

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## Typical Daily Schedule

<table>
<thead>
<tr>
<th>Time</th>
<th>Task</th>
</tr>
</thead>
<tbody>
<tr>
<td>5:00am</td>
<td>Arise</td>
</tr>
<tr>
<td>6:00am</td>
<td>Stretches</td>
</tr>
<tr>
<td>7:00am</td>
<td>Breakfast</td>
</tr>
<tr>
<td>8:00am</td>
<td>Workout with Trainer</td>
</tr>
<tr>
<td>9:00am</td>
<td></td>
</tr>
<tr>
<td>10:00am</td>
<td>Support Group Meeting</td>
</tr>
<tr>
<td>11:00am</td>
<td></td>
</tr>
<tr>
<td>12:00pm</td>
<td>Lunch with newly diagnosed patient</td>
</tr>
<tr>
<td>1:00pm</td>
<td></td>
</tr>
<tr>
<td>2:00pm</td>
<td>Conference Call</td>
</tr>
<tr>
<td>3:00pm</td>
<td>Doctor’s appointment</td>
</tr>
<tr>
<td>4:00pm</td>
<td>Errands on way home</td>
</tr>
<tr>
<td>5:00pm</td>
<td></td>
</tr>
<tr>
<td>6:00pm</td>
<td>Dinner</td>
</tr>
<tr>
<td>7:00pm</td>
<td>Personal time</td>
</tr>
<tr>
<td>8:00pm</td>
<td>Read and try to relax</td>
</tr>
<tr>
<td>9:00pm</td>
<td>Bed</td>
</tr>
</tbody>
</table>
In Conclusion

• PD is a very complex disease and the non-motor symptoms add much of that complexity---especially to us as patients.

• For each person, these symptoms appear and progress at differing rates at differing stages in the disease so the complexity of the disease increases exponentially and differently for each of us.

• The result is that each PWP needs a complicated and ever-changing support system to maximize their quality of life at every stage of the disease.

• When you see a PD patient, think about an iceberg – and the 90% of efforts you do not see that are required to keep him or her afloat.

Thank you for Your Commitment!