#### LIVING WELL WITH

## PARKINSON'S DISEASE

An In Home Caregiver's Checklist









#### We are more than our disease...

And yet many home care plans focus only on our medical needs.

Total wellness can be achieved, but only by taking care of the whole person, and not just a single part. This holistic approach places equal emphasis on the physical, environmental, and social needs of the patient, encouraging purpose and independence in the process.

Living well with a chronic disease can be vibrant, purposeful, and full of strength, leading to a reduction in hospital visits and relapses.

Our Total Wellness Checklist uses this interconnected model to guide families, empower patients, and unify health care providers.

#### Parkinson's Disease Overview:

Parkinson's disease is a degenerative disorder of the nerve cells in the brain which impairs muscle coordination and causes tremors. It is currently the second most common neurological degenerative disorder, after Alzheimer's disease. It affects an estimated 1.5% of the US population over the age of 65, and more than 4 million individuals over the age of 50 worldwide, a number expected to double by the year 2030.

In the normal brain, specific nerve cells produce the chemical dopamine, which transmit signals within the mid-brain to produce smooth movement of muscles. In Parkinson's patients dopamine-producing cells are slowly destroyed. This causes the nerve cells to fire wildly, leaving patients unable to control their muscle function. A diagnosis is made based primarily on medical history and a physical examination.

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# OUR TOTAL WELLNESS APPROACH TO HOME BASED CARE FOSTERS INDEPENDENCE, EMPHASIZING BETTER HEALTH IN FOUR KEY AREAS:



# NO. 1 PHYSICAL

The care giving team focuses on items such as checking vital signs, medication management, nutrition, exercise, and skin care.



# NO. 2 **ENVIRONMENTAL**

The care giving team focuses on items such as fall risk assessments, home modifications, mobility, stress triggers, housekeeping, and family support.



# NO. 3 PURPOSE & INDEPENDENCE

The care giving team focuses on items such as education, self-management, preservation of legacy, depression, transportation, personal history documentation, & mental stimulation.



# NO. 4 **SOCIAL ENRICHMENT**

The care giving team encourages social enrichment and removes potential barriers to isolation. Social interactions add purpose and reduce the risk of depression.



The care giving team focuses on items such as checking vital signs, medication management, nutrition, exercise, and skin care.

(Always check with your physician before changing medication, exercise routines, etc.

#### A. GENERAL

- O Check vital signs on a regular basis at the same time and conditions, and document these, keeping an eye out for irregularities
- Assess and manage discomfort such as dry eyes and muscle cramps
- O Assess for adequate sleep and ensure safety
- Bowel constipation is common for Parkinson's patients. Address it with diet, fluids, exercise, and/or medication
- Muscle rigidity is common and can decrease motion and increase pain

#### **B. NUTRITION**

- The patient may have trouble swallowing, which can increase the risk of choking and aspiration. Adjust the diet texture accordingly
- O Maintain bone health with daily intakes of 1500 mg of calcium and 800 IU of vitamin D
- O Balance medications with food, since they can cause nausea and poor appetite
- Adjust nutritional priorities as the disease progresses through the five stages

#### C. EXERCISE

- Exercise is encouraged for all Parkinson's patients
- O Consistent exercise will help maintain bone density, flexibility, and ease constipation
- Most patients will benefit from some form of rehabilitative therapy
- Address any barriers to exercise, i.e., pain and muscle rigidity



The care giving team focuses on items such as fall risk assessments, home modifications, mobility, stress triggers, housekeeping, and family support.

#### A. ASSESSMENTS

- O Conduct a fall risk assessment, including the patient's stability when standing, as this can be impacted
- Assess the patient for driving safety, looking for slow reactions, poor muscle control, and a decrease in cognitive processing
- O Conduct a home safety assessment, paying attention to obstacles, tripping hazards, and clutter

#### **B. MODIFICATIONS**

- Make sure floors are not slippery and remove throw rugs as they can be a fall risk
- O Temperature sensitivity may result in excess sweating or hot flashes. Provide ventilation or a fan.
- O Prominently display calming décor, including family pictures, warm lighting, and familiar items
- O There are many technological programs that can enable the patient to use a computer

#### C. FAMILY & COMMUNITY SUPPORT

- What family or friends will be available to assist with care?
- O What tasks will they each do? Create a schedule of support
- What community resources are available to supplement support from family and friends?



The care giving team focuses on items such as education, self-management, preservation of legacy, mental stimulation, depression, personal history documentation, and transportation.

#### A. MENTAL TASKS

- Be aware of decreased problem solving skills, difficulty making plans, setting goals, or understanding concepts, identifying techniques to supplement
- Learning new information will be difficult, identify how to best aid this
- O Identify the need for counseling or participation in a support group

#### **B. PHYSICAL TASKS**

- O Is transportation needed?
- O Encourage patients to help with tasks they are able to perform, such as folding laundry and writing a grocery list
- O Join the patient in playing a game, going shopping, or taking a walk together after lunch
- O Due to the tremors, performing tasks may take longer or be less accurate. Allow for adequate time and rest breaks

#### C. LEGACY

- O Has the patient prepared a living will, advanced directives, and set up power of attorney documents if needed?
- O Are there family relationships that need to be mended?
- O Has the patient financially prepared for their future care?
- O Work with the patient to document special lifetime memories

#### D. EDUCATION

- O Check for understanding from the family caregivers and patient about the disease process and terms
- O Sign up for the Northwest Parkinson's Foundation Newsletter at www.nwpf.org
- O The National Parkinson Foundation hotline provides access to information specialists to ask questions, order publications, and find support groups: 1-800-4PD-INFO
- O The American Parkinson Disease Association (www.apdaparkinson.org) and the Boston National Resource Center (888-606-1688) also provide phone and online support services

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The care giving team encourages social enrichment and removes potential barriers to isolation. Social interactions add purpose and reduce the risk of depression.

- O Recognize that a mask like expression is due to rigid facial muscles and may not indicate a true picture of feelings
- Assist with personal care and grooming, including a plan for incontinence care, in order to maintain dignity
- Are there barriers to the patient wanting to pursue social activities, such as embarrassment or fatigue? Can these barriers be overcome with assistance?
- O Recognize that the loss of mobility becomes an important factor in the patient's quality of life
- O Talk with the patient to determine past interests that could be incorporated into their day with special modifications
- O Encourage social engagement within the Parkinson's community if appropriate. Check www.nwpf.org for a list of activities

I Have Parkinson's Disease		
NAME		
DATE OF BIRTH	BLOOD PRESSURE	WEIGHT
KNOWN ALLERGIES		
PRIMARY MEDICATIONS		

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We take care of our clients like we would our own family members, no exceptions. Whether the solution is home care, care management, or a senior housing community, living well is possible and Fedelta can help you get there.

## SPECIAL CARE FOR YOUR UNIQUE NEEDS

- Individual goal setting and motivation
- Disease specific care plans
- Personality based caregiver matching
- Family caregiver training

#### **HOW WE CAN HELP**

- A Personal Care Manager assigned to every new client
- An extensive local team of nurses and caregivers
- Coordination of all care related activities
- Advocacy with medical professionals
- On-going advice & support



NWPF is the only independent regional Parkinson's organization serving the entire Northwest region. NWPF aims to establish optimal quality of life for the Parkinson's community through awareness, education, advocacy, and care. NWPF helps the Parkinson's community continue to Move, Connect and Engage.

#### MOVE

- · Dance for PD
- Yoga for Parkinson's
- · Choir for Parkinson's

#### CONNECT

- PD Link Northwest, a peer-to-peer support network
- Support Group listings and referrals
- Regional educational conferences

#### **ENGAGE**

- Email news updates and a tri-annual newsletter
- Educational speakers, forums and webinars
- Lending Library with many multimedia resources



This educational booklet is brought to you by a collaboration between Fedelta Care Solutions & the Northwest Parkinson's Foundation.





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