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Movement Disorders Program



# Progression in Care

OPTIONS FOR CARE AS PARKINSON'S DISEASE  
PROGRESSES

# Learning Objectives

1. Identify five stages of Parkinson's.
2. Learn about a variety of resources for people with Parkinson's and their care partners throughout the stages of the disease.
3. Explore practical suggestions and solutions to help promote positive outcomes for the PD family.
4. Understand the issues and challenges commonly faced by care partners and families affected by Parkinson's disease.

# The Parkinson's Foundation: Parkinson's broken into 5 stages.

	Early PD		Mid-stage PD	Advanced PD	
Stage of Parkinson's Disease	1	2	3	4	5
<b>Severity of Symptoms</b>	<b>MILD</b> Symptoms of PD are mild and only seen on one side of the body (unilateral involvement)	<b>MILD</b> Symptoms of PD on both sides of the body (bilateral involvement) or at the midline	<b>MODERATE</b> Symptoms of PD are characterized by loss of balance and slowness of movement	<b>SEVERE</b> Symptoms of PD are severely disabling	<b>SEVERE</b> Symptoms of PD are severe and are characterized by an inability to rise
	<b>SYMPTOMS</b> Tremor of one hand Rigidity Clumsy Leg One side of the face may be affected, impacting the expression	<b>SYMPTOMS</b> Loss of facial expression on both sides Decreased blinking Speech abnormalities Rigidity of the muscles in the trunk	<b>SYMPTOMS</b> Balance is compromised Inability to make the rapid, automatic and involuntary adjustments All other symptoms of PD are present	<b>SYMPTOMS</b> Patients may be able to walk and stand unassisted, but they are noticeably incapacitated Patient is unable to live an independent life and needs assistance	<b>SYMPTOMS</b> Patients fall when standing or turning May freeze or stumble when walking Hallucinations or delusions.



ParkinsonsDisease.net / Stages of Parkinson's Disease

# Stage 1

- ▶ During this initial stage, the person has mild symptoms that generally do not interfere with daily activities. Tremor and other movement symptoms occur on one side of the body only. Changes in posture, walking, and facial expressions occur.
- ▶ May have non motor symptoms such as depression, anxiety, sleep problems, and loss of smell.

# Education!!!

Newly diagnosed workshop

Parkinson's Foundation

MJ Fox Foundation

Brian Grant Foundation

Parkinson's Resources of Oregon

Davis Phinney Foundation

PD exercise groups

Support groups

TEAM!! – Neurologist, RN, PT, OT, SLP, PhD, MSW

# Tips for Talking To Kids

- ▶ If you have more than one child, initially talk to them separately.
- ▶ Provide education. Allay fears.
- ▶ Empower them. Maintain interests.
  
- ▶ *How to Help Children Through a Parent's Serious Illness by Kathleen McCue*
- ▶ <https://parkinson.org/pd-library/books/Helping-Children-Cope-with-Parkinsons>

# Employment

- ▶ Personal Choice
- ▶ ADA Protection
- ▶ Reasonable Accommodations -“any modification or adjustment to a job or the work environment that will enable a qualified applicant or employee with a disability to participate in the application process or to perform essential job functions.”
- ▶ Job Accommodation Network (1-800-526-7234)



# Telling Others

- ▶ There is no right or wrong way.
- ▶ Consider asking for what you need/want from others.
- ▶ You're in control. Share at the pace you feel comfortable.
- ▶ Helpful to come to terms with diagnosis. Counseling support can be beneficial.
- ▶ Invite others to learning opportunities.
- ▶ Educate as you share.

# Stage 2

- ▶ Still early. Symptoms start getting worse. Tremor, rigidity, and other movement symptoms affect both sides of the body. Walking problems and poor posture may be apparent. This person can still live alone, but daily tasks are more difficult and lengthy.

# 1. Legal and financial planning

- ▶ Disability planning
- ▶ Trusts
- ▶ Elder Care Attorney-Gifting, Medicaid planning, Trust funds
- ▶ Advance Directives
- ▶ POA

# Considerations

Know your team

Exercise regime

Counseling

Care partners increase activities

Motivation

Medication management

Care partners to take care of their well-being

# Stage 3

- ▶ Considered mid stage, loss of balance and slowness of movements are hallmarks. Falls are more common. The person is still fully independent, but symptoms significantly impair activities such as dressing and eating.

# Need for resources expand

- ▶ Life alert
- ▶ House keeping
- ▶ Meal prep
- ▶ Save energy for things that are more enjoyable
- ▶ Independent Living Facilities/Retirement communities
- ▶ Care partners to consider hiring help to offset extra duties

# Types of Home Assistance

- ▶ Home Health
  - ▶ Ordered by PCP, neurologist, or other provider
  - ▶ Home bound
  - ▶ 6 weeks, covered by MCR/insurance
  - ▶ PT,OT, SLP, RN, bath aide, MSW
- ▶ Home Care
  - ▶ Private pay/Medicaid/LTC insurance/VA
  - ▶ ADL's
  - ▶ Companionship
  - ▶ Light house keeping

# Stage 4

- ▶ At this point, symptoms are severe and limiting. It's possible to stand without assistance, but movement may require a walker. The person needs help with activities of daily living and is unable to live alone.



# Safe Living

- ▶ In home care
- ▶ Adult day care
- ▶ Assisted Living
- ▶ Home modifications

# Utilizing Care Givers

- ▶ Shopping
- ▶ Cleaning
- ▶ Meal Prep
- ▶ Exercise routine
- ▶ Walks
- ▶ Transportation
- ▶ Bathing
- ▶ Companionship
- ▶ Dressing
- ▶ Sleep/night time bathroom

# Financial Qualifications for Long Term Care

- ▶ Income and Asset Limit
  - ▶ Single: Income-\$2313 per month or Asset limit \$2,000
  - ▶ Married-both applying: Income: \$4626 per month Asset Limit: \$4000
  - ▶ Married-one applicant: Income- \$2313 for applicant, \$3160.50 for non-applicant. Asset Limit-\$2000 for applicant, \$126,420 for non-applicant.
  - ▶ Exemptions- Car. House if living in house or if you have a subjective intent to return home. Special needs trust.
  - ▶ 5 year look back –cannot have given money away to qualify.
  - ▶ \$167.00 to keep if living in a facility.
  - ▶ Income Caps Trust.

2019 Oregon Medicaid Long Term Care Eligibility for Seniors – American Council on Aging  
<https://www.medicaidplanningassistance.org/medicaid-eligibility-oregon>

Type of Medicaid	Single			Married (both spouses applying)			Married (one spouse applying)		
	Income Limit	Asset Limit	Level of Care Required	Income Limit	Asset Limit	Level of Care Required	Income Limit	Asset Limit	Level of Care Required
Institutional / Nursing Home Medicaid	\$2,313 / month	\$2,000	Nursing Home	\$4,626 / month	\$4,000	Nursing Home	\$2,313 / month for applicant	\$2,000 for applicant & \$126,420 for non-applicant	Nursing Home
Medicaid Waivers / Home and Community Based Services	\$2,313 / month	\$2,000	Nursing Home	\$4,626 / month	\$4,000	Nursing Home	\$2,313 / month for applicant	\$2,000 for applicant & \$126,420 for non-applicant	Nursing Home
Regular Medicaid / Aged Blind and Disabled	\$771 / month	\$2,000	None	\$1,157 / month	\$3,000	None	\$771 / month	2,000	None

# Medical Necessity for Medicaid

- ▶ ADL's
  - ▶ Dressing
  - ▶ Toileting/personal hygiene
  - ▶ Transferring/mobility
  - ▶ Continence
  - ▶ Eating/Feeding oneself

# Stage 5

- ▶ This is the most advanced and debilitating stage. Stiffness in the legs may make it impossible to stand or walk. The person requires a wheelchair or is bedridden. Around the clock nursing care is required for all activities. The person may experience hallucinations and delusions. There are many motor and non-motor symptoms.

# Care

- ▶ Home Health/Palliative Care/Hospice
- ▶ Home care
- ▶ Nursing homes
- ▶ Memory care
- ▶ Respite
- ▶ Adult day care
- ▶ Care partner counseling

# Barriers to accepting care

- ▶ Finances
- ▶ Guilt
- ▶ Having someone in the home
- ▶ “I can do it!”
- ▶ Hard to pinpoint timing of care
- ▶ Not knowing how to utilize care
- ▶ Trust and reputation
- ▶ Stigma
- ▶ Shame
- ▶ Control



The background is a solid teal color. There are several decorative elements: a red vertical rectangle in the top right corner, a large teal circle in the bottom left, a medium teal circle in the middle right, and a small teal circle in the top right. The text is centered in the middle of the slide.

Thoughts?  
Questions?