



OHSU
PARKINSON
CENTER

ESSENTIAL TOOLS

Parkinson's Team Care:

WHO, WHEN, WHY

LISA MANN, RN, BSN, MA

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NATIONAL PARKINSON[®]
FOUNDATION

Questions to be answered...

- **Why do I need a Healthcare TEAM ?**
- **Who should be on my PD TEAM?**
- **What can the PD TEAM do?**
- **When do I need my PD TEAM?**
- **How do I build my PD TEAM?**



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Why a Healthcare TEAM for PD?

- **Reality of medicine today**
 - Complex, expensive, fragmented
- **Parkinson's disease challenges**
 - Complex disease
- **Holistic approach beneficial**
- **EMPOWERMENT**



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Who should be on my PD TEAM ?

The obvious...

YOU and family carepartner



- Primary Care Physician
- Parkinson's disease:
 - Neurologist
 - Movement Disorders Specialist
- **PLUS....?**

Who should be on my PD TEAM ?

- **Allied Health Therapists:**
 - **Nurse**
 - **Social Worker**
 - **Occupational Therapist**
 - **Speech Language Pathologist**
 - **Physical Therapist**
 - **Dietitian**
 - **Pharmacist**
 - **Counselor-Psychologist-Psychiatrist**



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PD Symptoms: Motor

- Tremor
- Cramped handwriting
- Masked fascies
- Speech
- Swallowing
- Rigidity
- Slowness
- Gait & balance

Occupational
Therapist

Speech Language
Pathologist

Physical
Therapist

Secondary “Non-Motor” Symptoms & Therapy Complications

- Low blood pressure
- Bladder & bowel
- Nausea, weight loss
- Sleep disturbances
- Pain
- Fatigue
- Shortness of breath
- Senses affected
- Skin irritation

- Thermoregulatory disturbances
- Depression
- Anxiety
- Hallucinations/delusions
- Cognitive changes, dementia

- Stress
- Freezing, off cycles
- Complex med regimens
- Environment challenges

PD Symptoms: Non-Motor & Complications

Occupational Therapist

- Low BP
- Pain
- Fatigue
- Stress/anxiety
- Incontinence issues
- Memory changes
- Med management systems

Speech Language Pathologist

- Breath support
- Memory changes
- Swallowing eval
- Communication tools

Physical Therapist

- Low BP
- Pain
- Fatigue
- Freezing
- Safety
- Exercise
- Balance
- Mobility

PD NURSE

- **Education for patient & carepartner**
- **Patient advocate**
- **Physician contact**
- **Medication information**
- **Medication management**
- **Referrals support**
- **Team care coordination**



SOCIAL WORKER



- Education
- Carepartner / family support
- Employment
- Social Security disability
- Legal-financial planning
- Financial assistance
- Community resources

Area Agencies on Aging
Seniors & People with
Disabilities
(541) 682-4038



www.adrcoforegon.org

Other Team Members

- **Urologist**
- **Gastroenterologist**
- **Dietitian**
- **Hospital staff**
- **Dentist**
- **Elder Care Law Attorney**
- **Community Organizations**



Parkinson's Resources of Oregon, Brian
Foundation, Alzheimer's Association

Educate – Advocate

You may need to educate them....

- **Materials:**
 - Parkinson's Foundation
 - Aware in Care kit
- **Advocates**
- **Connect with PD specialist / nurse**

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What can a PD TEAM offer at different stages of Parkinson's disease?



Occupational Therapist	<ul style="list-style-type: none"> • Education • Promote socialization, interaction • Wellness maintenance (e.g. exercise) • Coping & problem solving skills for functional changes • Energy and endurance optimization • Safety risk training • Community mobility (e.g. driving, transportation) 	<ul style="list-style-type: none"> • Carepartner instruction • IADL independence • Managing community interaction • Understand/adjust for balance • Home safety • Low vision adaptation 	<ul style="list-style-type: none"> • ADLs (patient → carepartner) • Low vision techniques • Incontinence training • Sensory, perceptual cues for <ul style="list-style-type: none"> ◦ Maintaining orientation ◦ Verifying reality • Self-image adaptation
Speech Therapist	<ul style="list-style-type: none"> • Education • THINK LOUD : SHOUT • Lee Silverman Voice Therapy (LSVT) • Voice care • Facial and voice exercises • Communication evaluation 	<ul style="list-style-type: none"> • Carepartner instruction • Communication management • Cognition & memory assessment • Swallowing assessment • Adaptive equipment (e.g. ChatterVOX) 	<ul style="list-style-type: none"> • Cognition / memory adaptations • Swallowing management • Dietary modifications • Adaptive communication tools
Physical Therapist	<ul style="list-style-type: none"> • Education • THINK BIG (exaggeration of movement) • Postural awareness & alignment <ul style="list-style-type: none"> ◦ spinal flexibility; core strength; visual feedback; correlation with voice/ respiratory function • Gait pattern correction • Balance safety awareness • Pain control & stress reduction • EXERCISE & Activity 	<ul style="list-style-type: none"> • Carepartner instruction • Freezing / cueing strategies • Fall prevention • Environmental modification • Exercise/activity modification • Assistive devices, adaptive equipment 	<ul style="list-style-type: none"> • Positioning, seating systems • Assisted movement • Pain control • Adaptive equipment • Mechanical lifts • Caregiver body mechanics
Social Worker	<p>Education Carepartner / family support Community programs and resources Employment and Social Security Disability</p> <ul style="list-style-type: none"> • Disclosing the diagnosis • Considerations in continuing to work • When and how to apply for disability <p>Legal and Financial Planning</p> <ul style="list-style-type: none"> • Advanced directives for people with PD • Power of Attorney for Healthcare and Financiers • Personal financial considerations 		<p>Financial Assistance</p> <ul style="list-style-type: none"> • Insurance Options • Medicare/Medicaid • Paying for prescription drugs <p>Carepartner support</p> <ul style="list-style-type: none"> • In home care resources • Housing transitions (e.g. assisted living) • Respite
Nurse	<ul style="list-style-type: none"> • Education for patient & carepartner • Patient advocate • Physician contact • Medication information 		<ul style="list-style-type: none"> • Medication management • Referrals support • Team care coordination

WHEN do I need my PD Team? And how often?

- **Baseline**
- **Disease education**
- **New symptoms**
- **New goals**
- **Worsening of symptoms**
- **Safety, home adaptation**
- **Increasing dependence**
- **Caregiver training or stress**



Allied Health Team Questions: HAVE YOU EVER EXPERIENCED...?

If you answer “yes” to any of the questions below, you should ask your physician for a referral for occupational, physical, or speech therapy.

Occupational Therapy Questions:

- Trouble “getting started” in the morning?
- Trouble with zippers or buttons?
- Not able to stand up from the toilet?
- Trouble figuring out which way a shirt goes on?
- Difficulty telling how far down a step is from your foot?
- Problems writing out a check because your handwriting has changed?
- Not enough energy to get through the day?

Physical Therapy Questions:

- A fall, near falls or stumbling?
- Problems going up or down stairs?
- Difficulty turning around or turning corners while walking?
- Difficulty standing up from a chair or getting out of bed?
- Stiffness and you don’t know how to stretch?
- Need new equipment (walker or wheelchair) and don’t know where to start?
- Increased stress and unable to relax?
- Pain in your back or shoulders?

Speech-Language Pathology Questions:

- People having difficulty understanding/hearing you?
- Have the word on the ‘tip of your tongue’ without being able to find it?
- Difficulty remembering details of daily routine, conversations, etc?
- Easily distracted; Short attention span, etc?
- Trouble with swallowing?

Interdisciplinary Questions

- Concerns with maintaining employment?
- Questions about care-partner safety or burn-out?
- Questions about changes in your home for safety?

Overwhelmed? Prioritize

Ask your self:

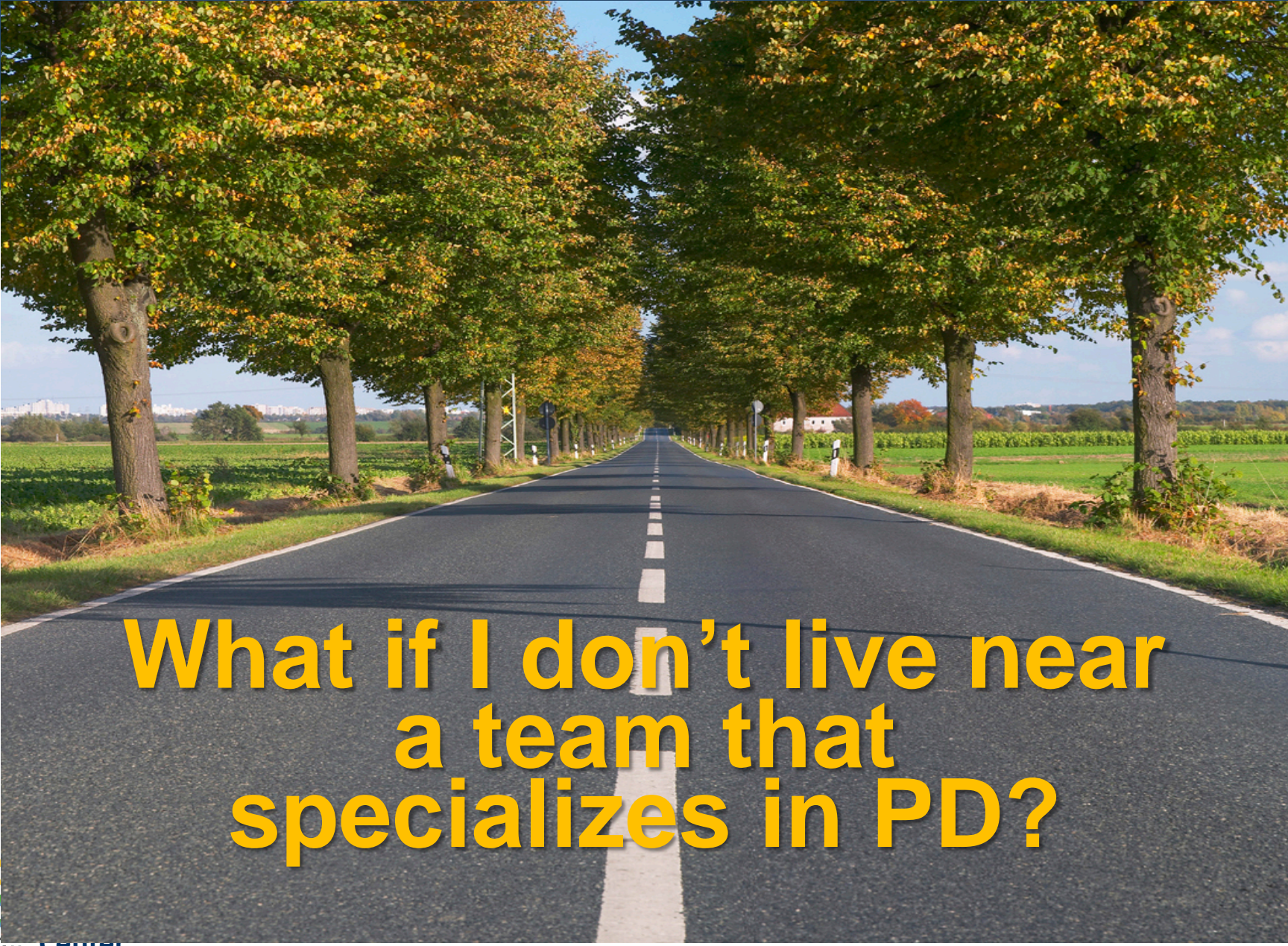
- **Quality of life goals**
 - Maintain maximum function
 - Maintain independence
 - Maintain connections
 - Share burden

CARE PARTNERS TOO!

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**What if I don't live near
a team that
specializes in PD?**

Take Charge: Simply Ask

- **Request referrals** from PCP
- OHSU Comprehensive Neuro Rehab Team (CNRT) Evaluation – PT, OT, ST
- **Local community rehab teams:**
 - Outpatient NEURO Rehab Team
 - Ask about PD experience
 - Advocate for PD experience

How do I coordinate care & advocate for communication?

- **MyChart**
- **CareEverywhere**
- **Request / share other providers' notes**
- **Request HCP to HCP call**
- **If OHSU patient, suggest OHSU Connect**
- **Communicate goals in advance**
- **Focus requests**



Take charge of your health You are **EMPOWERED!**

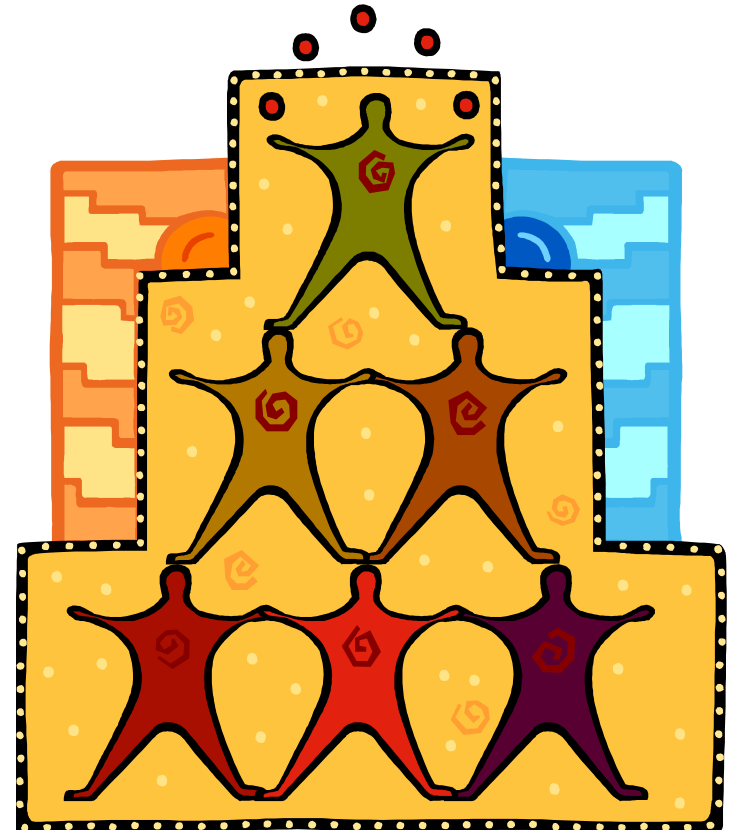
You can change impact of
disease through your own
actions and attitude:

ACTIVELY and
PROACTIVELY
participate in care

Take Home Points: You + TEAM

Meet your GOALS for improved quality of life Through a TEAM approach

- Promote health
- Maintain function
- Adjust to change
- Prepare for and change your future



Thank you!

Lisa Mann, RN, BSN, MA

503-494-5620 - mannli@ohsu.edu