ESSENTIAL TOOLS
Parkinson’s Team Care:
WHO, WHEN, WHY

LISA MANN, RN, BSN, MA
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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
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?
<table>
<thead>
<tr>
<th>Occupational Therapist</th>
<th>Speech Therapist</th>
<th>Physical Therapist</th>
<th>Social Worker</th>
<th>Nurse</th>
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</thead>
<tbody>
<tr>
<td>• Education</td>
<td>• Education</td>
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<td>Education</td>
<td>• Education for patient &amp; carepartner</td>
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<td>• Promote socialization, interaction</td>
<td>• THINK LOUD : SHOUT</td>
<td>• THINK BIG (exaggeration of movement)</td>
<td>Carepartner / family support</td>
<td>Patient advocate</td>
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<td>• Wellness maintenance (e.g. exercise)</td>
<td>• Lee Silverman Voice Therapy (LSVT)</td>
<td>• Postural awareness &amp; alignment</td>
<td>Community programs and resources</td>
<td>Physician contact</td>
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<td>• Coping &amp; problem solving skills for functional changes</td>
<td>• Voice care</td>
<td>• spinal flexibility; core strength; visual feedback; correlation with voice/respiratory function</td>
<td>Employment and Social Security Disability</td>
<td>Medication information</td>
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<td>• Energy and endurance optimization</td>
<td>• Facial care</td>
<td>• Gait pattern correction</td>
<td>Disclosing the diagnosis</td>
<td>• Medication management</td>
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<td>• Safety risk training</td>
<td>• Voice exercises</td>
<td>• Balance safety awareness</td>
<td>Considerations in continuing to work</td>
<td>Referrals support</td>
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<td>• Community risk training</td>
<td>• Communication evaluation</td>
<td>• Pain control &amp; stress reduction</td>
<td>When and how to apply for disability</td>
<td>Team care coordination</td>
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<td>• ADLs (patient → caregiver)</td>
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<td>• EXERCISE &amp; Activity</td>
<td>Legal and Financial Planning</td>
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<td>• Carepartner instruction</td>
<td>• Carepartner instruction</td>
<td>• Advanced directives for people with PD</td>
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<td>• IADL independence</td>
<td>• Communication management</td>
<td>• Power of Attorney for Healthcare and Financiers</td>
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<td>• Managing community interaction</td>
<td>• Cognition &amp; memory assessment</td>
<td>• Personal financial considerations</td>
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<td>• Understand/adjust for balance</td>
<td>• Swallowing assessment</td>
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<td>• Home safety</td>
<td>• Adaptive equipment (e.g. ChatterVOX)</td>
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<td>• Low vision adaptation</td>
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<td>Positioning, seating systems</td>
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<td>• Assisted movement</td>
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<td>• Adaptive equipment</td>
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<td>• Mechanical lifts</td>
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<td>• Caregiver body mechanics</td>
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<td>Financial Assistance</td>
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<td>• Insurance Options</td>
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<td>• Medicare/Medicaid</td>
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<td>• Paying for prescription drugs</td>
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<td>Carepartner support</td>
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<td>• In home care resources</td>
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<td>• Housing transitions (e.g. assisted living)</td>
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<td>• Respite</td>
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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!

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