

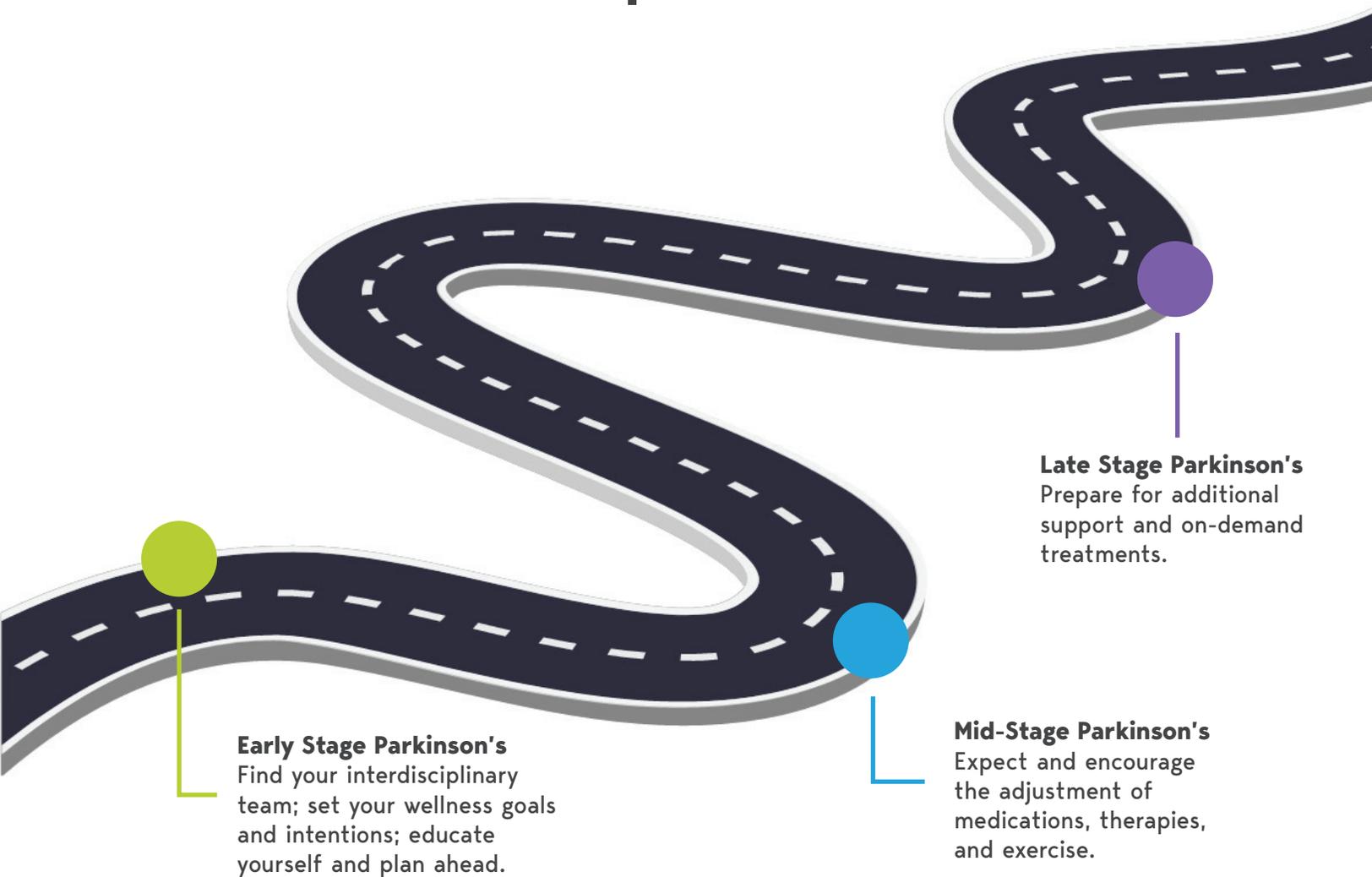
# Road Map to *Care*

Planning for Your Loved One's Needs  
at Each Stage of the Disease

**Care partners need support.** In a survey, it was found that **caregivers average 46.7 hours of caregiving a week** (44% are doing 49 or more hours a week). **86% say caregiving has had a negative impact** on their physical and emotional health. To support you along the way, consider support groups, counseling, and respite services<sup>1</sup>.

Caregiving tasks are centered on providing emotional support, managing healthcare appointments and advocating for your loved one, administering medications, managing budget/finances, and assisting with mobility and daily care.

## Road Map at a Glance



**Read on for more information** on what to expect, seek out, and plan for on your journey with PD.

# Early Stage Parkinson's

## Motor Symptoms

- » Mild and present on one side of the body (unilateral), such as tremor
- » Slow movements (bradykinesia)
- » Rigidity of muscles—loss of arm swing
- » Might notice decrease in facial expression,
- » Gait changes such as slower, shorter steps

\*Note: postural instability is not common in early stages and could indicate the need for further evaluation.

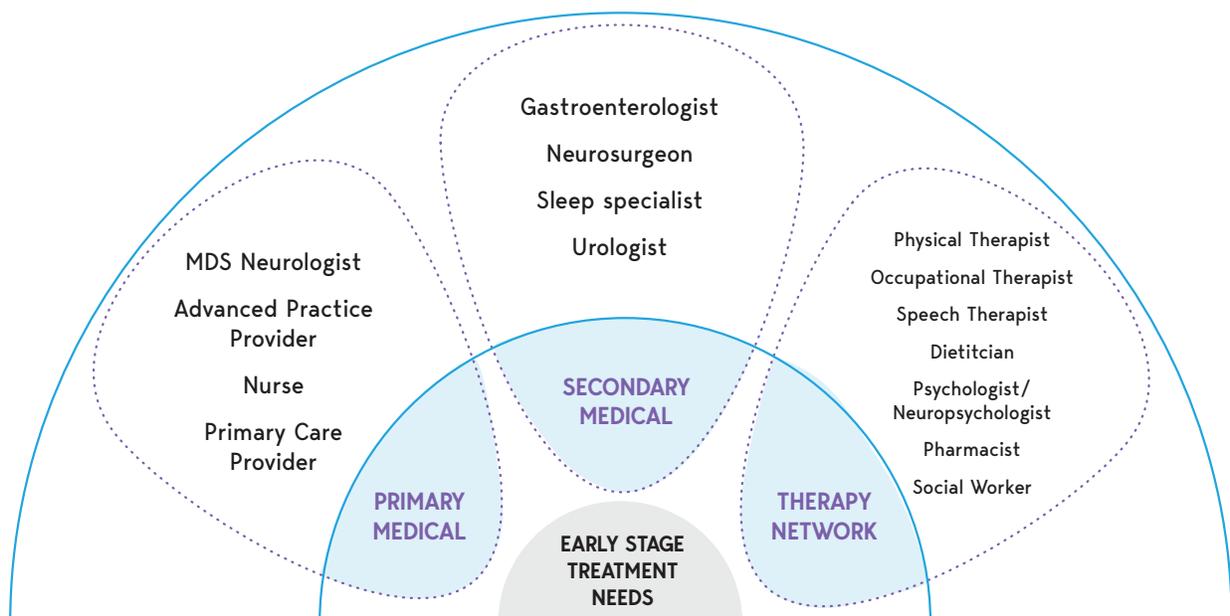
## Non-Motor Symptoms

- » Loss of sense smell
- » Constipation
- » Depression/Anxiety
- » Acting out dreams (REM Sleep Behavior Disorder)

\*Note: major cognitive deficits should not appear in early stages within a year from motor-symptom onset. If present, it indicates further evaluation is needed.

## Early Stage Treatment Needs

- » A comprehensive evaluation by a movement disorder specialist and interdisciplinary team.
- » Evaluation by a physical and speech therapist to address any changes or concerns and set quality of life (QOL) goals.
- » Identify value-based quality of life goals.
- » Timing and medication choice are dependent on age and symptom severity.
- » Medications work well and disease may have little impact on daily life.
- » Treatment of non-motor symptoms such as sleep disturbance, constipation and depression are important as these can have an impact on QOL.
- » Care goal: restorative/pre-habilitative (before symptoms become a problem).



## Early Stage: What to Do

- Seek education from reliable sources** such as PMD Alliance, Michael J Fox Foundation, Parkinson Foundation.
- Seek caregiving education** early to prevent complications and misinformation.
- Discuss what quality of life means to you** with your loved one and your physician. What do you want to continue doing (what brings you joy)? Set treatment goals to achieve it. (Medications and therapy approach should be part of this discussion.)
- Determine if or what you are ready to tell others.** This is a personal decision and dependent on your situation, i.e. if you are still working. Many people continue to work for years.
- Consider lifestyle modifications:** change of diet and exercise can have a profound impact.
- Address mood issues** as they impact QOL in you or your loved one.
- Support is key:** consider joining a support group.
- Consider financial interventions/planning for later care needs.** Will you be aging in place?
- Prepare advance directives:** These discussions may be difficult, but don't wait until you need them!

**This is the time for understanding the journey ahead and assessing what you can put in place now to make the road less bumpy later.**

## Mid-Stage Parkinson's

### Motor Symptoms

- » Moderate symptoms affecting both sides (bilateral)
- » Increased slowness (bradykinesia) with tasks taking much longer
- » Experience of dystonia (involuntary muscle contractions) during OFF periods which may cause pain, during peak dose or both during on/off (diphasic)
- » More problems with balance standing and walking, shuffling steps and freezing of gait (FOG). Increased fall risk.
- » Assistance needed with some activities of daily living (ADLs).
- » Noticeable fluctuations in motor symptoms with shorter ON time. Development of dyskinesia (dance-like involuntary movements associated with long-term use of Levodopa).
- » Still independent with most ADLs

\*Note: This is for information and not everyone may experience these symptoms

### Non-Motor Symptoms

- » Cognitive changes: some changes in memory, slowness of processing, and decision-making.
- » Anxiety and mood issues more pronounced, which can also fluctuate like motor symptoms. Can include panic attacks.
- » Apathy
- » Sleep issues more pronounced, including REM Sleep behavior disorder, insomnia, sleep apnea, and vivid dreams.
- » Fatigue/daytime sleepiness
- » Communication changes: softer, hoarse voice
- » Impulse control disorders (can be related to medications) such as gambling, shopping, eating, and hypersexuality (may be more pronounced in younger onsets).
- » Beginnings of hallucinations: sense of presence and illusion (feeling someone is in the room, mistaking objects for something else, ie. a sock looks like a mouse).
- » Erectile/urinary dysfunction
- » Low blood pressure-neurogenic orthostatic hypotension can cause falls.

**Aging in place or need to downsize? If you haven't already addressed this, now is the time. If you haven't completed advance directives, consider meeting with an elder law attorney.**

## Mid-Stage Treatment Needs

- » Use of add-on therapies for wearing OFF
- » Medications to treat depression, anxiety, and sleep
- » Evaluation of cognition
- » Other interdisciplinary team members activated, such as sleep specialists, GI, urologist, neuropsychologist
- » Therapy to address gait changes, balance, speech/swallow challenges, issues like urinary concerns through pelvic floor rehab.

## Mid-Stage: What to Do

- Care is rehabilitative** and maintenance.
- Exercise-rehab-exercise.** Move it or lose it!
- Maintain or obtain new interests.** Focus on the things your loved one can do and stay as active and engaged as possible. Socialization is important.
- Use of safety aides** may be needed at times
- Track symptoms** and address motor/non-motor symptoms early: communication with the physician/health care team is very important! Don't be afraid to speak up.
- Ask for physical and occupational therapy** if it hasn't been recommended. Be proactive.
- Speech therapy to address low volume.** This requires daily practice.
- Expect and encourage the use of multiple medications** to manage symptoms. There are many great medications to address symptoms. Learn about them and advocate for them!
- Medication management is key;** on time, every time. Make sure you keep a list of ALL meds and a journal of symptom fluctuations. Non-motor symptoms also fluctuate with motor symptoms. Maintain pill box, alarm reminders, consider automated pill dispenser.
- Look for signs of swallowing problems** (coughing, clearing throat, wet sounding speech). If you haven't already, have a speech therapist evaluate for swallowing changes.
- Look for signs of symptoms of UTI** (pain isn't always present and signs are usually not physical. Look for sudden changes in cognition).
- Reduce expectations of your loved one:** physical abilities are less predictable. ON/OFF is more of a challenge and fatigue is a big issue. Seek out help for depression if you have not already.
- Look for signs of cognitive changes** (such as slow processing).
- Address driving concerns.**
- Consider having family and friends regularly spend time with your loved one** so you can have some time for yourself. This gives you a break and provides opportunity to transition to having others aside from you helping.
- Let the PwP do as much as possible!** If they can safely do a task, then let them so they can stay active and reduce tasks you would have to take on.
- Advance care planning.**

# Late Stage Parkinson's

## Motor Symptoms

- » Increased rigidity that affects mobility and swallowing (drooling)
- » Increased dystonia (involuntary muscle contractions)
- » Super OFF/Akinesia (inability to move)
- » Limited mobility: use of walker or wheelchair. Difficulty getting up from chair. advancing to 24/7 assistance.
- » Increased FOG (freezing of gait)/falls.
- » Tremor may lessen at this point.
- » Pain: musculoskeletal, neuropathic, central pain syndrome
- » Severe motor fluctuations/dyskinesia

## Non-Motor Symptoms

- » Fatigue, excessive daytime sleepiness
- » Sleep problems: insomnia, REM Sleep Behavior Disorder, sleep apnea
- » Increased anxiety and depression
- » Increased cognitive changes/dementia/confusion
- » Decreased appetite
- » Possible hallucinations and delusions-lack of insight-risk of behaviors/falls related
- » Increased dysautonomia: low blood pressure/dizziness (OH or nOH), breathlessness, heat/cold intolerance, urinary and GI dysfunction (worsened constipation, delayed gastric emptying, loss of bladder control, urgency, retention)

## Late Stage Treatment Needs

- » Increasing use of on-demand treatments to supplement add-on treatments to minimize OFF time and manage dyskinesia.
- » Interdisciplinary team interventions for complex symptoms such as swallowing concerns, nutritional needs, pain control.
- » In-home therapy
- » Community health management to reduce hospitalizations. Frequent hospitalizations may lead to difficulty managing weight loss/malnutrition, and skin breakdown.
- » Potential need for skilled nursing care (SNF)
- » Additional support through hospice care.

## Late Stage: What to Do

- » **Additional support is needed:** engage either in-home supports or consider Long Term Care (LTC) transition needs. These can include:
  - Home care aides: self-pay or LTC insurance
  - Home health nurses: Medicare/insurance, but short-term
  - Home health therapists: Medicare/insurance, but short term
  - Assisted living facilities (ALF): self-pay or LTC insurance (some Medicaid programs)
  - Nursing Facilities: Medicare for SNF (short term), self-pay, LTC insurance and Medicaid
  - Hospice care: Medicare/insurance. Care moves from restorative to comfort.