

Frequently Asked Questions (FAQ)

What is PD SELF?

PD SELF (the Parkinson's Disease Self Efficacy Learning Forum) is a national program of the Movement Disorders Foundation designed to provide people with Parkinson's (PWP) an in-depth understanding of the disease and self-efficacy tools to manage PD with confidence thereby improving the quality of their life. PD SELF was developed in 2013 by PWP Diane Cook and validated through a clinical trial sponsored by the Colorado Neurological Institute in Denver, CO. The 2020-2021 season will be the seventh continuous year it has been given. It is now in 13 metropolitan areas.

What is Self-Efficacy?

Self-efficacy is a scientifically based approach that helps people with Parkinson's develop the motivation, skills, and knowledge to manage PD. Self-efficacy can be defined as the ability to have influence over the conditions that affect our lives.

What do past participants say about the program?

-- "Parkinson's disease is a most powerful change and you can either run away from it or towards it. PD SELF helps you to embrace it!"

--- "Self-efficacy helps me to focus on what I can do in a realistic way rather than what I cannot do."

-- "Jump in – both feet, full immersion. You will learn so much about yourself, your disease, and opportunities to thrive, even as you are better prepared for adversity."

Who is eligible?

People with Parkinson's disease (PWP) and their care partner who:

- Are newly diagnosed and within 3 years of diagnosis
- Can commit to attending a bi-weekly program over 4 months
- Have access to a computer or tablet with Wi-Fi

Those most likely to benefit from the program:

- Enjoy learning and are interested in improving the quality of their life
- Are able to actively engage in group activities and discussions
- Can commit to attending at least 80% of the 8 sessions
- Have an email and the ability to conduct email correspondence
- Have no limiting co-morbidities (additional illnesses or conditions that might prevent full participation in the program)

How often and when does it meet?

The program has 8 sessions spread over 4 months. Each 1-1/2 hour virtual group session will meet two times a month at a time agreed upon by the local facilitators. In addition, there will be small group meetings as a part of each session where participants will have an opportunity to meet with others in a small group discussion setting as we have found these to be the most effective in cementing the requisite behavioral adjustments that participants find most helpful.

In each local area, if the containment of the corona virus permits, some sessions may be held in person. However, as PWP, we know how much more at risk many of us are, and thus we will err on the side of caution in having any given in-person sessions.

How many people will attend each session?

We are recruiting 30 to 40 newly diagnosed people with Parkinson's and care partners (CPs) for each group. Each will then function as a closed, cohort group. This means the group will start and end together as a unit and no new members will be added, nor will guests (except for speakers) be generally permitted.

Who delivers the program?

A health care professional and a person with Parkinson's both trained in the application of self-efficacy for Parkinson's

Is there a cost?

There is no cost to attend.

WHAT WILL I LEARN?

These skills will be taught and practiced by participants throughout the course:

- Journaling
- Goal setting
- Self-monitoring
- Language of Parkinson's
- Questioning
- Reframing
- Problem solving
- Tenacity
- Overcoming obstacles
- Realistic optimism
- Evaluating options
- Managing negative emotions
- Handling stress
- Interpreting medical news
- Resilience

The eight session topics (many taught by physicians or medical professionals):

1. Adapting to Parkinson's Disease
2. Introduction to and Acquiring Self-Efficacy
3. Creating Your Personal Health Care Network
4. Benefiting from Exercise & Neuroplasticity
5. Understanding PD Medications & Treatments
6. Understanding Non-motor Symptoms
7. Strengthening the Relationship Between PWP and Care Partner
8. Research and Moving Forward

How do I apply?

People with Parkinson's should send an email to the nearest geographical group. (See list at end) Please provide your name, address, and phone number, and a short explanation about why you are interested in the program. Your local co-facilitator will contact interested individuals and interview potential participants. Please apply no later than August 31, 2020.

More questions?

Send an email to pdself.hartford@gmail.com or contact Amanda Brill (860) 696-4653 or Evelyn Foran (860) 289-8890.

Program locations:

Albany (NY), Colorado Springs (CO), Denver Central (CO), Denver South (CO), Detroit (MI), Evansville (IN), Hartford (CT), Houston (TX), Milwaukee (WI), Philadelphia (PA), Phoenix (AZ), Richmond (VA), Multi-regional program