

Week 8: Building Your Healthcare Team

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- ▶ As a person living with Parkinson's, your needs for care and support can vary and evolve as the disease changes. Here are some of the people who can make valuable contributions to your care and well-being.





Lining your bench!

- ▶ Think of building your health care team like lining your baseball bench.
- ▶ Each individual has a special set of skills that you need to succeed and WIN!
- ▶ As you are carefully “drafting” your players, you need to assess their strengths and weaknesses as well as assessing your needs.
- ▶ At times, you need to “trade” players on your bench to suit your needs.

Movement Disorder Specialist

Neurologist with additional training in Parkinson's disease and other movement disorders; most individuals do see a neurologist - but finding someone who has specific understanding in PD can be very beneficial

Has extensive knowledge of Parkinson's therapies and ongoing research.

A MDS closely works with your neurologist or current doctor; likely to have relationships with other specialists or allied care professionals who have specific PD experience (PT, OT, SP, Counselors, Holistic professionals, etc)

A MDS can review medications and recommend adjustments as well

Finding the right one takes time - find a good fit! Ask around, do your research. Find someone who listens to you! It's ok to get another opinion.

The [MDS Movement Disorders Specialist Finder](#) can help you locate a doctor in your area.

Allied care professionals



Allied care professionals include physical therapists, occupational therapists, speech therapists, counselors and nutritionists. As members of your treatment team, they can help you manage many symptoms and other aspects of living with Parkinson's



They can help you continue to do the things you want to do. Research shows that working with allied care professionals may help prevent or delay some difficulties as Parkinson's progresses.



Some people call on allied care professionals for the long term, to help with some of the symptoms of PD. Others use them when a particular issue arises, on an as-needed basis. You may need help from different professionals at different stages of your Parkinson's. Talk to your doctor about whether it is appropriate for you to include an allied care professional on your team.

Physical Therapist

- ▶ A physical therapist (PT) can help you maintain or improve mobility and manage certain types of pain by working with you on exercises for walking and balance, strength, and range of motion. A PT can also design an exercise regimen for your specific symptoms and abilities.
- ▶ PT's can also be trained in specific PD interventions. (LSVT BIG, PwR, Delay the Disease)

Occupational Therapist

- ▶ An occupational therapist (OT) helps people with activities of daily life, such as self-care skills, education, work and social interaction.
- ▶ An OT will help someone with Parkinson's disease prepare for, and adapt to, changes in their disease.
- ▶ An OT can teach you the best ways to move from sitting to standing, for example, or what to do if you find yourself freezing or losing balance.

Speech Therapist

A speech therapist can help you maintain and improve communication skills. Many people with Parkinson's have difficulty communicating because they speak softly or in a monotone, or they slur words.

As Parkinson's progresses, swallowing can become more troublesome and can pose a choking risk when eating. Speech therapists can teach you ways to chew and swallow to ease symptoms.

Therapist/Counselor

- ▶ A therapist/counselor can help people with Parkinson's disease manage depression, anxiety and other emotional changes that are common non-motor symptoms.
- ▶ They can also help you prepare for conversations or situations that may arise with a Parkinson's diagnosis, such as telling your employer, family/friends or children about your disease.

Nutritionist/Dietitian

- ▶ Eating well is important for overall good health. A nutritionist/dietitian can help you evaluate your diet and make changes, including helping you plan menus and make shopping lists.
- ▶ Many people with Parkinson's experience issues like unwanted weight loss or constipation, which can be managed with dietary changes.
- ▶ A nutritionist/dietitian can work with you to develop an individualized nutrition program.

Care partners

Play a major role in the well-being of a person with Parkinson's disease.

When a person is diagnosed with Parkinson's disease (PD), someone who is close to them – whether their spouse, child, parent or friend – usually becomes the primary care partner.

Care partners take on many responsibilities, from accompanying a loved one to doctor appointments to managing more household responsibilities.

Care Partners

▶ Help in Managing Care

- ▶ Even though care partners do not need special medical training, they play a central role in the medical care of people with PD.
- ▶ Accompany your loved one to doctor's appointments, with their permission. You can offer an outside view on how the person with Parkinson's has been doing in the interim since the last visit. You may also recognize new symptoms or subtle changes that the person with Parkinson's doesn't, such as changes in mood or behaviors, withdrawal from social interaction, or speech that has become softer or more monotone.
- ▶ When you and your care partner attend appointments together, you both hear what the doctor has to say. You can compare notes afterward and together discuss management options offered. And you can both be clear on the treatment plan.
- ▶ Keeping track of all the details associated with medical care can be overwhelming. Here are some tips to help:

Prepare for appointments

Prepare a list of your questions for the doctor before appointments

Stay organized with a calendar that you can take to doctor visits. Note doctor and therapy appointments, start and stop dates of medicines, and any side effects you notice.

Keep a list of all doctors' phone numbers and addresses. Keep a separate list of all medications, their dosages and instructions, and the names of the doctors who prescribed them.

Learn about Parkinson's disease. Gather information about symptoms, treatment options, how other medical conditions may affect your health, and clinical studies that need volunteers.

Familiarize yourself with the terms of your medical insurance. Know what services, including medication coverage and therapy session benefits, are included. Engage the services of a social worker if you need help navigating these issues.

Know your rights in terms of disability coverage, family leave and elder rights.

Discuss important plans and decisions for the future. Talk about wills, advanced directives and other life issues.

YOU!!



Questions?