

PFNCA Parkinson's Pointers Lecture Series



PARKINSON FOUNDATION
OF THE NATIONAL CAPITAL AREA

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.



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What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

With support of its **Medical Advisory Board**, the **Parkinson Foundation of the National Capital Area** developed a scorecard to help you assess how you are doing in your fight against Parkinson's. The scorecard can help guide conversations with your medical providers.

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

There are ten statements

If you agree with the statement, place a check mark in the corresponding box


What's your score?

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.


I will review each statement and explain why we added it to the scorecard.

If you want to follow along, I will go front left to right. Let's begin...

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.



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PARKINSON'S SCORECARD

Place a check in the box next to each statement if you agree ☒

I am seeing a Movement Disorder Specialist. <input type="checkbox"/>	I understand the medicines I am taking and am comfortable with them, including dosages. <input type="checkbox"/>
I have spoken with my physician about the benefits of physical therapy. <input type="checkbox"/>	I have spoken with my physician about the benefits of Speech therapy. <input type="checkbox"/>
I understand the importance of exercising regularly and do so. <input type="checkbox"/>	I have made efforts to meet others with Parkinson's to learn from their experiences. <input type="checkbox"/>
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I am seeing a Movement Disorder Specialist.

☐

Movement Disorder Specialists are neurologists with additional training in Parkinson's disease, and are often the best kind of doctor to see for a definitive diagnosis or to work with to create an ideal effective treatment plan. They typically receive one to two years of added training at a specialty center for Parkinson's Disease and other movement disorders after completing general neurology residency.

Why is seeing a Movement Disorders specialist important?


- Accuracy of diagnosis
- Better understanding regarding appropriate dosing of medications
- Greater awareness of up to date treatments and familiarity/comfort with using these treatments
- Better understanding of prognosis
- Familiarity of other medical professionals who have specialty training/interest in Parkinson's Disease. For example, physical therapists.

Not sure, where to find a Movement Disorder Specialist – PFNCA has a Medical Advisory Board.

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I understand the medicines I am taking and am comfortable with them, including dosages.

☐

It is important to understand the various medications you are taking for Parkinson's and other health conditions you face. If you have questions about your medications, consult your physician.

Why is it important to understand my medications

I understand the medicines I am taking and am comfortable with them, including dosages.

☐

Understanding your medications gives you a better understanding of your disease and how it is being treated.

It can help you understand very important changes in your disease that can lead to more effective changes in your medication. Examples are “wearing off” and “dyskinesias.”

There can sometimes be a discrepancy between what your physician thinks you are taking and what you are actually taking.

If you are ever hospitalized, it is extremely important for you to know what you are taking so you can continue your regimen in the hospital.

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What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

I have spoken with my physician about the benefits of physical therapy.

☐

As your Parkinson's advances, it is important to understand how physical therapy can benefit you. Ask your physician about physical therapy for those with Parkinson's, which may be covered by your health insurance.

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

I have spoken with my physician about the benefits of physical therapy.

☐


It is never too soon to consider physical therapy

There are certain aspects of Parkinson's disease that do not always respond to medication, such as balance problems and freezing.


It is particularly important to work with a physical therapist that has a special interest or training in Parkinson's disease. The Big program is an example.

Physical therapy can also allow you to be exposed to a community of people with Parkinson's and people who treat Parkinson's.

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I have spoken with my physician about the benefits of Speech therapy.

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As your Parkinson's advances, it is important to understand how speech therapy can benefit you. Ask your physician about speech therapy for those with Parkinson's, which may be covered by your health insurance.

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I have spoken with my physician about the benefits of Speech therapy.

☐


Speech problems such as soft speech and stuttering are very common. Often patients are not aware that they are speaking too softly.

Also, physicians are frequently not aware of speech problems. This could be related to time of day that patients are seen. Also, patients often will do better in the office than they normally do at home.


Speech therapy can also improve cognition.

Speech therapy can also improve swallowing.

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I understand the importance of exercising regularly and do so.

☐

Exercise helps improve balance and mobility for those with Parkinson's

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

I understand the importance of exercising regularly and do so.

☐

Exercise has been clearly shown to improve balance and mobility, and is often more effective than medications are in treating these problems.

It has also been consistently shown to improve cognition and decrease the onset of mild cognitive impairment.

It is extremely important for mood.

It is the one thing that has been shown to slow down the progression of Parkinson's disease.

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I understand the importance of exercising regularly and do so.


☐

It is not clear what types of exercise are better than others.


There has been some research that forced exercise such as tandem biking is helpful. There has been some research that boxing is particularly helpful.

What seems to be very important is exercise frequency. I typically recommend if patients can do it, exercising up to 4 or 5 days weekly. Any exercise is helpful though.

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I have made efforts to meet others with Parkinson's to learn from their experiences.

☐

Parkinson's can isolate you. Make an extra effort to meet others with the disease and learn about their experiences. Attending a support group or other programming for those with Parkinson's is a great way to meet others.

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I have made efforts to meet others with Parkinson's to learn from their experiences.

☐


There is a “Parkinson’s personality” characterized by introversion and decreased novelty seeking. It is very important to resist this inclination.

Social interactions improve mood and cognition.


Support groups can be empowering

Working with support groups and socializing with others with Parkinsons is a true sign of acceptance of the disease which is key in fighting it.

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I know the importance of speaking louder and do so.

☐

Parkinson's causes weakening of vocal cords. It is important to speak louder in social settings to be part of the conversation.

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I know the importance of speaking louder and do so.

☐

As mentioned earlier, patients are often not aware they are speaking too softly.

Speaking too softly can make patients feel that people are not listening to them, particularly in group settings which can be very discouraging and contribute to isolation.

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I know the importance of speaking louder and do so.

☐


It can also have an impact on interpersonal relationships with caregivers and those closest to you.

Speech therapy, and in particular, the Loud program can be very helpful in teaching patients to speak more loudly.

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I have spoken with a financial planner about how having a chronic disease may impact my financial situation.

☐

When diagnosed with a chronic disease, it is important to understand how it may impact your long-term financial health. Expenses such as medications, the need for assisted living and home health aides should be understood. It may also be helpful to communicate about this with your family.

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I have spoken with a financial planner about how having a chronic disease may impact my financial situation.

☐

If you are not retired, it is also important to have a conversation with your physician about retirement planning. For example, it is important to get a sense as to whether or not your Parkinson's disease is going to have an impact on when you need to retire and whether or not long-term disability is going to be necessary at some point.

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I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted.

☐

Those with Parkinson's may experience complications if hospitalized. It is important to communicate with your Movement Disorder Specialist if you are admitted to the hospital, and to inform the hospital staff that you require medications at specific times and other considerations for them to know.

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I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted.

☐

Again, know your medications. It is also important to explain the timing of your medications when you are in the hospital.

Your neurologist can write a letter about the importance of timing of the medications. They can also include medications you can't have such as Haldol or Reglan.

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

I have a plan in place if I am hospitalized, to minimize the risks I may face if I am admitted.

☐

It is also important you get physical therapy when in the hospital. Prolonged bedrest can very quickly lead to deconditioning.

It is very common to experience an exacerbation of your Parkinson's symptoms while in the hospital.

Confusion can also occur.

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I am aware of how to seek help in the event that my mental health changes.

☐

Some with Parkinson's experience changes in their mental health. If you feel you are experiencing such changes, speak with your primary care physician or a neurologist.

What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

I am aware of how to seek help in the event that my mental health changes.

☐

Depression and anxiety are extremely common Parkinson's symptoms. They occur early or late in the disease. They are also very treatable.

Hallucinations and confusion can occur. These are often the result of medication side effects and they can be treated as well.

Topic: What's Your Parkinson's Score: Create a plan to fight Parkinson's and execute it.

What's your score?

Total # of
check marks

Score Results

- 9+** You have a plan to fight PD, are executing it and well-positioned to help others take steps to fight the disease
- 6-8** You are well on your way to effectively fight PD
- 4-5** You have made a great start to fight PD and can target your efforts to fight even harder
- < 4** You would benefit from focusing more on your fight with PD

Curious about these questions—visit: www.parkinsonfoundation.org/scorecard

The Parkinson's Scorecard is a project of the Parkinson Foundation of the National Capital Area (PFNCA), a non-profit organization that helps people live well with Parkinson's. Learn more about PFNCA and/or make a donation at pfnca.org.

How PFNCA Can Help...

Exercise & Speech --

Exercise and strengthening vocal cords – PFNCA provides more than 300 wellness classes at no cost each month at 34 locations in Virginia, Maryland and Washington, D.C. You can learn more at www.pfnca.org. Many exercise classes are led by Physical Therapists and programs called Communication Club are led by Speech Therapists.

How PFNCA Can Help...

Socialization –

Attending PFNCA Wellness Classes, this quarterly lecture series, the PFNCA Symposium and/or Walk Off Parkinson's are great ways to meet others facing Parkinson's.

There is also a list of area support groups on PFNCA's website.

How PFNCA Can Help...

Hospitalization Awareness --

In January, PFNCA launched a hospitalization guide that was developed by members of PFNCA's Medical Advisory Board. The guide is distributed to those who register for PFNCA's wellness classes. In the future, PFNCA plans to make it more widely available.

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Question & Answer Session

Dr. Randolph Stephenson, MD

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