

PD SUPPORT GROUP DISCUSSION GUIDES

FOUR DISCUSSION GUIDES

These guides have been developed to assist with providing information and facilitating discussion during support group meetings. Each guide serves as a standalone piece, and they are meant to be covered in separate support group meetings, depending on the needs of the group.

- I. Tremors and dyskinesia**
Why you need to know the difference
- II. You are not alone**
Understanding the day-to-day effects of OFF and dyskinesia
- III. Levodopa is the gold standard to treat PD**
– things you should know

CARE PARTNER PERSPECTIVE

- IV. I am struggling, too**
Being a care partner to a person with Parkinson's who experiences difficulties with movement

I. Tremors and dyskinesia:

Why you need to know the difference

Goals:

- Learn about movement changes you may experience with PD, called motor complications
- Know the difference between tremors and dyskinesia – what to look for; how they are similar and how they are different – and why this is important to know
- Identify where and when dyskinesia and tremors occur for you
- Discuss how dyskinesia and tremors can look different for different people

Overview:

What are PD motor complications?

PD motor complications occur when there are changes in your ability to move. When levodopa starts working, you may experience periods of good symptom control, called **good ON time**, when you can move well. As levodopa begins to lose its effect, you may have periods in which PD symptoms are much more noticeable and movement becomes more difficult – this is called **OFF time**^[1].

However, sometimes when levodopa levels are too high, you may also experience **dyskinesia**, which also impacts movement in different ways than OFF time.

If you experience OFF and good ON states several times throughout the day, you are experiencing motor complications, which limit your ability to have good movement control as you go about your daily activities.

More about OFF time

When levodopa medication is at low levels or is beginning to lose its effect, symptoms of Parkinson's, such as slowed movement, tremors, rigidity, and balance problems, may appear, making movement more difficult. This is called OFF time. You may fluctuate between good ON time, when you can move and function well, and OFF time throughout the day. These movement challenges can be disrupting and unpredictable.

Symptoms of OFF may include:

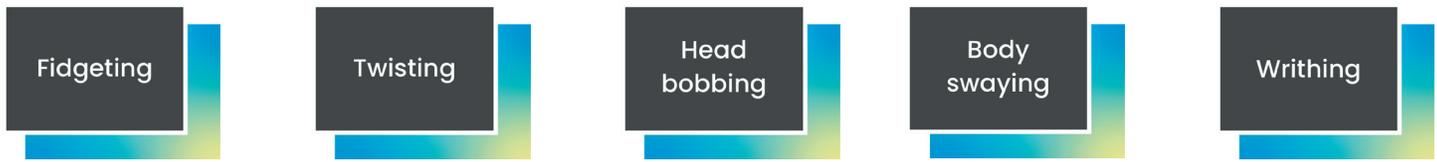
- **Tremors:** Involuntary, rhythmic movements that look like shaking.
- **Bradykinesia:** Slowness of movement
- **Rigidity:** Stiffness of the limbs and torso
- **Instability:** Difficulty with balance with problems like standing from a low or soft chair or a tendency to teeter backward or lurch forward

Having OFF time is very common for people with Parkinson's: about 50% of people with Parkinson's start to experience OFF episodes within the first 2 years of levodopa treatment, rising to 70% after 9 years^[2,3].

More about dyskinesia

Sometimes when your levodopa is working – you may also experience dyskinesia, which occur with high levodopa levels. **Dyskinesia** is involuntary erratic, writhing movements of the face, arms, legs or trunk that can negatively impact many aspects of daily life. These movements are often fluid and dance-like but may also cause rapid jerking or slow and extended muscle spasms. Dyskinesia is different than OFF time, including tremors, because it is not a symptom of Parkinson's itself, but is caused by levodopa and is often when the medication is at peak levels.

Dyskinesia often looks like:



A fine balance: achieving good ON time

When levodopa is at effective levels and is working as expected, people with Parkinson’s are able to move and function well. This balanced state is known as **good ON time**.

Levodopa works well in treating Parkinson’s disease—often for several years without causing OFF or dyskinesia. This period is often called the ‘honeymoon’ period, where the person with PD experiences good movement control throughout their day. However, as dopamine-producing brain cells deplete over time, the ability to store dopamine diminishes and the effects of levodopa do not last as long. This is the point where a person with Parkinson’s will start to experience OFF time, triggering the need to take more doses of levodopa throughout the day, which may in turn trigger dyskinesia.

Did you know?

Studies show that one-third of people taking levodopa are currently experiencing dyskinesia^[2].

Over 50% of people with PD experience OFF episodes, dyskinesia or both within 5 years, and up to 100% after 10 years^[4,5]. Adjusting levodopa to treat motor complications for good movement control can be challenging, resulting in a “trade-off” of accepting either OFF or dyskinesia.

Both OFF and dyskinesia impact good ON time—the time when you are most able to engage in tasks and social activities. Maximizing good movement by minimizing OFF and/or dyskinesia is critical to increasing overall good ON time, so you are able to spend time doing more of what you love, with the people you love.

Why do I need to know the difference?

Recognizing and understanding your movement challenges and what is causing them is important. With this knowledge, you can make a plan with your doctor to achieve the right treatment approach for you – one that maximizes the amount of time that you feel your best. For example, if dyskinesia is wrongly called tremors, a doctor might recommend a higher levodopa dose, which could actually lead to more dyskinesia. Selecting the right medicines that work for you become increasingly important as your PD progresses. Having challenges with moving (including OFF and dyskinesia) were cited as the top symptoms affecting quality of life in a survey of people with Parkinson’s disease for at least 6 years^[6].

Questions for discussion:

- After reading the overview above – What causes dyskinesia? What causes tremors?
- In your own words, describe how you recognize the difference between dyskinesia and tremors.
- Describe the movement of tremors and how it feels to you.

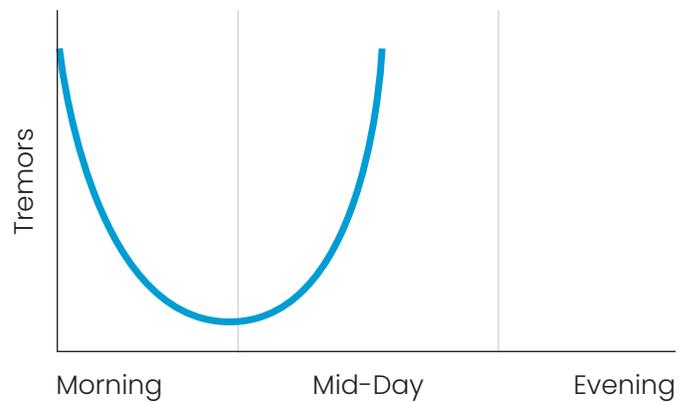
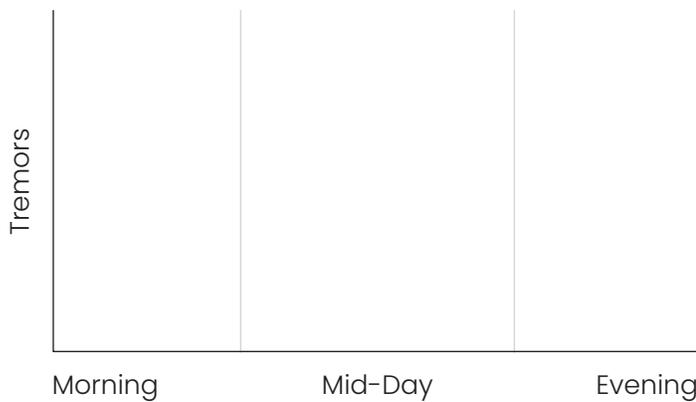
- Is there a specific time of the day when tremors are worse?
- What are some ways you have found helpful to manage the times when you experience limited movement control throughout the day?

Activities:

List where on your body you feel your tremors. Also list where you usually experience dyskinesia.

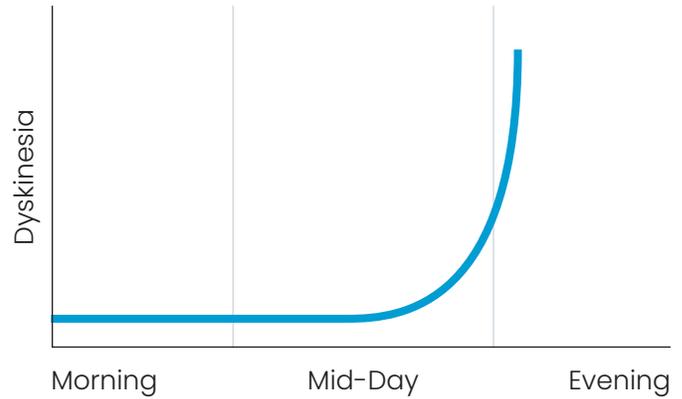
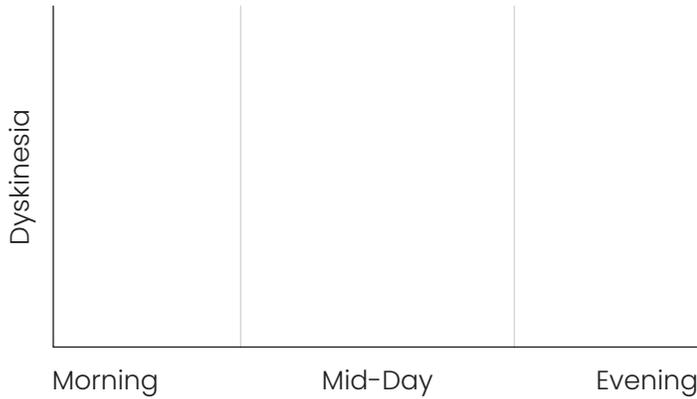
Draw a graph representing when you experience your **tremors** throughout the day:

For example, Steve experiences his tremors first thing in the morning, and when his afternoon levodopa wears off around 3 pm. This is what his graph looks like:



Draw a graph representing when you experience **dyskinesia** during the day:

For example, Steve experiences his dyskinesia most in the early evening. This is what his graph looks like.



Which of the following phrases remind you of your tremors:

- Rhythmic shaking that I can't stop
- Stiffness in my arms and legs
- Moving slowly
- Makes me want to stay home because I am embarrassed
- Makes me feel isolated and lonely

Which of the following words remind you of your dyskinesia?

- Fidgeting
- Twisting
- Head bobbing
- "Dancing"
- Face tightness
- Can sometimes stop me doing tasks or hobbies

Key takeaways - "Getting a clearer picture"

What did you learn today about your OFF time/tremors and dyskinesia you did not know before? Write your thoughts and observations below and share with your group during the next meeting.

[1] Hauser RA Clinical Neuropharmacology 2000
 [2] Turcano P, Mielke MM, Bower JH, et al. Levodopa-induced dyskinesia in Parkinson disease: A population-based cohort study. Neurology. 2018;91(24):e2238-e2243
 [3] Stocchi F, et al. Parkinsonism Relat Disord. 2014
 [4] Kim H-J, Mason S, Foltynie T, Winder-Rhodes S, Barker RA, Williams-Gray CH. Motor Complications in Parkinson's Disease: 13-Year Follow-up of the CamPaIGN Cohort. Movement Disorders. 2020;35(1):185-90
 [5] Mizuno Y, Shimoda S, Origasa H. Long-term treatment of Parkinson's disease with levodopa and other adjunctive drugs. Journal of neural transmission 2018;125(1):35-43
 [6] Politis M, Wu K, Mollot S, Bain PG, Chaudhuri RK, Piccini P. Parkinson's disease symptoms. The patient's perspective. Movement Disorders 2010; 25:1646-51

II. You are not alone: Understanding the day-to-day effects of OFF and dyskinesia

Goals:

- Discuss how OFF and dyskinesia affect everyone differently
- Share how lack of movement control can affect your daily tasks and activities
- Not being able to move well can affect you socially and emotionally - learn more about how good movement can help you feel more connected to your friends and family

Overview:

Having difficulties moving can be unpredictable, disruptive, and frustrating.

Challenges with moving can often occur without warning, which can make you feel like you do not have control. OFF time can cause slowed movements, freezing or tremors which can make regular tasks time consuming and difficult to accomplish. Dyskinesia, even when mild, can feel embarrassing and physically and emotionally draining - causing anxiety which in turn can make dyskinesia worse^[1].

Having limited movement control caused by OFF or dyskinesia, may prevent you from doing activities and spending time with friends and family.

OFF time and dyskinesia can get in the way of all sorts of things.



Social events

Meetups with friends and family, birthdays, weddings, and other events may make you feel awkward to be around other people because you do

not know when your levodopa may wear OFF or if your dyskinesia will appear. Special events with other people can be stressful and may cause more dyskinesia due to anxiety, so you may opt to stay home.



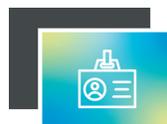
Daily routine activities

Uncontrolled movements make simple tasks like walking, typing, signing your name, cleaning the house, texting, or calling a friend difficult. Daily tasks may become embarrassing, irritating, and time-consuming.



Hobbies

Hobbies you would normally enjoy like yoga, tennis, gardening, dancing or painting may become difficult to do.



Work

You may not feel confident in day-to-day work tasks or speaking on the phone, or you may want to avoid feeling embarrassed around co-workers.



Meals

You may not be able to enjoy meals without dreading an accidental food or drink spill, so you may avoid eating meals with other people.

Discussion questions:

-  Share with your group your experiences with OFF and/or dyskinesia. As you hear others share, think about how your experience is unique or different from other members in your group.
-  What daily activities do you find challenging when you experience being OFF and/or having dyskinesia -- such as household tasks, walking around the block, texting a friend?
-  Do you try to plan your day around anticipated episodes of OFF and/or dyskinesia during certain times of the day or in certain situations? If so, how?
-  How does OFF and/or dyskinesia affect you in public or in social situations? Talk about when OFF and/or dyskinesia seem to worsen in public settings.
-  Is there anything that you do that you find helpful when you experience OFF and/or dyskinesia in public or in social situations?
-  Does worrying about OFF and/or dyskinesia seem to make either of them worse? What else do you think makes these worse?
-  What are some ways you have tried to manage your OFF time? How about dyskinesia? Through medication? Exercise? Diet? Better planning for your day?

Activities:

- If you could list your 'OFF and dyskinesia toolbox' – what would it include? Share with others the tools you find helpful when to minimize your OFF time, coping with being OFF and/or managing your dyskinesia at home and in public.

- Family members or care partners are not always present, and not everyone has regular support from others. What are the best strategies to cope with movement challenges when you are on your own?
- What are some interesting ways you have managed awkward situations in public when others don't understand why your symptoms have suddenly worsened or movement has become more difficult for you? Share your ideas and stories with your group.

Key takeaways – “Getting a clearer picture”

Fill in this sentence:

“When I am having an episode of OFF and/or dyskinesia,

I may need/want to _____ but instead, I _____ .”

For example: “I may need to go to the grocery store but instead, I make do with the ingredients I have at home.”

Recognizing the importance of maintaining a good quality of life is critical to living well with Parkinson's. What are some things that you find helpful to manage OFF and/or dyskinesia? Share the sentence you completed above with your group during the next meeting.

Adjusting levodopa

This approach may involve changing how much levodopa you take and how often you take it, and it may require you to split up your daily dose into smaller doses taken more frequently. Depending on what your doctor prescribes, taking levodopa in smaller doses throughout the day may not mean you are taking more levodopa throughout the day; rather you could be spreading out the dose into smaller doses taken more frequently.

This approach can be tried with the goal to have you get just the amount of levodopa to control OFF, but not enough to cause dyskinesia. Taking too much levodopa can cause increased dyskinesia, and taking too little levodopa can cause increased OFF. It is possible that treatment strategies that adjust or limit levodopa therapies may result in a person with PD to face a “trade-off” of either accepting OFF or dyskinesia.

Other treatment options

There are treatments that address OFF, dyskinesia and both.

Talk to your doctor about what might work best for you.

80%

Approximately 80% of people taking levodopa experience dyskinesia and OFF. It is a delicate balance to address OFF with enough levodopa without triggering dyskinesia^[3,4,5].

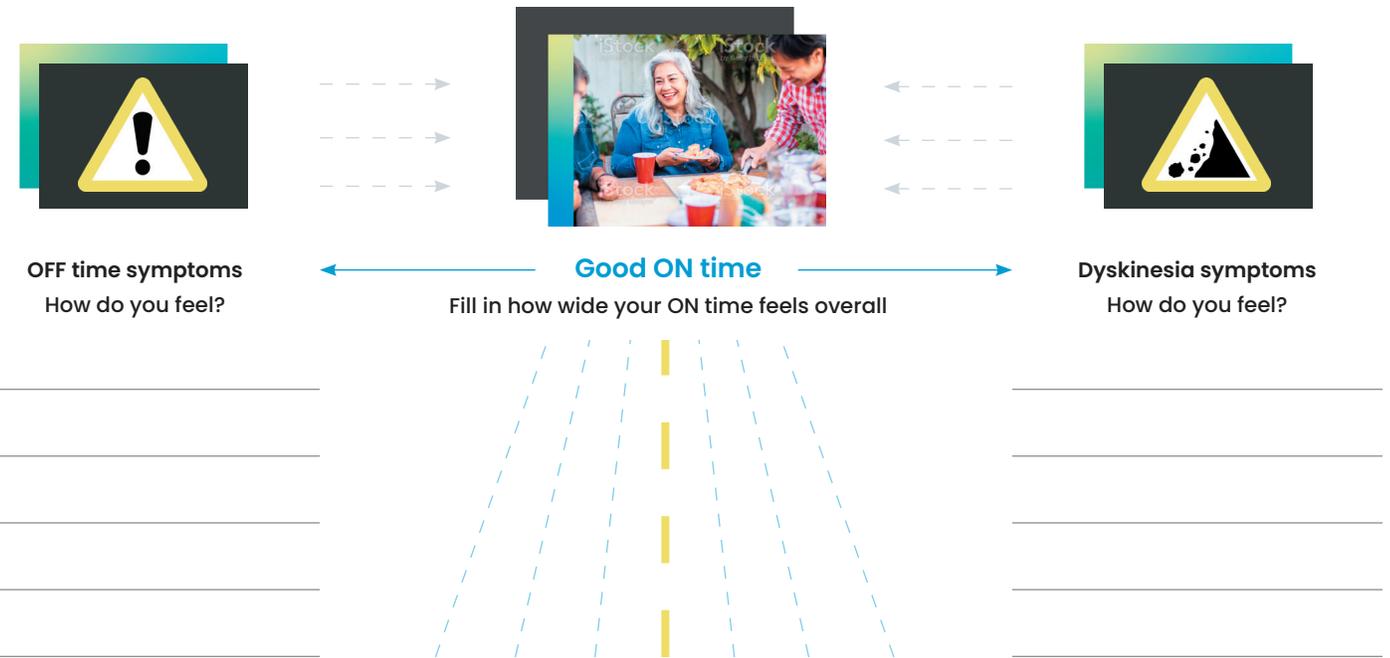
Discussion questions:

-  If you're taking levodopa, how effective is it to help you treat your PD symptoms?
-  Has your doctor ever adjusted your dose? Why? Was it effective?
-  What happens if you miss a dose of levodopa? How do you feel?
-  Do you experience OFF time and/or dyskinesia when you take levodopa? If so, how long after your dose do you experience it?
-  Have you found other ways to manage your PD symptoms? Diet? Exercise? Mindful practices?
-  Have you tried the treatment approaches mentioned in the overview above? What did you find helpful – and why? What didn't work so well?

Activities:

- See the example of the path below – there is OFF on one side and dyskinesia on the other. Underneath the example, draw what your “good ON time” looks like – is it a wide or narrow path? What are the symptoms on each of the sides of the path that you experience?
- If you have tried other treatment approaches besides adjusting your levodopa dose – use your path outline below to illustrate how that affected your good ON time. Did it help you have better good ON time, giving you a wider path? Or did one of the symptoms get worse?

- How does exercise affect the diagram below?



Key takeaways – “Getting a clearer picture”

Think about the drawings you just did – and think about ways that you were able to improve your good ON time. What is one thing you can do to better manage your OFF and dyskinesia – and enlarge the path of good ON time?

Is this something you’d want to discuss with your doctor during your next visit? Please share what you’ve written below with your group for the next meeting.

[1] Jankovic J, et al. CNS Drugs. (2007)
 [2] Politis M, Wu K, Mollot S, Bain PG, Chaudhuri RK, Piccini P. Parkinson’s disease symptoms. The patient’s perspective. Movement Disorders 2010; 25:1646–51
 [3] Olanow CW, Kieburtz K, Rascol O, et al. Factors predictive of the development of Levodopa-induced dyskinesia and wearing-off in Parkinson’s disease. Mov Disord. 2013;28(8):1064–1071.
 [4] Santos-García, D., de Deus Fonticoba, T., Suárez Castro, E., Aneiros Díaz, A., McAfee, D., Catalán, M.J., Alonso Frech, F., Villanueva, C., Jesús, S., Mir, P., Aguilar, M., Pastor, P., García Caldentey, J., Estelrich Peyret, E., Planellas, LL, Martí, M.J., Caballol, N., Hernández Vara, J., Martí Andrés, G., Cabo, I., Ávila Rivera, M.A., López Manzanares, L., Redondo, N., Martínez-Martin, P., McAfee, D. Non-motor symptom burden is strongly correlated to motor complications in patients with Parkinson’s disease. Eur J Neurol. 2020. doi:10.1111/ene.14221
 [5] Hauser RA, McDermott MP, Messing S. Factors associated with the development of motor fluctuations and dyskinesias in Parkinson disease. Arch Neurol 2006;63:1756–60.

CARE PARTNER PERSPECTIVE

IV. **I am struggling, too:** Being a care partner to a person with Parkinson's who experiences difficulties with movement

Goals:

- Things to know about OFF and dyskinesia that impact on care partners and the families of people with PD
- Understanding how you may help identify OFF and dyskinesia with someone who is experiencing it, and how you can ask for help
- Ways to be a supportive care partner

Overview:

What are PD motor complications?

PD motor complications occur when there are changes in your partner's ability to move. When levodopa starts working, your partner may experience periods of good symptom control called **good ON time**. As levodopa begins to lose its effect, your loved one may have periods in which PD symptoms are much more noticeable and movement becomes more difficult – this is called **OFF time**. However, sometimes when levodopa levels are too high, your partner may also experience **dyskinesia**, which also impacts movement in different ways than OFF time.

If your partner experiences OFF and good ON states several times throughout the day, your partner is experiencing motor complications, which limit his/her abilities to have good movement control throughout the day.

More about OFF time

When levodopa is at low levels or begins to lose its effect, symptoms of Parkinson's, such as slowed movement, tremors, rigidity, and balance may appear, making movement more difficult. This is called OFF time. Your partner may experience good ON time, when movement is controlled, and OFF time throughout the day. These movement difficulties can be disrupting and unpredictable.

Symptoms of OFF may include:

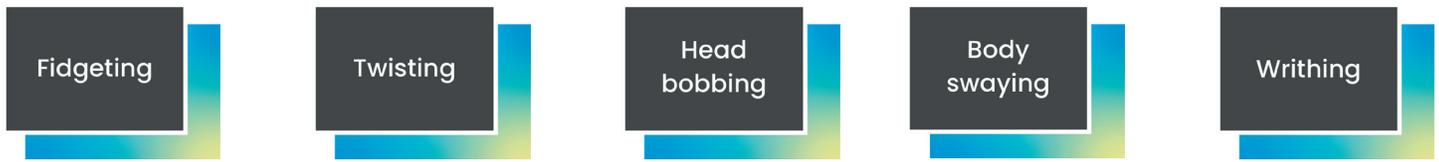
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Having OFF time is very common for people with Parkinson's: about 50% of people with Parkinson's start to experience OFF episodes within the first 2 years of levodopa treatment, rising to 70% after 9 years^[1,2].

What is dyskinesia?

Sometimes when your levodopa is working – you may also experience **dyskinesia**, which occur with high levodopa levels. Dyskinesia is involuntary erratic, writhing movements of the face, arms, legs or trunk that can negatively impact many aspects of daily life. These movements are often fluid and dance-like but may also cause rapid jerking or slow and extended muscle spasms. Dyskinesia is different than OFF time, including tremors, because it is not a symptom of Parkinson's itself, but is caused by levodopa and is often when the medication is at peak levels.

Dyskinesia often looks like:



A fine balance: achieving good ON time

When levodopa is at effective levels and is working as expected, people with Parkinson's are able to move and function well. This balanced state is known as **good ON time**.

Levodopa works well in treating Parkinson's disease – often for several years without causing OFF or dyskinesia. This period is often called the 'honeymoon' period, where the person with PD experiences good movement control throughout their day. However, as dopamine-producing brain cells deplete over time, the ability to store dopamine diminishes and the effects of levodopa do not last as long. This is the point where a person with Parkinson's will start to experience OFF time, triggering the need to take more doses of levodopa throughout the day, which may in turn trigger dyskinesia^[3].

Did you know?

Studies show that one-third of people taking levodopa are currently experiencing dyskinesia^[1].

Adjusting levodopa for good movement control can be challenging, resulting in a "trade-off" of accepting either OFF or dyskinesia.

Both OFF and dyskinesia impact good ON time – the time when you are most able to engage in tasks and social activities. Maximizing good movement by minimizing motor complications is critical to increasing overall good ON time, so you are able to spend time doing more of what you love, with the people you love.

OFF time and dyskinesia can get in the way of all sorts of things

Sometimes movement difficulties occur during specific times of day, following a pattern; however, often times they can come on without warning, which can make you the person with Parkinson's and their loved ones feel like they don't have control. OFF time may cause slow movements, tremors and freezing. Dyskinesia, even when mild, can feel embarrassing. Difficulties moving, whether caused by OFF or dyskinesia – can be physically and emotionally draining, causing anxiety which in turn can cause more dyskinesia^[8,9]. The challenges your loved ones face with movement difficulties in PD may prevent you and your loved one from doing activities and spending time with the people you love.

As a care partner – it is important to also care for yourself and better understand your emotions and reaction when your loved one is OFF and/or experiencing dyskinesia. Emotions, such as frustration, annoyance and embarrassment are normal and nothing to be ashamed of. It is important to allow ourselves to feel these emotions. Give you and your loved one a "break" when experiencing mixed feelings and emotions about your loved one's difficulties with controlling their movements, as it is a part of the journey of living with Parkinson's disease.

It is important to have an open and supportive discussion with your loved one about how they feel when they do not have good movement control. Speaking with your loved one about how they feel when they are OFF or dyskinesic can help them recognize they may be experiencing motor complications more than they realize. Even if the erratic movements are obvious to you, a person with Parkinson's might not be aware of the full effects of their movement challenges. With a gradual increase in movement difficulties, these are not always so apparent to the person experiencing them.

Although OFF episodes can also occur unpredictably, you may already be helping your loved one manage predictable lows in their treatment cycle by planning down time during these times or ensuring that he/she take the next dose of medication on time. However, dyskinesia may be more challenging to predict. Being able to recognize dyskinesia and understanding that it occurs as a result of high levels of levodopa and can also interfere with motor control, you can help your loved one maintain the delicate balance of maximizing the amount of good ON time they have. Therefore, it is even that much more important to have a good dialogue with your loved one and so that you can help advocate for the management of their movement difficulties with their doctor. Working as a team, you can help your loved one maximize their good moments, but you can't do this alone. So speak with your loved one and their doctor about what you are noticing.

Discussion questions:

-  When your loved one experiences OFF, what does that look like to you? How does your loved one respond when he / she experiences OFF?
-  What does your partner's dyskinesia look like? How does your loved one react when he / she experiences dyskinesia?
-  What does good ON time mean to you? How does it make you and your loved one feel, and how is your behavior different during good ON time?
-  How do you try to help your loved one when he / she experiences OFF and/or dyskinesia?
-  What do you feel when your loved one is experiencing OFF and/or dyskinesia? As a care partner, you may want the focus to always be on our loved one; however, it is important to recognize the emotional and physical toll that it takes on you and it is important to express these feelings so you can better understand your own reaction and emotions. For example, do you ever feel frustrated or physically drained?
-  Do you find that your loved one wants to talk about their OFF and/or dyskinesia? What are some ways you've found it helpful to discuss it? If your loved one does not want to talk about their OFF and/or dyskinesia, how does that make you feel?
-  If you are unable to share your emotions about the impact of motor complications with your loved one, is there someone else you can speak to about how you feel? Are there reasons why you might feel nervous talking to your loved one?
-  What advice would you give to a care partner whose loved one has only recently begun to experience dyskinesia, which can often be quite surprising and sometimes embarrassing for the care partner?

