

# Disclosing Your Diagnosis of PD



# Common Concerns

- How will others react?
- Will it upset family members or cause them to worry?
- Will friends treat you differently or drift away?
- Will colleagues continue to value your input and abilities?
- **Many have no concerns about disclosing their diagnosis**

# *Who do you want to tell?*

- People you feel closest to
  - Spouse/partner, immediate family members, close friends
- Broader circle of people you know
- Are there other people you feel responsible for telling?
  - Employer, supervisor, co-worker(s)

# *Why* do you want others (this person) to know?

- Explain what is going on with you, especially if they have expressed concern for your well-being
- Reduce your stress level about your symptoms
  - You won't have to try to cover up or compensate for your difficulties
  - Eliminates speculation about your condition
- Rally their support and let them know how they can help you
- Openly dialogue about how it might affect your relationship & expectations of each other

# ***What do you want others (this person) to know about your diagnosis?***

- How it affects you
  - Talk about your particular symptoms to help them understand what is happening to you
- What you are doing to manage your symptoms
- That you are still able to work & do the things you enjoy
  - Make sure to share the good things!
- Offer specific ways others (this person) can support you
- ***Be clear on whether you want the information kept private or if it can be shared with others***

# ***How & where do you want to share the information?***

- In person
- Over the phone
- Written information
- Invitation to attend an education meeting together (PD 101)
- Choose a time and place where you can talk with the person without interruption

# *When is the right time to discuss your diagnosis?*

- You may want to tell some individuals soon after the diagnosis
  - This may help you begin the coping process
- Tell others after you have had time to come to terms with the diagnosis yourself
- Your initial conversation may cultivate ongoing discussions about your experience living with PD
  - Your symptoms and needs will likely change overtime
- ***The best time to tell others is when you are ready!***

# ***How do you want to prepare for these conversations?***

- Consider writing out what you want to say beforehand
- Consider talking to a knowledgeable professional beforehand
- Attend a support group to learn from others' experiences



# ***How can you prepare others (this person) for the conversation?***

- Let the person know that you want to talk to them about something important
- Ask them to *listen* to what you have to say
- Don't be afraid to tell them how *you* are feeling
  - *"I feel uneasy, but there is something I want to tell you. I hope I will feel better after I talk about it with you."*

# *What kind of responses do you anticipate?*

- Surprised, tearful, silence, signs of discomfort
  - Pay attention to body language
- Relief that there is an explanation for the changes they have perceived in you
- Disbelief or denial (*“You’re too young to have PD,” “You look fine”*)
- Lots of questions
- Opinions or suggestions for what you should do
- Comments that reflect misconceptions or lack of knowledge about PD
- Encouragement, offers of help

# Guiding Principles

- Disclosure needs to be tailored to fit the particular person & purpose (*“One size does not fit all”*)
- The more others learn about PD, the more comfortable they will feel being with you
- Open & honest communication can help both you & others in your life adjust to your PD diagnosis
- Having PD is not *your* fault
- You are still you
- You *can* live with PD

# The Five W's Of Life

*Who* you are is what makes you special.  
Do not change for anyone.

*What* lies ahead will always be a mystery.  
Do not be afraid to explore.

*When* life pushes you over,  
you push back harder.

*Where* there are choices to make,  
make the one you won't regret.

*Why* things happen will never be certain.  
Take it in stride and move forward.

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