



Common Behavioral Issues in Parkinson's Disease and Useful Strategies

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Rigidity and
trembling of head

Forward tilt
of trunk

Reduced arm
swinging

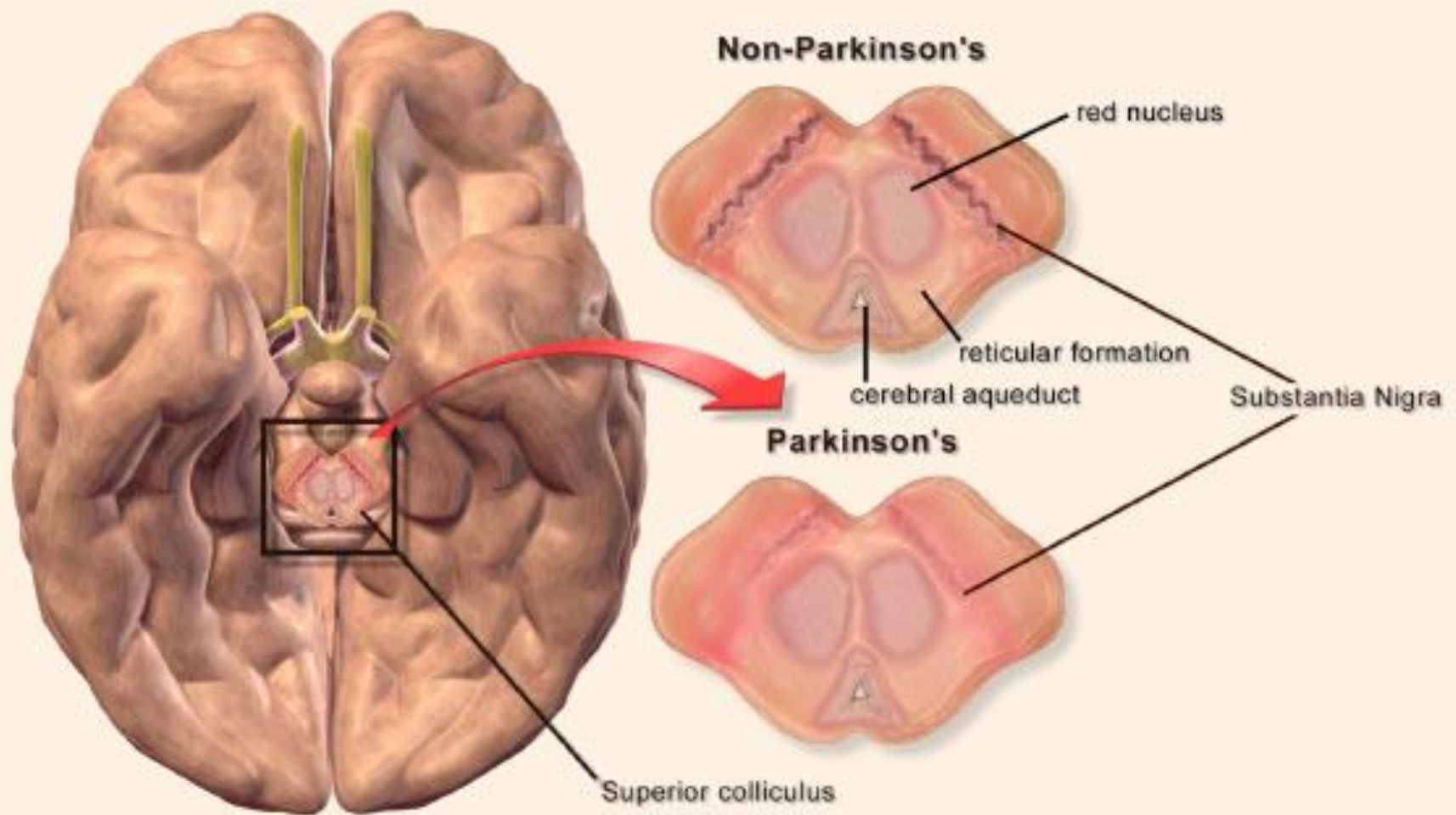
Rigidity and
trembling of
extremities

Shuffling gait
with short
steps

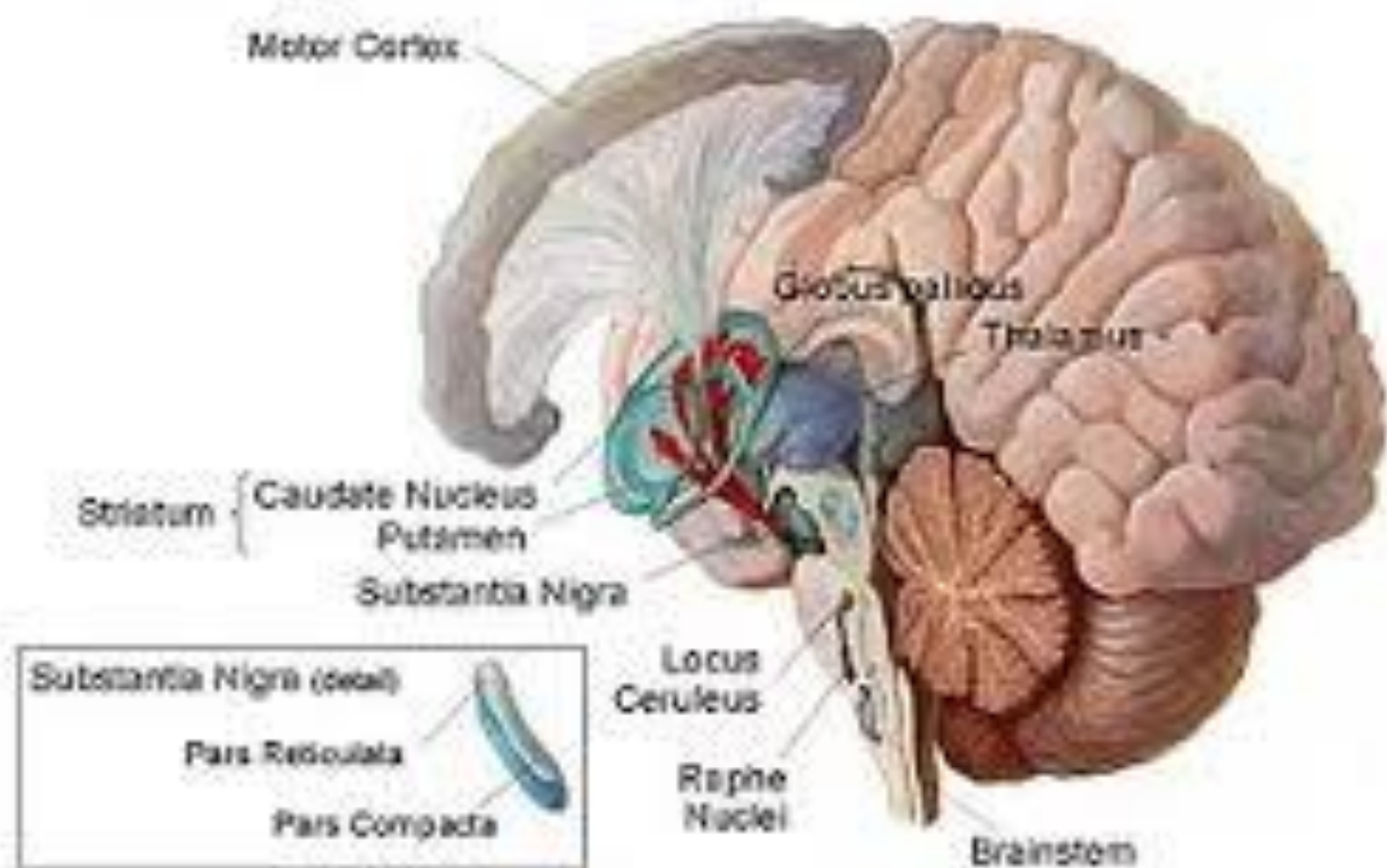


Topics

- Personality changes
 - Apathy, disinhibition, hypersexuality, pathological gambling
- Cognitive changes
 - Slowness, attention, executive functioning, memory (retrieval deficits)
 - Hypophonia, micrographia
- Psychiatric Symptoms
 - Psychoses, hallucinations, depression, anxiety
- Sleep Issues
 - REM sleep behavioral disorders

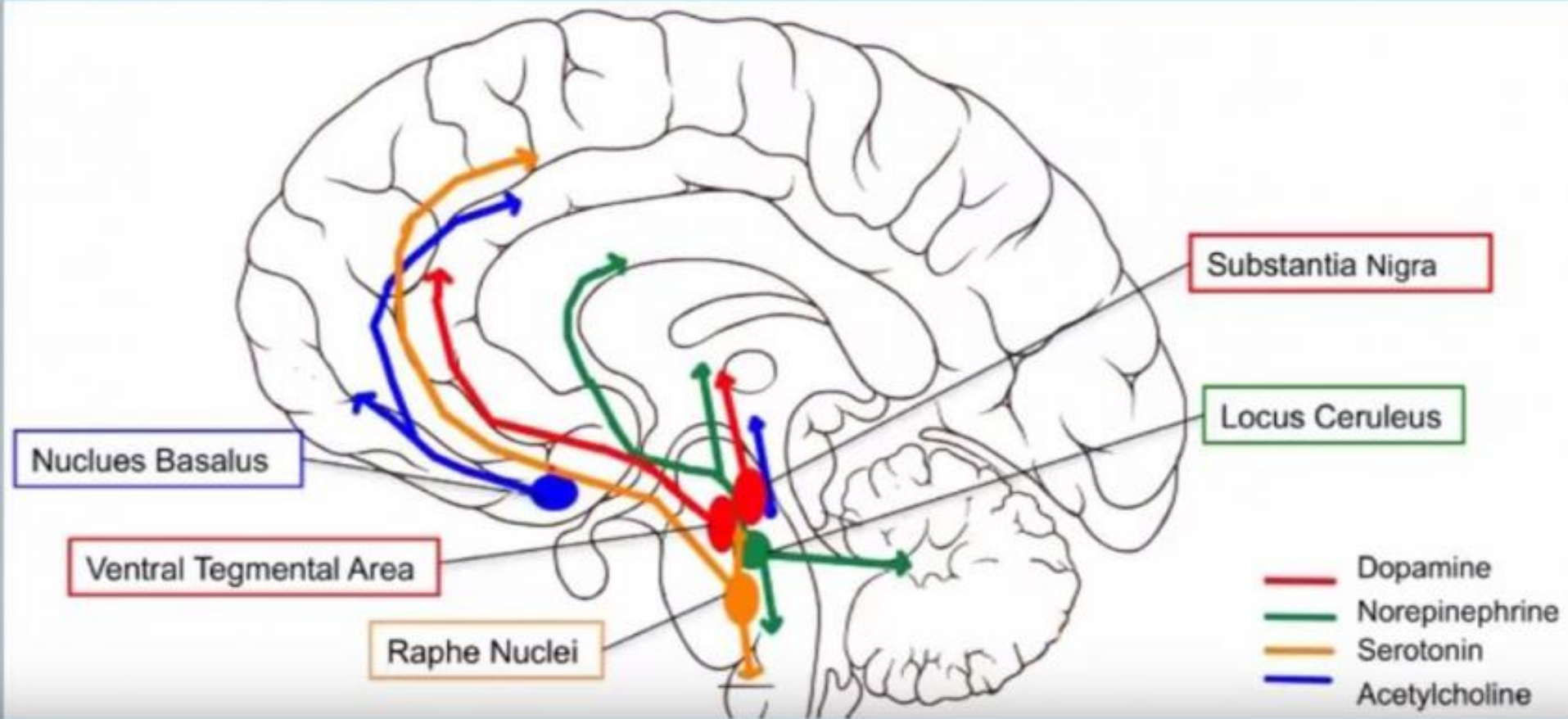


Brain Regions Affected by Parkinson's Disease



Parkinson's disease

Multiple Systems Affected in Parkinson's Disease



When do these symptoms occur?

- Symptoms can be present from the early stages of the disease
- Sometimes they are present even before the appearance of classical motor symptoms, likely in relation to dopamine depletion in basal ganglia and/or to dysfunctions of other neurotransmitter systems,
- Others develop later, in some cases in relation to dopaminergic treatment
- Sometimes they never occur

How Can I Make My Life Better With Parkinson's Disease?

Education and support

- Design strategies to help regain a sense of control over your life and improve your quality of life.
- Find out as much as you can about the illness.
- Talk to your friends and family about it. Don't isolate them. They will want to be involved in helping you.
- Do things you enjoy.
- Do not be afraid to ask your health care providers to repeat any instructions or medical terms that you don't understand or remember. They should always be available to answer your questions and address your concerns.
- Use of resources/support services offered by your community.
- Learn to manage stress. Organize a daily routine that will reduce stress, with down time for both you and your family members.

What Types of Help Are Available?

Support groups:

- useful for sharing experiences.
- provide an environment where you can learn coping strategies
- can share approaches you have discovered with others
- gain strength in knowing that you are not facing hardships alone

Individual counseling: Sometimes people have problems that are better addressed in a one-on-one atmosphere. You can may more effectively express sensitive or private feelings you have about your illness and its impact on your lifestyle and relationships.



Psychological Challenges

Apathy: lack of interest, enthusiasm, or concern

Apathy and Lack of Initiation

- Apathy = inattention, indifference, lack of motivation.
 - Example: less concern for things about which a person used to demonstrate a great deal of care and concern.
 - A person with apathy might appear to be disengaged, or not emotionally invested in what is going on around them.
 - Apathy is prevalent in PD.
- A lack of initiation often accompanies apathy, but can also occur by itself in the absence of apathy.

STRATEGIES

- Medicines: stimulants are useful but may increase irritability and agitation. Antidepressants may offer some benefit, but are more helpful if there are concurrent symptoms of depression.
- Behavioral interventions can be successful. Typically, once a person has started an activity, they will participate.
- Often it is the person doing the initiating—the spouse, friend or caregiver—who needs support/encouragement.
- Apathy and a lack of initiation are part of the disease. Telling the person with PD that they are lazy will only increase tensions. Try not to interpret a lack of initiation or activity as laziness.

STRATEGIES

Educate other people about the person's inability to begin or initiate behaviors and encourage them to include the person in activities.

Use calendars, schedules, and regular routines. Cell phones, smart phones and tablets can be used to set reminders or alerts. Phone calls and texts from family members and caregivers can encourage participation.

Decreases in initiation can come with mild organizational difficulties. If an activity requires a series of tasks that are overwhelming or difficult to organize, the person with PD may need extra help in order to participate.

Impulsivity/Disinhibition

Impulsivity: Difficulty regulating or controlling emotional responses and impulses.

Can lead to people losing their temper more easily, drinking too much, or inappropriate sexual relations.

Disinhibition usually presents as the person having trouble controlling a sudden desire to do or say something that comes to mind, even when the behavior is hurtful, repetitious, or socially or sexually inappropriate.

Disinhibition can sometimes contribute to illegal behaviors, such as gambling.

Challenges in Impulse Control

- When a person fails to resist the drive to behave in ways that result in distress or impaired social and occupational functioning (but behaviors are w/in realm of normal behavior)
- In PD, behaviors most commonly include pathological gambling, excessive spending and hypersexuality (2-5% of patients)
- Often, the behaviors continue despite the knowledge that performing them will lead to bad outcomes and adverse consequences.
- This point helps differentiate them as a disorder of behavior as opposed to a disorder of cognition.

STRATEGIES

- Medications: Talk to doctor, who may reduce medications or switch to different medication that may be less likely to precipitate the behaviors.
 - Stopping dopamine agonists may eliminate behaviors **BUT**
 - **Stopping or changing medication doses without guidance can produce unwanted side effects in other aspects of functioning.**
 - Assess mood; this may be contributing

STRATEGIES

- **Behavioral measures:**
 - Behavioral interventions include taking away credit and bank cards, and limiting account access in the case of gambling.
 - 12-step gambling groups can also be helpful.
 - Restricting use of the Internet and video player can help in hypersexuality.

STRATEGIES

- Active listening - letting the person express his or her feelings rather than rapidly reacting to a behavior.
- Remaining in control may help calm the person with PD. Regulating one's responses can help avoid escalation of the situation. Practice staying calm in order to avoid reacting emotionally.
- A set routine and a predictable daily schedule can reduce feelings of confusion or fear and decrease the frequency of behaviors
- Be sensitive to the person's efforts to apologize. Avoid reminding the person of their behavior after the fact. This lack of control is part of the disease and is not by choice.

Cognitive Symptoms:

- Fatigue
- Bradykinesia/Bradyphrenia
- Attention/executive deficits
- Memory (poor retrieval, intact recognition)



Mild Cognitive Impairment and Executive Dysfunction

- Short-term memory retrieval is often difficult
- Multi-tasking becomes very difficult if not impossible
- Thought processing may be slower
- Abstract thinking becomes more difficult
- Motivation to initiate tasks and follow them through becomes difficult
- Insight into physical and cognitive limitations may be limited
- Visual perception is often altered

Fatigue/Bradykinesia/Bradyphrenia

- Fatigue: extreme tiredness, typically resulting from mental (cognitive) or physical exertion or illness
- Bradykinesia: means slowness of movement and is one of the cardinal manifestations of Parkinson's disease.
- Bradyphrenia: a medical term for slowed thinking and processing of information.

STRATEGIES

- **Planning ahead, prioritizing, and pacing.**

Plan activities (chores, exercise, and recreation) ahead of time. Space them out throughout the day.

- If you become tired during an activity, stop and rest. Ask for help. Divide the tasks among family and friends.

- **Plan periods of rest.** Be sure to get plenty of rest. You may need to plan at least one rest period every day.

- Avoid working long days.
- Rest between recreation and leisure activities.

STRATEGIES

- **Conserve your energy.** Using less energy with daily tasks can help you have more energy to do more activities during the day.
 - You may need to cut down on some of your activities or use energy-saving devices or techniques.
 - Do most important tasks when feeling most rested.
- **Allow extra time to do things.** Give plenty of time to complete tasks. PD symptoms often worsen if person feel rushed and/or stressed.

ENERGY CONSERVING TIPS FOR THOSE WITH PARKINSON'S DISEASE

- Simplify your tasks and set realistic goals. Don't think you have to do things the same way you've always done them.
- Practice good sleep hygiene (bedtime routine; consistent bedtime; avoid watching TV, eating, using computer, etc. in bed)
- Rest 20-30 minutes after a meal.
- Limit naps so you are able to sleep at night.
- Avoid extreme physical activity.(but exercise daily).
- Avoid caffeine late in the day

STRATEGIES

- Relaxation and stress management techniques
- Mental imagery





EXECUTIVE FUNCTION

Shifting

Flexibility

Inhibition

Self-Monitoring

Working Memory

Impulse Control

Planning

Initiation

Organization

Updating

Problem Solving

Emotional Control

Organization/Planning

- Organization involves the planning, sequencing and prioritizing of information.
- Difficulties can impact a person's abilities to conduct basic ADLs, as many everyday activities require a complex set of steps
- Affects problem solving, logical thinking and deductive reasoning

STRATEGIES

- No medications specifically for organizational difficulties.
- Behavioral techniques:
 - Limit the amount of information the person is given at one time
 - Maintain regular schedules and routines as much as possible
 - Review schedules and routines frequently and keep them up to date

STRATEGIES

- Use calendars, white boards, to-do lists, etc. that can be easily referred to during the day.
- Write down steps/instructions, directions
- Keep things in one place
- Keep things that are used together close to each other
- Put things back where they belong and eliminate clutter!
- Use watch alarms, automatic shut-off appliances, blister-packed medications

STRATEGIES

- Get the person's attention before asking a question or giving information
 - Maintain attention while communicating
 - Keep eye contact while speaking to each other
- Use cues (verbal, timer) to indicate change in task/focus
- Finish one task before moving on to another
- Simplify the environment (“declutter”)
- Have another person attend appointments
 - Can help with decision making/problem solving
- Brainstorm when decisions needed

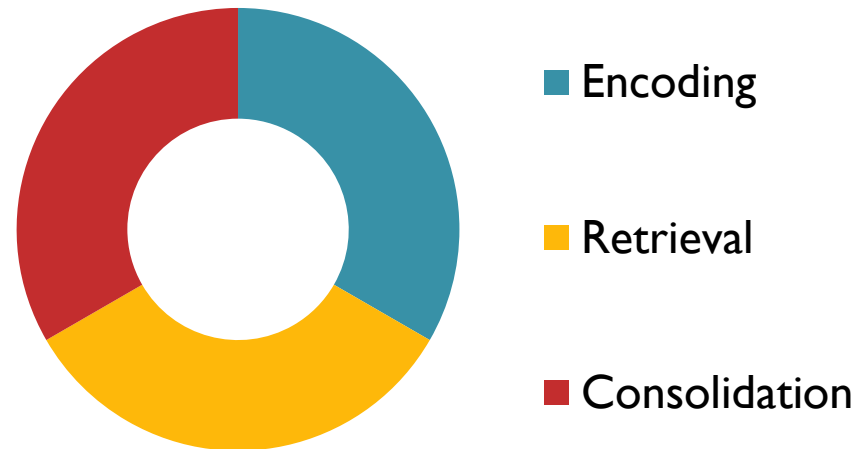
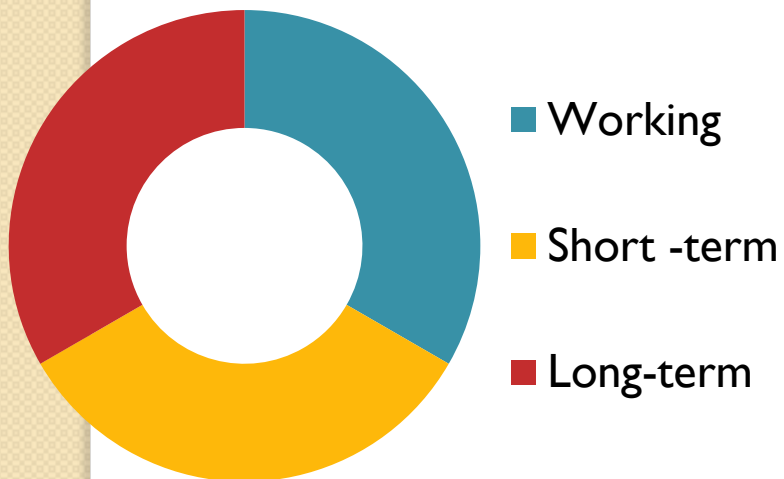
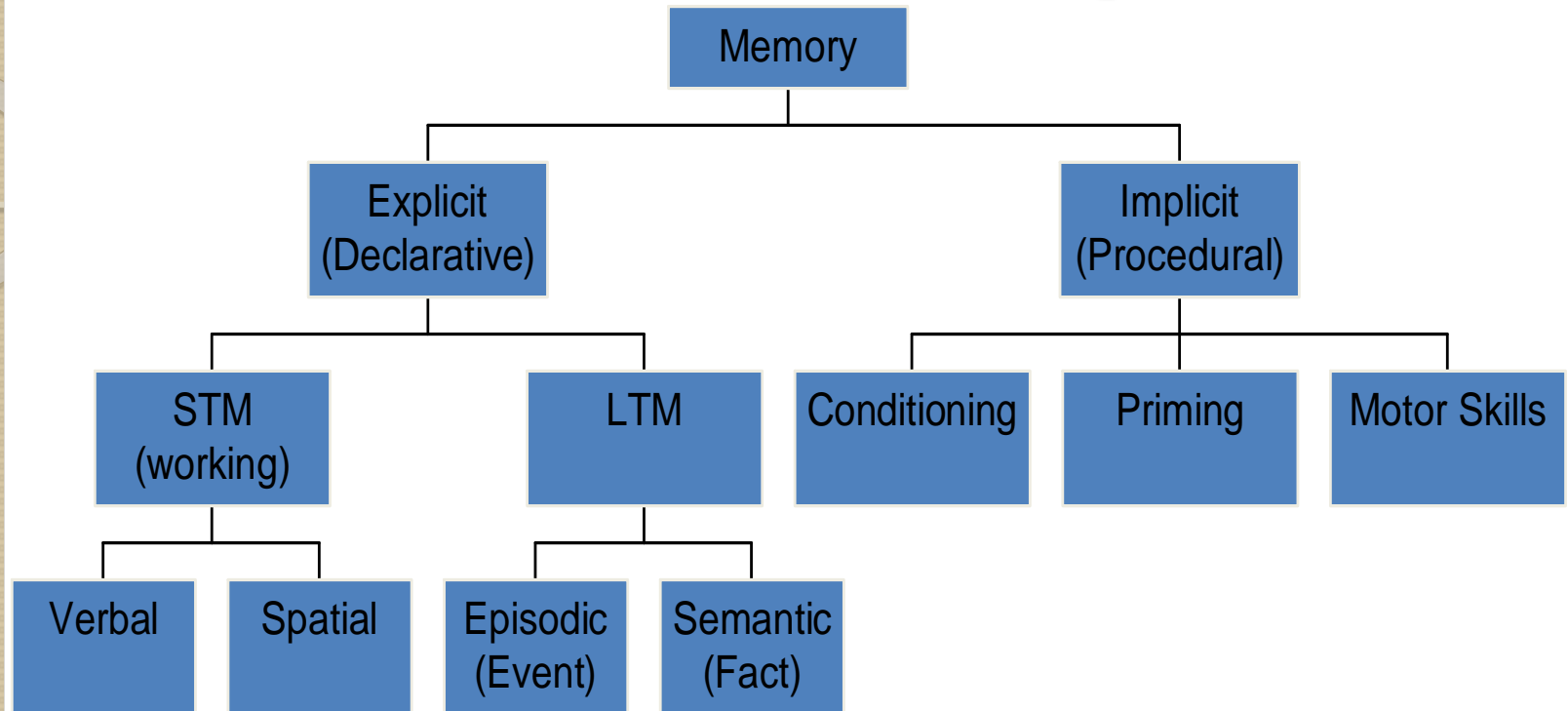
STRATEGIES FOR EXECUTIVE DYSFUNCTION

- Practice functional activities that challenge memory and reasoning skills



- Try to maintain a quiet, distraction-free environment when learning new information
- Encourage rehearsal of new material repeatedly, and categorize and visualize information
- Allow plenty of time to process new information and to respond in conversation

What is “Memory”?



Learning and Memory Problems

- Retrieval difficulties: ability to elicit information from memory
- Implicit memory: recall of a collection of coordinated skills, movements, etc.
- Short-term memory: memory for recent events, information
- Can be influenced by other factors including psychiatric symptoms, environmental influences, and other cognitive symptoms (impulsivity, organizational problems)

Primary Memory Treatment Strategies

- Organize/Categorize information
- Translate into your/their own words
- Relate something new to something familiar
- Break down info into small pieces
- Multi-sensory input
- Provide opportunity for repetition. Rehearse during the first hour after the event

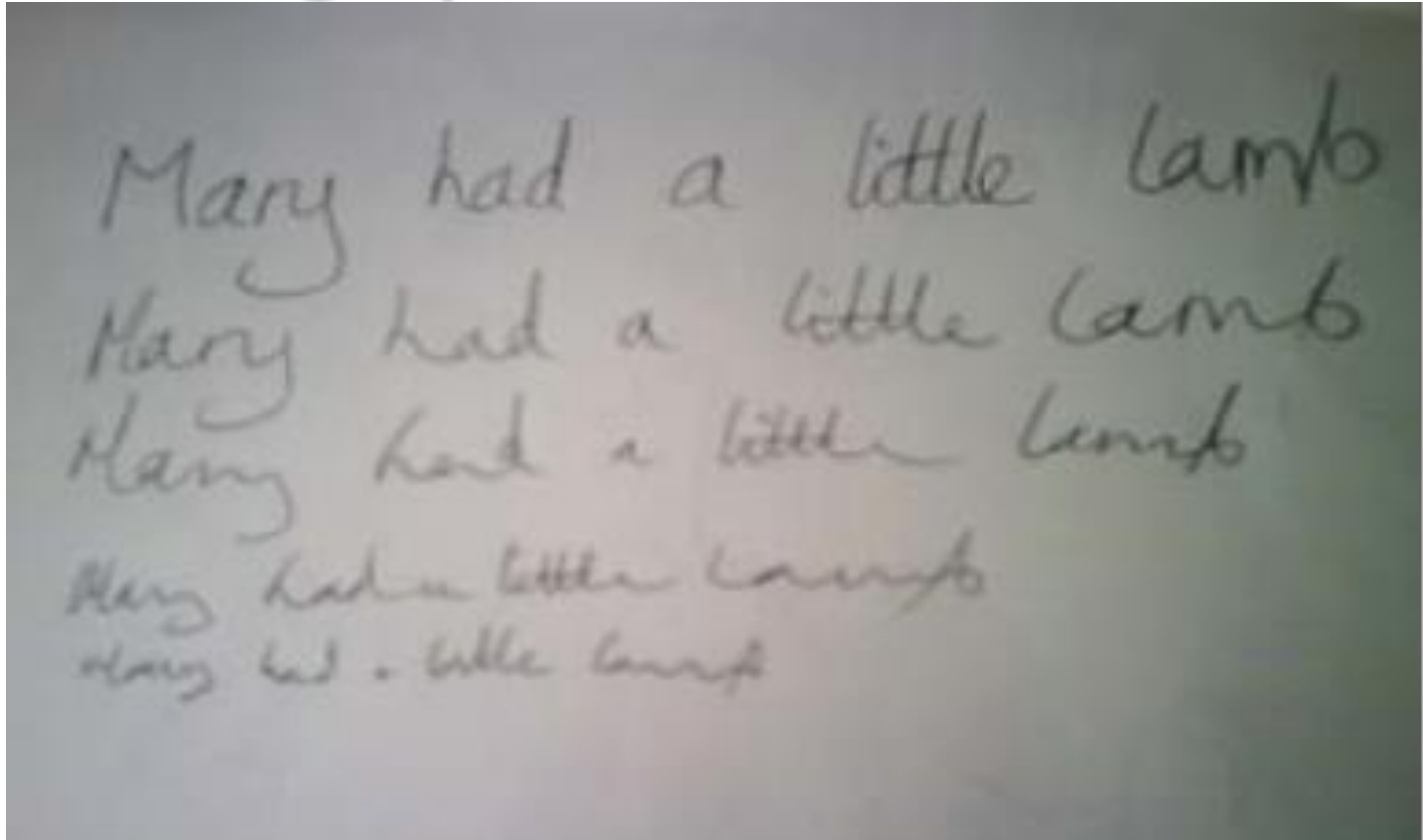
Primary Memory Treatment Strategies

- Provide verbal reminders/ written prompts
 - Checklists and written reminders can be helpful
- Use Lo-Tech Devices
 - Sticky notes, dry eraser boards, watches
- Use technology when helpful
 - Text message reminders from caregivers, calendar or alarm on tablet or phone

Primary Memory Treatment Strategies

- Keep day-to-day activities as routine as possible
 - Regular, consistent structure will enhance learning and recall
- A person with PD may have a more difficult time retrieving information, but that does not mean that they can't.
 - When asking a question, give the person enough time to respond.
- Think about how you ask for information:
 - Offer simple alternatives or a limited list of choices to assist with recall.
 - Either/or questions often work well.
 - Avoid asking open-ended questions

Micrographia:



The quick red fox jumped over the lazy dog ~~TODAY~~ IS TUESDAY

Parkinson's disease

Essential tremor

STRATEGIES



- Eliminate distractions
- Sit at a table in a sturdy chair with elbow & wrist supported
- Remind loved on to take their time and visualize themselves writing BIG
- Try a variety of pens
- Practice, practice, practice!

EVIDENCE-BASED PRACTICE FOR REHABILITATION IN PD: PRACTICE, PRACTICE, PRACTICE

- Individuals with PD have been shown to improve their performance on fine and gross motor tasks with frequent, regular practice
- Individuals with PD have been shown to improve performance on measures of cognitive skill with frequent, regular practice

Hypophonia (“soft speech”)

- With hypophonia, there may also be a change in perception.
 - The voice has become softer, but to the individual it still feels normal, and a request to be louder is often met with resistance or a comment such as “that feels like I’m shouting.”
- Can result in withdrawal from social interactions

STRATEGIES

- **Home Practice**

- Skill is lost because of the disease having an impact on the way the muscles work
- Practice helps retain improvements made in therapy
- Remember person is not being lazy or not trying hard enough

- **Group classes can improve outcomes**

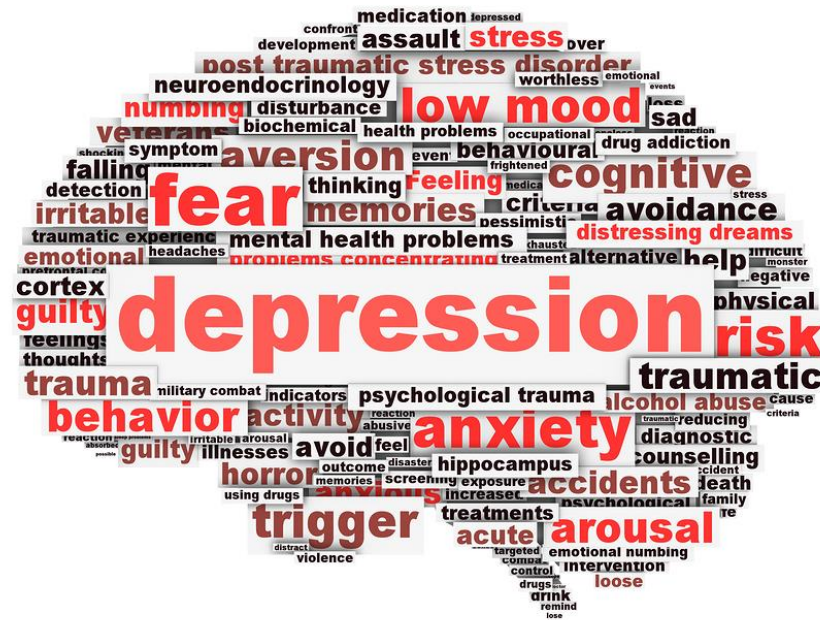
- Group classes and after-therapy programs can be helpful as they provide a light-hearted atmosphere.

- **Sometimes, it's psychological**

- Person can feel overwhelmed or like it is “too hard”
- Can be addressed by family or in therapy

- **Embrace tech to empower patients**

- There are apps available for home practice such as **Speak Up For Parkinsons** for improving loudness. There are also speech aid devices such as **Speech Easy**.
- **Can be done on computer or phone**



Psychiatric Symptoms

Affective Distress

What Is Parkinson's Disease Psychosis (PDP)?

PDP is a group of nonmotor symptoms, including:

- Hallucinations: seeing, hearing, smelling, or feeling things that aren't real
- Delusions: believing things that aren't true
- Illusions: seeing a real image but thinking it's something different

Not everyone with Parkinson's will have PDP, but many will face it at some point.

Causes of PDP

- Some medicines can trigger PDP, including:
 - Dopamine medicine (carbidopa/levodopa) which helps with smoother movements.
 - Over time, too much of the medicine can cause chemical and physical changes in the brain which may lead to PDP
 - Changes in your dose or a new medicine
 - OTC medicines, such as some antihistamines or aspirin
- Delirium or infections like UTIs can also trigger PDP

STRATEGIES FOR CAREGIVERS/FAMILY

- Reframe: It's not easy to see someone you're caring for have hallucinations or delusions. Remember that Parkinson's causes the symptoms, and your loved one can't control what he or she is thinking, feeling, or seeing.
- It's important to tell your family's healthcare provider what's going on -- even if he or she doesn't ask about it.
- He/she can help you decide if a change in medicine will help, explore other treatment options, and suggest ways that you can talk to and soothe the person you're caring for,

Depression

- When facing a diagnosis of Parkinson's disease, it is understandable that a person might feel anxious or depressed. But mood disorders such as anxiety and depression are real clinical symptoms of PDs, just like rigidity and tremor. In fact, depression can start before motor symptoms are even observed.
- At least 1/2 of PD patients may suffer from clinical depression at some point during the course of their disease.
- Depression can affect long-term outcomes for the worse by hindering critical elements of an overall treatment regimen such as staying socially connected, exercising to manage motor symptoms, or being proactive about seeking care.
- What should you look for? A lack of enjoyment in activities and situations that you used to enjoy
 - Pay attention to observations made by family and friends as well

Depression

Symptoms of Major Depressive Disorder:

- Depressed mood most of the day, nearly every day
- Decreased ability to find pleasure or interest in usual activities
- Significant decrease or increase in appetite or weight
- Fatigue or loss of energy nearly every day
- Changes in sleep – insomnia or hypersomnia
- Restlessness or feeling physically slower
- Decreased ability to think, concentrate, and make decisions
- Feelings of guilt or worthlessness
- Recurrent thoughts of death or committing suicide.

STRATEGIES

- **Medications:** selective serotonin reuptake inhibitors (SSRIs), selective serotonin and norepinephrine reuptake inhibitors (SNRIs), atypical antidepressants, and antipsychotic or neuroleptic medications. **CONSULT WITH YOUR DOCTOR.**
- **Support Groups** can be helpful.
- **Behavioral interventions**
 - Encourage the person to talk to someone they know and trust about depression. Taking this first step is often the most difficult. .
 - Reinforce maintenance of routines and schedules.
 - Monitor and report conversations about suicide and death

STRATEGIES

- Behavioral strategies:
 - Exercise (force yourself) – even just a little
 - Reach out and stay connected with friends/family – face to face when possible
 - Keep up with social activities, volunteer, care for a pet
 - Schedule a regular, weekly activity
 - Join a class or a club
 - Do things that make you feel good
 - Aim for 8 hours of sleep
 - Practice relaxation techniques
 - Reduce intake of caffeine, alcohol,, trans fats, and foods with chemical preservatives or hormones
 - Get a daily dose of sunlight (at least 15 mins/day)

Anxiety

- Anxiety can present in a variety of ways including:
 - General nervousness
 - Excessive worrying
 - Repetitive thoughts about troublesome topics
 - Fidgeting hands
 - Shallow breathing , Rapid heart rate, Sweating
 - Restlessness
 - Fear/Panic
- **Social anxiety** is worry or fear about how one will be perceived in social settings.
- **Panic disorder** involves an acute onset of overwhelming anxiety and feelings of dread, often accompanied by physical symptoms
- Anxiety symptoms will typically become worse in new situations or when the person perceives him or herself as having insufficient skills to handle the situation.

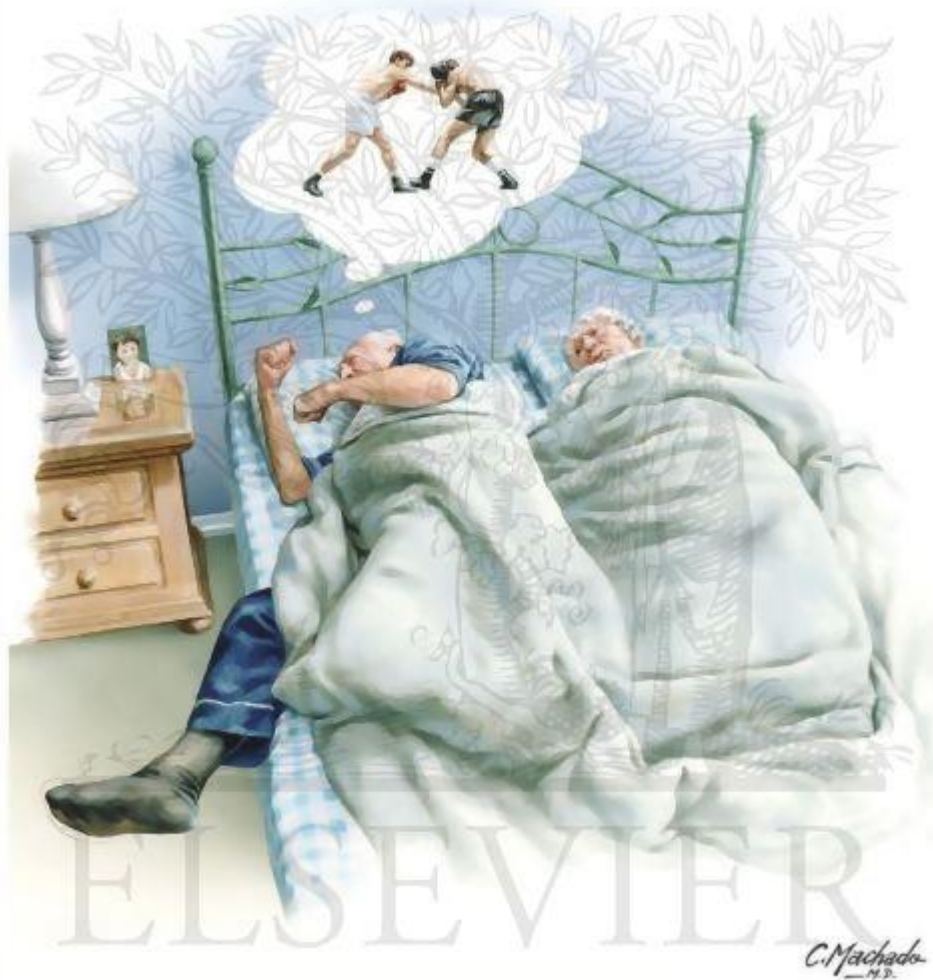
STRATEGIES

- Medications: Discuss with your doctor
- Cognitive-behavioral interventions can help avoid or minimize the likelihood of a person with PD becoming anxious.
 - The cognitive component looks at a person's anxious thoughts and teaches him or her how to challenge these beliefs. First step: identify the anxiety provoking thoughts (e.g., "I won't be able to finish this project at work," or, "everyone thinks I can't be helpful because I have PD").
 - 2nd step: Develop a challenging statement to the original thought (e.g., "I don't know what everyone else is thinking, but my family still thinks I am helpful around the house"). Making positive self-statements, such as "It's OK," can be effective in reducing anxiety.
 - The behavioral component - interventions that minimize the physiological aspects of anxiety, including relaxation training.

STRATEGIES

- Establish regular routines and stick to them.
- Keep the home environment simple.
 - An overabundance of stimuli can lead to the person with PD becoming overwhelmed.
- Simplify requests and demands.
- Sometimes it is helpful to refrain from discussing future events until the day before the event is to occur.
 - In other cases, again depending on the person, gently introducing an event in advance and adding details over time can minimize anxiety.
- Look for any identifiable trigger(s) and recommend that the person with PD discontinue the activity that is contributing to the feelings of anxiety.

Sleep Issues



REM sleep behavior disorder

- In a person with REM sleep behavior disorder (RBD), the paralysis that normally occurs during REM sleep is incomplete or absent, allowing the person to "act out" his or her dreams. RBD is characterized by the acting out of dreams that are vivid, intense, and violent. Dream-enacting behaviors include talking, yelling, punching, kicking, sitting, jumping from bed, arm flailing, and grabbing.

Sleep Cycles: REM and NREM

- Normal sleep has two distinct states: non-rapid eye movement sleep (NREM; 4 stages) and rapid eye movement (REM) sleep
- During REM sleep, rapid eye movements occur, breathing becomes irregular, BP rises, and there is a loss of muscle tone (paralysis).
- However, the brain is highly active, and the electrical activity recorded in the brain during REM sleep is similar to that recorded during wakefulness.
- REM sleep is usually associated with dreaming.
- REM sleep accounts for 20%-25% of the sleep period.

STRATEGIES

- Clonazepam, a benzodiazapine, curtails or eliminates the disorder about 90% of the time.
- The advantage of the medication is that people don't usually develop a tolerance for the drug, even over a period of years.
- When clonazepam doesn't work some antidepressants or melatonin may reduce the violent behavior

STRATEGIES

- Bedroom safety precautions
 - Move objects away from the patient's bedside. This includes night stands, lamps, or other objects that could cause injury.
 - Move the bed away from the window.
 - Place a large object such as a dresser in front of the window.
- Maintain a normal total sleep time. Sleep deprivation will increase RBD. Monitor for any sleepiness.
- Avoid certain medications and alcohol. They can cause or increase RBD.
- Treat any and all other sleep disorders that will disrupt your sleep and increase RBD.

Summary

- Research suggests that:
 - People with PD who maintain active lifestyles have more slowly progressing symptoms than those who do not
 - People with PD who maintain their participation in valued daily activities are less depressed and adapt better to their diagnosis than those who do not, regardless of the severity of their symptoms



Questions/Comments?

