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“Pearls” for Living with Parkinson Disease

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Sharing is Caring



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What we can share:

- Diagnosis
- Knowledge
- Tips
- Emotions





“Pearls” for Diagnosis

- Not everyone reacts the same
- Identify your supports
- Seek information from credible resources
- Make a list of your questions for appointments
- Stay connected





“Pearls” of Knowledge

- You help shape your prognosis
 - Exercise makes you stronger
 - Being sedentary makes you weaker
 - You are what you eat
 - Your mood will impact your mobility
 - Your sleep will impact your mood
- Our goal is independence
 - This doesn't mean ALONE
 - It may require asking for help
 - Identify your resources: especially your local Aging and Disability Resource Center (ADRC)
 - You may need a device to keep you safe in your home
- Learn more about PD
 - Ask questions at your PD visits
 - WPA website materials
 - Attend support groups



“Pearls” for Everyday Living





Reducing Medication Cost

- Check insurance on covered pharmacies
- Shop around pharmacies for prices
- Ask for a tier exception
- See if you qualify for assistance programs
 - Medicare.gov
 - Pharmaceutical company indigent programs
 - Good Rx
 - Prescriptionhope.com
 - Patient Access Network Foundation (PAN)



Managing Medications

Set up medications to avoid missed or overdose

- pill boxes
- locked or timed boxes
- bubble packs

If swallowing pills is a problem:

- Make sure you sip water first!
- Take in applesauce or Greek yogurt
- Talk to your provider about medication options
 - orally disintegrating carbidopa/levodopa (Parcopa)
 - Rytary capsules that can be opened and sprinkled
 - Neupro transdermal patch
 - immediate release carbidopa/levodopa can be crushed
 - extended release can be broken in half but not crushed
 - Rescue medications include Apokyn (injection), Inbrija (inhaler) and Kynmobi (sublingual film)

Swallowing and PD

- Levodopa can improve swallowing
 - It can be used as part of your treatment goal
 - It is important to know when your medications “kick in”
- Avoid eating larger meals when “off”
- Eat when less tired- may need to move your main meal to noon
- Avoid hard, dry or crumbly food
- Take your time- eat in a comfortable, quiet space
- If taking a long time to eat and food gets cold- consider smaller, more frequent meals, or easier foods to eat
- Use heated plates
- Report problems to your provider- they will likely order a Speech Therapy (ST) bedside or video swallow study
- Using an incentive spirometer can help clear the airway

Water and PD

The PD triad: Constipation, Dizziness and Confusion

Your brain is 80% water!

Dehydration causes cognitive slowing, fogginess, lack of concentration and in some cases confusion and hallucinations.

- Signs you need to drink more water:
 - Dry skin
 - Constipation
 - Mental fog
 - Fatigue
 - Headaches
 - Dark urine
 - Dizziness
 - Muscle Cramps

Water Your Brain

- Make water more flavorful by adding fruit, a sprig of mint or lime. Infused water is natural and contains more nutritious vitamins and antioxidants.
- Switch your soda to sparkling water or mineral water
- Avoid added sugars or artificial colors
- Sip! Don't chug!
- Dehydration can actually cause bladder spasms and retention
- Your body only absorbs about a Dixie cup of water every 30 minutes...the rest you will urinate out.
- Cant remember to drink water?
 - Get a BPA free cup that has time and measures printed on it
 - Purchase a light up cup-to remind you to drink every 30-60 min
 - People with memory problems may enjoy sugar free popsicles to help stay hydrated

Bladder in PD

- Avoid urgency by getting to the bathroom every 2 hours whether your bladder says so or not!
- Sip don't chug!
- Avoid caffeine stimulants
- Massage your abdomen over the bladder area after urination
- Bladder medications that have a side effect of "dry mouth" can "dry your thinking"
- Pelvic floor exercises can be prescribed instead of medications

Bowel in PD

- Fiber
- Water
- Probiotics
- Diet
- Apple cider (patient recommendation): the "murky stuff!"
- Medications to improve gut motility may be needed

Random “Pearls”

Off time or sedentary ideas

- Double vision exercises
- Hand exercises
- Practice Meditation
- Reading, audiobooks or brain games
- Limit multi-tasking when “off”

You may have to change the time of day you normally do things to accommodate your PD: that’s okay! Make room for change.

Don’t walk with Bi-focal or Trifocal lenses

“Pearls” for Emotions

Anxiety, depression and sleep disruption are part of PD but there are methods to improve them.

Learn Meditation

- helps you feel calmer and less stressed
- can lower the risk of Alzheimer's by reducing the stress hormone cortisol, which has been known to increase the risk of developing **dementia**.
- increases cortical thickness and grey matter (keep it plump) which slows the aging rate of the brain

Seek resources and keep practicing. It takes time to become skilled.

Meditation can greatly improve your sleep quality

Meditation

- Create a special peaceful environment, free of distractions
- Try it for just ten minutes a day for one month with the simple goal of developing more positive emotions, reduce stress, and strengthen focus in daily life.

If you have a few minutes in the morning or evening (or both), rather than watching TV, turning on your phone or going online, see what happens if you try quieting down your mind.

Other Considerations

- Create a vision board to help you through those “tough days” and any apocalyptic thoughts.
- Cognitive Behavioral Therapy- We can all acquire better tools to deal with our obstacles.

Neuroscience Group Memory Care Program

Who should schedule an appointment?

Medical evaluation is essential when memory loss interferes with the ability to carry out activities of daily living and seems progressive. Here are some of the warning signs:

- Challenges in planning or problem solving
- Difficulty completing familiar tasks
- Confusion with time or place
- Trouble with visual images and spatial relationships
- Change in ability to recall words or express self in conversation or writing
- Misplacing things and losing the ability to retrace steps
- Decreased or poor judgment
- Withdrawal from work or social activities
- Changes in mood or personality

What are some of the benefits of an appointment at the Memory Care Center?

- Identify treatable causes of memory changes
- Manage symptoms with medication and other interventions
- Open access to valuable support services and education
- Allow planning for the future



<https://neurosciencegroup.com/memory-care-center/>



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Thank You!

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