ADULT CHILDREN OF PEOPLE WITH PD TIPS & TOOLS

Sharing experience, solutions and hope



COGNITIVE DECLINE

Discuss one topic at a time

When you switch topics, make the switch clear

Tell the person the topic first and what you want to get out of the discussion

Ensure there is comprehension along the way

Remember that PD will impact executive function (problem solving, ordering of tasks, reading emotions)



MOOD: Depression Anxiety Apathy

- All of these things are a natural part of PD and the reduction in dopamine
- Normalize it, expect it
- Join the person in the walk, get them moving with you, let them borrow from your energy and enthusiasm
- Ask the person with PD and care partner to keep a log of this over the course of 1 week to track and share with the doctor
 - when this happens
 - timing as it relates to meds
 - what was the person doing at the time
- Medications can help these things.
- Exercise, movement, intentional activity.



SUPPORTING FROM A DISTANCE

- Let the care partner know they are doing a good job (they are doing a job they did not plan to do and are learning as they go)
- Encourage social activity to reduce the tendency to withdrawal
- Create a plan for surgeries and hospital stays to reduce confusion/strain in times of emergencies
- Check in on how the person with PD AND CP is doing
- Ask direct questions and let the person know you want to really hear it all
- Remember what you see when you visit is not the *real* situation, people with PD rally for a day or two and some daily challenges can be reduced

HAVING HARD DISCUSSIONS

- Use standard tools that provide a guide for walking through hard conversations (ie. 5 Wishes)
- Do the tool as well. We should all have it, doing it together will help everyone learn and be on a level playing field.
- Start with "I need to have this discussion and I am nervous" or "I am unsure how to do this but here goes".
 Stating the fear/anxiety up front, takes the sting out.
- Remember that PD is a degenerative disease. If it is not talked about now it will be eventually and likely at a time that is more stressful

