**Lynhon Stout, MSW**

**Support Group Leader**

**Caregiver of PD Spouse**

**6-6-2025 Parkinson’s Conference**

**Opening Comments:**

**Caregiving is one of the most difficult jobs on the planet. (Keven Klos)**

**Caregiving described as the most rewarding, frustrating, gratifying, challenging, amazing and demanding job you’ll ever have the honor and privilege of fulfilling. (Shelly Carter)**

**Being a caregiver requires infinite patience, physical and emotional strength, health care navigation skills and a sense of humor. (Rosalynn Carter)**

Great book for Caregivers ***WHAT I NEED FROM YOU*** – by Felicity Klos and Keven Klos, M.D. What people with PD need in terms of help and support through the disease process. How they preferred to be treated. (Some of the comments presented are from this book.)

**Some of my personal thoughts on caregiving:**

What I did Well:

1. Studied on Parkinson’s- Focused on finding information,
2. Listened to my partner, they want to be heard and need to feel validated and to know their symptoms are real.
3. Went to every appointment with him and recorded information and next appointments
4. Document issues and med times – side effects, off times, progression- write it all down
   1. Discussed those with Dave BEFORE meeting with doctor so no surprises.
5. Worked with the team
6. Make sure family knows what is happening, how to take meds, and needs of PD
   1. Don’t assume families know about Parkinson’s
   2. Every Patient is different
7. Attended support groups and informational meetings, zoom

Support groups can help because people attending understand and can emphasize, often advise and just be a listing ear when you need it the most. Members know how it truly feels to live with PD and be a source of comfort. (Caryn Crenshaw, RN)

1. Joined APDA
2. Received information from on line sites -Michael J. Fox Foundation, Davis Phinney Foundation, Parkinson’s Foundation, APDA
3. LOVED HIM WITH ALL OF MY HEART

What I could have done Better:

1. Let him speak for himself

2. Having more patience all of the time

3. Listened more

4. Not nag

**Important items to know:**

**ABOUT PERSON WITH PARKINSONS (PD)**

**\*\*\*\*\*\* They have anxieties/fears — loss of independence. disease complications and progression, burden to others, worry about the medicines/treatments**

**Advice to You caregiver from people with PD**

1. **Don’t over-care for your loved one**
2. Let them do what they can even when it takes longer-getting dressed, etc.
3. Don’t be a helicopter spouse – watching and following every move to prevent falls
4. Don’t treat PD like a child- instructing what to do and not to do
5. Don’t use tone of voice like talking to a child
6. Find a balance to help when needed but encourage your love one to be more active and self-sufficient.
7. **Be patient with me**
   1. Let us try to do it on our own even if slow and making mistakes
   2. PD takes longer to think about what they want to say and formulate their thoughts- spouse sometimes jumps in and speaks for them
   3. Takes more time to get ready on their own
   4. Don’t stop doing activities -Example church was important to PD, but spouse thought it was too hard to get in and out of car, and around church, so stopped going.
8. **People with PD want to be helped, not helpless.**
9. **Give us a chance**
   1. Let us try to do on our own even if slow and making mistakes (typing)
10. **Don’t let me hold you back**
    1. Use respite
11. **Get Prepared**
    1. Complete all legal documents
    2. Expect the Unpredictable

**FOR CAREGIVERS/CARE PARTNERS**

Caregivers feel stress as they see health decline.

Caregiving is emotionally and physically challenging.

Caregivers experience loss of emotional and physical connection to person with PD.

Caregivers are concerned about the future.

Caregivers may be lonely, angry, sad, anxious, exhausted, heartbroken, scared and grieving- all while putting other’s needs ahead of their own.

Caregiving can impact caregiver’s health.

Caregivers may have less personal time and time for family obligations and activities.

1. **Anxieties of caregivers -**Caregiver’s can manage your fears/anxiety by:
2. Maintain a mindfulness practice such as starting a journal or creating a grateful list.
3. Get emotional support through friends, support groups, on-line training, therapist
4. Refocus on current tasks or other topics
5. Minimize time with negative people
6. Deep breathing exercises.
7. Seek calm through spiritual means
8. Study/research on Parkinson’s
9. Attend support groups and training
10. **Communication**
    1. It is most important to work on better communication.
    2. Handle your emotions by talking with someone or practice mindfulness
    3. Never assume you know what they are feeling – use active listening, don’t interrupt
    4. Ask what are their concerns and what could you do better or different
    5. Help them release those fears and anxieties – let them express them
    6. Tell them what you need
    7. Use I statements: I feel \_\_\_\_\_\_ when \_\_\_\_\_\_\_
    8. Sandwich statements – say a positive comment on either side of a need statement
11. **Nagging -is constantly harassing someone to do something. – instead encourage and remind –** Some PD patients express spouse/care partner nags. Do you find yourself saying “do this, do that and don’t forget to do this? Caregiver is concerned about well-being of loved one, but needs to understand nagging.
12. Nagging may rob a person of their motivation and desire for most activities.
13. It builds up frustration, shame and feelings of anger.
14. PD response may be passive aggressive or forgetting (short term memory)
15. Many of the problems we nag about posture, short steps, soft voice are automatic functions of the brain that we as caregivers do not think about. Person with PD must.
16. We nag about these as we hear professionals give advice. Better received by a professional.
17. Low dopamine levels result in lack of motivation
18. Bad days, mental symptoms and apathy may affect motivation of the PD.
19. They don’t want to be a burden

**Ideas on how to interact so you are not Nagging:**

**1. Discuss the expectation of both partners**

a. Discuss how much exercise and type

b. Discuss reasons why PD might not want to exercise- physical exertion, times

when medication is not working, disease is flaring up, uncomfortable or in more

pain, muscles may be weak.

**2. Do Not criticize**

a. PD may not feel good about feeling ashamed on any lack of consistency with their

exercising. They may not be lazy or apathetic.

**3. Find an Exercise partner - you**

**4. Remind with kindness**

**5. Affirm positive response and celebrate accomplishments**

a. Nagging puts a strain on a relationship and does not usually end up changing behavior

b. Say please

c. Give the patient a chance to respond to a request and honor their decision on how

they which to respond**.**

1. **Self-Care tips for Caregiver** 
   1. Carve out moments for yourself
   2. Take Care of yourself
   3. Maintain a Mindfulness Practice
   4. Meditation. Gratitude Reflection
   5. Get emotional support
   6. Seek Help with Caregiving
   7. Know your resources
   8. Stay engaged with loved one
   9. Know your work as a caregiver is appreciated
   10. Talk with others who understand
   11. Let go of guilt
   12. Join a support group
   13. Stretch and breath
   14. Get some laughs
   15. Get rest
   16. Prioritize nutrition
   17. Reduce caffeine
   18. Listen to music
   19. Treat yourself
   20. Make time for hobbies
   21. Play with fury friend
   22. Read books
   23. Self-help mantras
   24. Consider professional help
   25. Be kind to yourself

Closing Comment:

From *What I Need From You –*“ If you put the needs of your loved one with PD above yours, if your pour your love into your family member with PD, then you are a successful caregiver. No one on the planet will be able to care for your loved one like you can. Only you can love your loved one with the deepest unconditional love.