Care partners: Taking Care of your Partner, Taking Care of Yourself!

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Outline

- Part 1: Challenges of being a care partner
- Part 2: Strategies for helping yourself and your partner

Part 1: Challenges of Being a Care Partner

Parkinson’s Disease

- A challenging disease for many reasons:
  - It is typically diagnosed in individuals in their 50’s-60’s who are in the midst of a life transition (e.g., thinking about retirement)
    - Often leads to making significant decisions about finances, leisure, and long-term healthcare
    - Places an increase physical and emotional responsibility on the care partner, especially as the disease progresses

Parkinson’s Disease

- A challenging disease for many reasons:
  - A distinct presentation from patient to patient
  - A distinct progression from patient to patient
  - As such, no one care partner will have the exact same experience as another; however, there is plenty of commonality

Neuropsychiatric Disorder

- Motor
  - Tremors
  - Gait Disturbance
  - Slowed movements
  - Dyskinesia's
- Sleep
  - REM Sleep Disorders
  - Restlessness
- Cognitive Impairment
- Emotional
  - Anxiety
  - Depression
  - Apathy
- Behavioral
  - Hallucinations
  - Impulse control disorders

Motor Symptoms

- Tremors that may begin on one side of the body and progress to the other
  - Creates a challenge for self-care
- Gait instability (e.g., freezing, poor balance)
  - May lead to falls
  - Reliance on using an assistive device
- Bradykinesia
  - Slower movements in general

Motor Symptoms

- Care partners report mental stress attributable to maintaining surveillance for falls and repeatedly cueing for protective behaviors.
- The unpredictability of motor symptoms and the rigors of administering medications on schedule limit the capacity of care partners to plan for activities outside the home and contribute to social interactions.

Sleep Disturbance

- REM Sleep behaviors
  - Thrashing around in bed acting out dreams
    - May become unintentionally violent
  - Screaming/hollering
  - Sleepwalking
- Restlessness from medications

Sleep

- Persons with PD may experience disturbed sleep in association with nonmotor symptoms such as pain, depression, and hallucinations, as a consequence of restless legs syndrome or REM sleep behaviors.
- Care partners who share their bed with the person are also likely to have insufficient or poor-quality sleep.
- Care partners who sleep separately may nonetheless need to assist the person overnight.
- Up to 95% of PD care partners complain of sleep disturbance, which is a risk factor for developing depression

Speech

- Communication can be strained and lead to significant frustration due to hypophonia, decreased fluency, and attentional difficulties
- Eventually, the partner may become slower in their thinking and therefore slower in their responses
- Fluency may eventually decrease to a point that language becomes sparse

Smell

- Reduced sense of smell is a common symptom
- Can impact taste, and therefore, may lead to reduced appetite/decrease in weight
- May eventually impact self-care such as necessity for bathing, cleaning oneself

Depression

- Depressive symptoms include sadness, lack of enjoyment, pessimism, guilt, and suicidality.
- Depression is likely to narrow the behavioral repertoire of the person with PD and reduce warmth and reciprocity in the care partner relationship.
- Depression amplifies fatigue and reduces motivation, effecting a further reduction in independence and the capacity to perform activities of daily living.

Anxiety

- Anxiety often precipitates avoidance of triggering situations, stigma, manifesting as agoraphobia, which limits the capacity of care partners to maintain their social network unless they leave the person with PD at home.
- However, anxiety may also lead to excessive reliance on the care partner for reassurance and supervision, a form of conditioned safety behavior that can be overwhelming for the care partner.
- In extreme situations, persons with PD are intolerant of being alone and become distressed when the care partner is out of sight.

Apathy

- A feeling of indifference that may lead to a lack of behavior:
  - Initiation
  - Motivation
  - Desire
  - Affection
  - Interest
  - Decision-making

Apathy

- Apathy includes both loss of motivation and loss of emotionality.
- This is manifest in diminished goal-directed activity and reduced spontaneous or evoked emotional display.
- It overlaps with but is distinct from depression and dementia. Similar to those persons with depression, persons with PD who display apathetic symptoms lack warmth, and this may reduce the positive emotional feedback received by the care partner.
- Persons who are more severely affected will require their care partners to structure their daily routine and may even need prompting to complete basic tasks such as washing or brushing of teeth.

Hallucinations

- Most of the time, visual hallucinations are vivid in color, therefore it is difficult to know that they are not real
- Often involve family members
- May be frightening
- More prone to occurring at night, upon waking, or sleeping

Impulse Control Disorders

- One of the most challenging behaviors that may be part of PD
- Can lead to care partner embarrassment and difficulty talking to medical professionals and/or social supports about these issues
- Compulsive behaviors such as pathological gambling, hypersexuality, binge-eating, compulsive shopping, and dopamine dysregulation are relatively common complications of PD treatment.
- The behaviors themselves, even if transient, may have lasting financial, social, and legal consequences that can add to the burden on a household.

Impulse Control Disorders

- Hypersexuality, if associated with the use of pornography or with extramarital affairs, can lead to a sense of betrayal in the care partner.
- Furthermore, many persons with ICDs are secretive about their compulsions and may persist with their behaviors, despite vowing to cease them, which fuels mistrust if they are subsequently discovered.
- Other persons with PD lack insight into the harms associated with their ICDs and may avoid interventions or refuse to comply with clinical advice.

Cognitive Functioning

- Mild neurocognitive impairment in PD
  - Typically represented by declines in cognitive functioning without it having an impact on daily functioning
- Major neurocognitive disorder in PD
  - Represented by a decline in cognitive functioning in combination with an associated functional decline
    - E.g., inability to manage ADL/IADL's independently
  - 75% of PD patients may exhibit MND 10 years following diagnosis

Attention and Concentration

- Variability in focus
- Attention becomes shorter
- Challenges with complex/divided attention which leads to poor multi-tasking
- May fluctuate in response to medication “on” and/or “off” states

Processing Speed

- Bradyphrenia
  - Slowed thinking
  - Slowed ability to process information
  - Subsequently, there is a reduced ability to react/respond quickly
  - There may be a significant lag in response

Executive Dysfunction

- Decision making
- Judgment
- Problem-solving
- Planning
- Shifting Set
- Mental Flexibility
- Organization

Visuospatial Abilities

- Perception of distance
  - Makes driving difficult
  - Can lead to falls
- Reduced spatial abilities
  - May become disoriented by familiar surroundings
  - Confusion when navigating, following directions

Learning and Memory

- Reduced ability to learn new information in large quantities
- Reduced ability to retrieve recently learned information
- Intact long-term memory
- Benefit from cues and repetition

A Complex Diagnosis

- Given the complexity of the disease as it impacts multiple systems, it is not surprising that the responsibility felt by the care partner is quite significant

Facts about PD care partners

- Due to nature of PD, caregiving is typically longer
- Care partners may have more medical conditions that may lead to challenges with caregiving
  - Back pain, arthritis, unsteady knees
  - Especially if they neglect their own health and well-being

Caregiver Burden

- Caregiver burden has been defined as “the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical and spiritual functioning.”

Zarit, S.H. (1986)

Caregiver Burden

- Persistent burden may lead to strain, an enduring change in the caregiver's sense of well-being that predisposes to burnout.
- Not only does this create an "invisible patient" in the patient–physician–caregiver system, but it also diminishes the effectiveness of the caregiver and their ability to maintain their informal role as a partner in treatment.

Responsibilities

- The caregiver of a person with PD assumes many responsibilities, including care coordination, medication administration, prompting for self-care, communication and advocacy on behalf of their loved one, surveillance of falls, and provision of emotional support, while also playing an increasing role in directly assisting the person with activities of daily living as the disease advances.

“Invisible Patient”

- Due to responsibilities, care partners tend to neglect their own health
- Due to potential changes in finances (e.g., early retirement, losing job due to caregiving), may lose health insurance
- Health of care partner becomes secondary to that of the partner

Adverse Effects of Caregiver Burden

- The more responsibility the caregiver has, the more likely that this may lead to increased feelings of depression and anxiety.
- When one’s physical and emotional health declines, so does one’s ability to care for others.
- May lead to feelings of hopelessness and subsequently worthlessness

If You Do Not Take Care of Yourself, Who Will Take Care of Your Partner?

Part 2: Strategies for Taking Care of Yourself and Your Partner

Essential to Recognize Stress

- In one's busy life, it is important to be able to recognize when stress is impacting our lives
- Perhaps other people may tell us that we are being more irritable, short fused
- Notice bags under our eyes due to lack of sleep
- Weight loss due to not enough time to eat

Keep Track of Stress

- Keep a journal
  - At the end of the day, describe the emotions you experienced on that day
  - Try to identify triggers for these emotions
  - This will help with identifying patterns
    - Does irritability happen more when you had a poor nights sleep?
    - Do “Off” periods create more anxiety?

How to Alleviate Caregiver Stress

- Identify Supports available to you
  - Informal
    - Friends
    - Family members
    - Support Groups
  - Formal
    - Respite care
    - Long-term planning

Informal Support

- Support groups
  - Not only avenues to “vent”, but venting sure does help
  - Learn that you are not alone
    - Helps normalize feelings you may be having
  - Problem-solving through shared experiences
  - Learn about resources available to you

Informal Supports

- Friends and Family
  - Ask for help (especially with nonessential tasks)
    - Help with grocery store shopping
    - Picking up medications
    - Walking the dog
    - Sitting with your partner for a few hours
    - Cooking meals

Formal Support

- Respite care
  - Ask for help of friends and family members
  - Agencies
  - Few hours counts
  - Being organized can lead to feeling a sense of reassurance about leaving your loved one with someone else
  - Will help with carving time for yourself, for self-care
    - Reading, catching up with friends, getting a haircut, meeting with a counselor

Respite Should not be a Luxury

- Prioritize pleasurable activities
  - Track your response to them
- Exercise
- Find humor
- It is rejuvenating!
  - Will feel more energized
  - Effective
  - Mood will improve

Formal Support

- Paid assistance
  - Having someone help with cleaning the home
  - Completing yard work
  - Walking the dog
  - Transportation (e.g., Uber)

Formal Support

- Psychotherapy
  - If needed, attending sessions with a therapist can allow for an avenue to relieving stress
  - Skill learning and building to manage own emotions and behaviors
  - Will help you be heard!

Formal Support

- Future planning
  - Planning for the future will alleviate significant amounts of stress, as it will give you some control over the unknown
  - Make legal decisions about who gets appointed durable power of attorney, financial conservator
  - If possible, speak with a financial planner
  - Long-term living arrangements
  - While possible, finalize a will
  - Social workers, local agencies for the aging

Helping Your Partner

- Communicating with Healthcare Providers
  - Organize the information
    - Have a binder or computer document with updated information (e.g., medications, etc.)
    - Write down questions prior to the appointment; write down answers during the appointment
    - Keep track of recommendations
    - Use a calendar
    - Fixed schedule for medications that include alarms

Helping Your Partner

- Motor symptoms
  - Encourage use of assistive device if they are recommended
  - Simplify home navigation
    - Pay attention to rugs, chords, stairs
  - Allow for extra time
  - Encourage independence
    - Getting dressed, shaving (electric razor)
  - Ask for help with transfers

Helping Your Partner

- Sleep disturbance
  - REM sleep behaviors
    - Increase safety for possibly rolling off bed
    - Sleep walking (e.g., locking doors)
    - Medications may help
    - If too severe, for your safety, consider separate beds (in the same room, if preferred)
  - Practice good sleep hygiene

Helping Your Partner

- Hallucinations
  - Reassurance without fear
  - Nightlight, or low light may help with the experience of misperceptions at nighttime
  - Discourage wandering behavior at night, especially alone

Helping Your Partner

- Impulse control disorders
  - Most of the time it is DUE TO medications for PD
  - Modification of medications with consultation of medical provider can help with this
  - Medications for impulse control are helpful
  - Encourage partner to be open about these behaviors
  - Restrict access to compulsion
  - Understanding that it is the disease, not your partner

Helping Your Partner

- Depression, Anxiety, and Apathy
  - If severe enough, help your partner get help
    - Counseling and/or medications can help alleviate this
    - Learn together about each other’s triggers
    - Engaging in activities they enjoy and find meaningful

How to Increase Motivation

- Having regularly scheduled times during the day in which different tasks are carried out, separated by rest breaks or leisure activities, can facilitate set shifting.
- Breaks typically need only be brief in duration.
- Observing when one’s ability to focus begins to wane will help determine the optimal time for a break.

How to Increase Motivation

- Increased structure in your environment or in an activity can help with initiation difficulties.
- Building in routines for everyday activities is important.
- As routine tasks and their completion become more automatic, the need for dependent initiation will be reduced.
  - For example, the morning routine can be broken down into a sequence of steps, and these steps can be written down on index cards or a simple list.
  - You might then follow the list of steps each day until the routine becomes automatic.

How to Increase Motivation

- Tasks or assignments that seem too large can interfere with one's ability to get started.
- Breaking tasks into smaller, more structured steps may reduce one's sense of being overwhelmed and increase initiation.
- Structured planning and organization efforts around these goals are important.

How to Increase Motivation

- Verbalizing a plan of approach at the outset of any goal will be crucial.
- A good place to start can be to develop a plan for familiar tasks in a more efficient manner and then carry out the plan.
- Your motivation may be enhanced by initially focusing on the development and completion of familiar plans.

How to Increase Motivation

- Certainly, if the lack of motivation is related to a severe depressive disorder, medication and psychotherapy may be considered
  - Antidepressant medications are likely to help ameliorate the symptoms

Improving Communication with Your Partner

- Verbal
  - Slow down
  - Breakdown phrases
  - Try to be more concrete
  - Express a concept in multiple domains
    - Say it, write it down
  - Focus on one-on-one communication vs. group communication
  - Speech and Language therapist referral

Improving Communication with Your Partner

- Nonverbal
  - Due to disease, facial expression may be much more limited
  - Social cues reduced
  - Voice may be more monotone and not have the emotional valence
  - Gesture are less spontaneous

Communication Strategies

- Look at them when speaking to them
- Check in with them if something they said is not clear
- Ask them about how they are feeling
- Don’t be afraid to tell them how you are feeling

Helping Your Partner

- Cognitive Impairment
  - Attention/concentration
    - Be realistic on expectations
    - Break tasks down into steps
    - Limit interruptions
    - One task at a time
    - Take breaks and do something less serious

Helping Your Partner

- Processing speed
  - Slow down
  - Allow for extra time (patience is a virtue)
  - Repeat information
  - Simplify information
  - Often “yes” and “no” questions may be the most appropriate

Helping Your Partner

- Executive functioning (organizing, planning, problem-solving, mental flexibility)
  - Make decisions together
  - Limit options
  - Structure the week with a visual calendar (but be reasonable)
  - Plan as much as possible, this will allow to come up with potential road blocks that can lead to frustration

Helping Your Partner

- Visuospatial/visuoperceptual difficulties
  - Be an observant passenger
  - If there is a concern about driving, an on the road test is essential
    - Consider the safety of your partner and that of everyone else
  - Encourage use of maps/GPS
  - Make surrounding simpler
    - Rooms, outdoor spaces

How Both You and Your Partner Can Stay Healthy

Activity to Stay Cognitively Intact

- Cognitive Exercises
- Physical Exercise
- Socialization

Cognitive Exercises

- Memory, like muscular strength, requires you to "use it or lose it." The more you work out your brain, the better you will be able to process and remember information.
- The best brain exercising activities break your routine and challenge you to use and develop new brain pathways.

Criteria for Cognitive Exercises

1. IT’S NEW!
    - No matter how intellectually demanding the activity, if it’s something you’re already good at, it’s not a good brain exercise. The activity needs to be something that’s unfamiliar and out of your comfort zone.

Criteria for Brain Exercises

2. **<u>IT’S CHALLENGING</u>**
   - ✧ Anything that takes some mental effort and expands your knowledge will work. Examples include learning a new language, instrument, or sport, or tackling a challenging crossword or Sudoku puzzle.

Criteria for Brain Exercises

3. **<u>IT’S FUN!</u>**
   - ✧Physical and emotional enjoyment is important in the brain’s learning process. The more interested and engaged you are in the activity, the more likely you will be to continue doing it and the greater the benefits you will experience.

How to Make Cognitive Exercises Enjoyable

You can make some activities more enjoyable by appealing to your senses

- Listen to music
- Light a scented candle
- Reward yourself after you have finished

Types of Cognitive Exercises

- Play games that involve strategy, like chess or bridge, and word games like Scrabble.
- Try crossword or number puzzles such as Sudoku.
- Read newspapers, magazines, and books that challenge you.

Types of Cognitive Exercises

- Get in the habit of learning new things: games, recipes, driving routes, a musical instrument, a foreign language.
- Take a course in an unfamiliar subject that interests you. Take on a project that involves design and planning, such as a new garden, a quilt, or a koi pond.

Types of Activity

- Cognitive Exercises
- Physical Exercise
- Socialization

Physical Exercise

- If you get clearance from your medical provider to exercise, do it!
- There are many exercises that have been proven to be effective in Parkinson’s patients

PD and Exercise

- A study by Hirsch and colleagues (2016) reviewing 8 separate PD studies investigating exercise and PD, revealed a trend towards improving cognitive functioning

Boxing

- A study by Combs and colleagues (2011) demonstrated that PD patients who exercise via fairly regimented boxing, demonstrated improvements in walking, balance, and in their ability to perform their activities of daily living.
- This full-body workout, tests balance, agility, hand-eye coordination, which can all be affected by PD.
- It can build muscle strength and importantly, offer an outlet for frustration.

Mind-Body Exercises

- Mind–body exercises increase self-consciousness of the body, thereby increasing the energy, mental clarity, concentration, and ability to tolerate physical discomfort.
- Movement based mind–body interventions comprise low-impact exercises, which enhance mind–body coordination and awareness through the practice of a sequence of controlled motions and focused attention.

Mind-Body Exercises

- A meta-analysis of mind-body exercises in PD populations show moderate effects in improving motor symptoms and functional mobility.
- Included Tai chi, yoga, and dance

Kwok, et al. (2016)

Types of Activity

- Cognitive Exercises
- Physical Exercise
- Socialization

Socialization

- Socialization is the key for cognitive health
  - Isolation is unstimulating
  - Isolation has been demonstrated to be related to increased depression
  - Isolation has been shown to be related to mental decline
    - Interferes with learning and leads to lack of engagement in stimulating activities (Luo & Waite, 2014).
    - Lead to neurodegeneration due to built up stress affecting the immune system (Cacioppo & Hawkley, 2009).

Socialization

- Socialization is key because it decreases isolation
- It increases motivation to do things
- It allows you to learn from others
- It gives you an opportunity to practice your cognitive skills

Types of Socialization

- Volunteering
- Joining a book club
- Attending the local senior center
- Going out to dinner
- Getting together with friends to go to a movie
- Taking a cooking class
- Hosting dinners at home

Socialization

If you do it? You are more likely to incorporate all other levels of activity!

Summarize

- Parkinson's Disease is a complex disease
- No two care partners will have the exact same experience
- Caregiver stress is a real problem
- Taking care of yourself, will allow you to take care of your partner
- Be proactive, plan, and ask for help.

Resources

- APDA – Pacific Northwest Chapter
  - Caregivers Day off Program
  - Offer 20 hours of care per year
  - https://www.apdaparkinson.org/community/northwest/resources-support/caregivers-day-off-program/

Resources

- **The National family caregiver support program (nfcsp)**
  - Established in 2000, this program provides grants to states and territories, based on their share of the population aged 70 and over, to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible. The care recipient must be 60 years of age or older.
  - Services include:
    - Information to caregivers about available services
    - Assistance to caregivers in gaining access to the services
    - Individual counseling, organization of support groups and
    - caregiver training
    - Respite care
    - Supplemental services, on a limited basis
  - To access this program as well as other state-based programs, contact your local Area Agency on Aging (AAA). Your local AAA can also provide information on adult day care, case management, home modification, home health services and much more. They will let you know whether services are free or available on a sliding fee scale. To find your local AAA:
  - Eldercare Locator Service www.eldercare.gov 1-800-677-1116

THANK YOU, FOR ALL THAT YOU DO!

Contact Email:
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