

Care Partners in Parkinson's Disease

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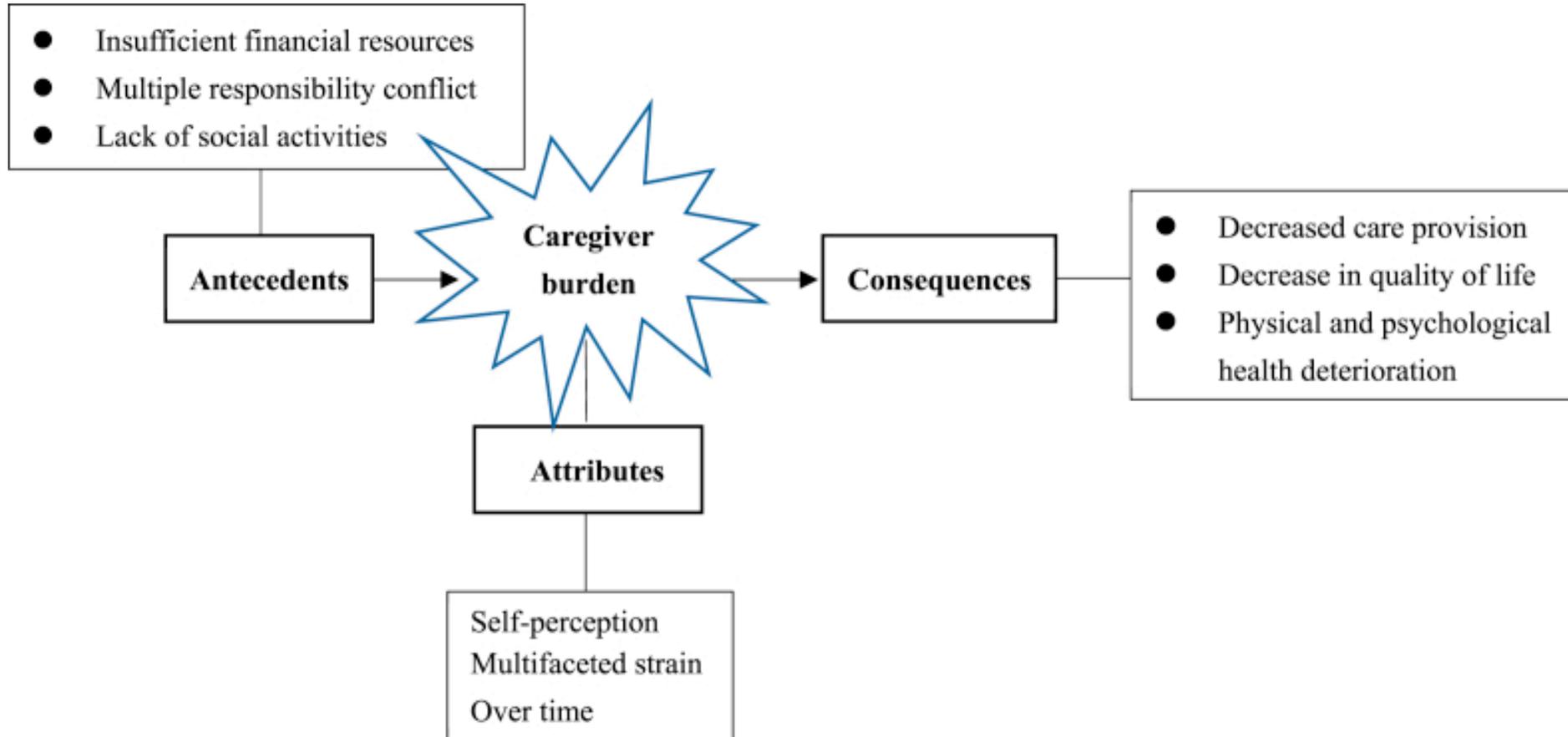


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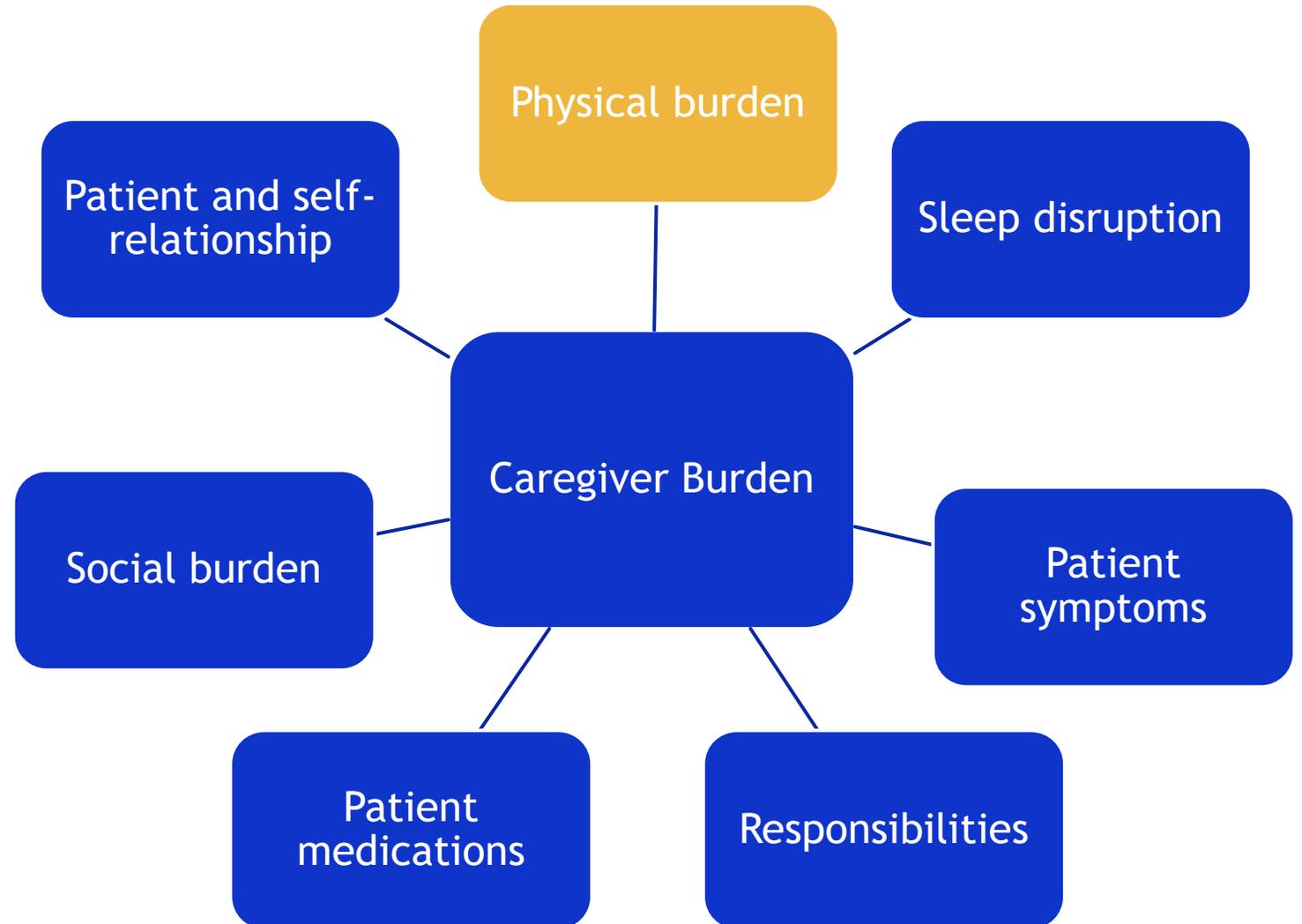
What is caregiver burden?

Caregiver Burden



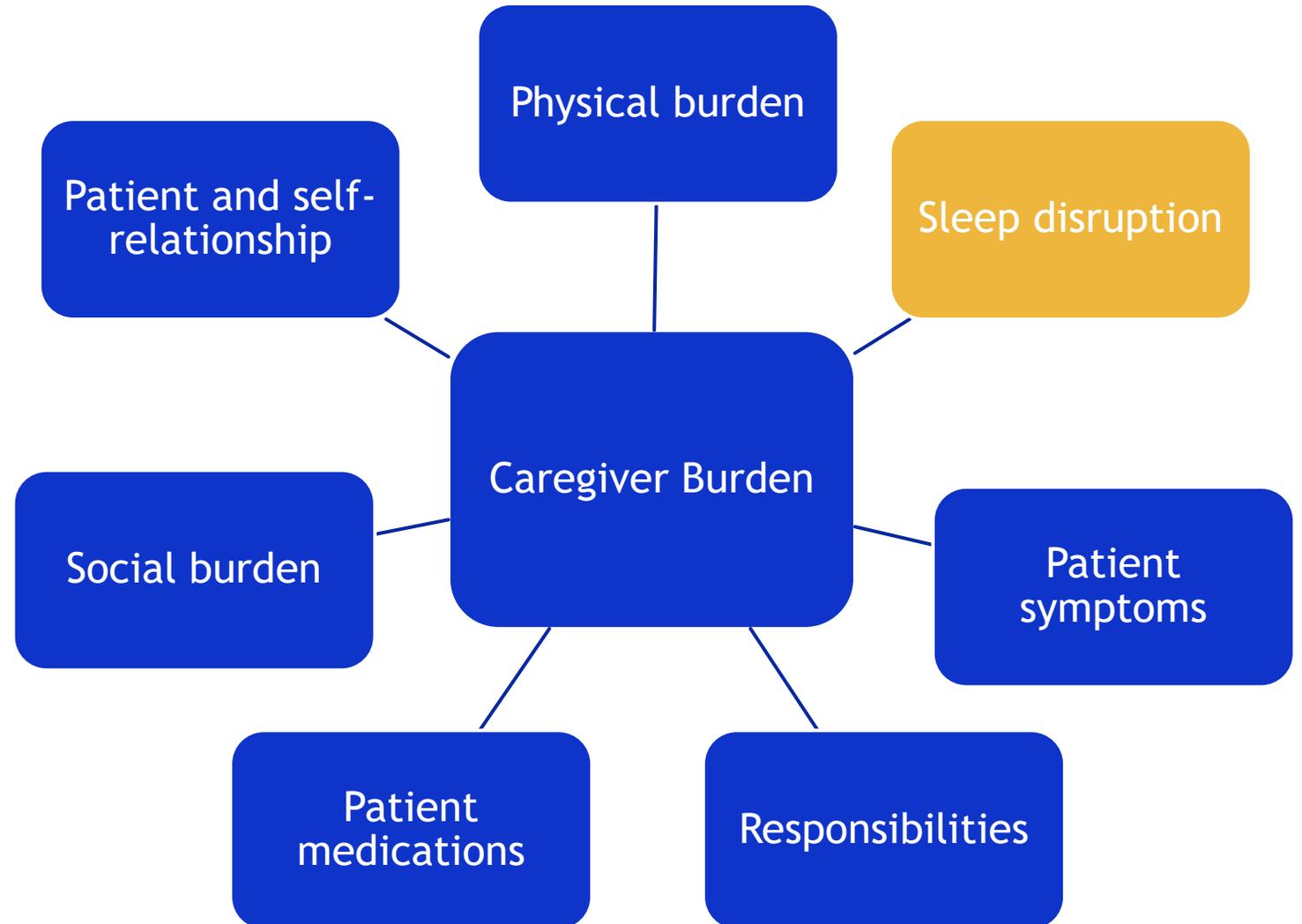
Caregiver Burden in Parkinson's Disease

- I have been injured as a result of caring for him/her, e.g. back strain as a result of lifting.
- I feel physically capable to help him/her with activities of daily living such as toileting, dressing, showering, bathing, and lifting.



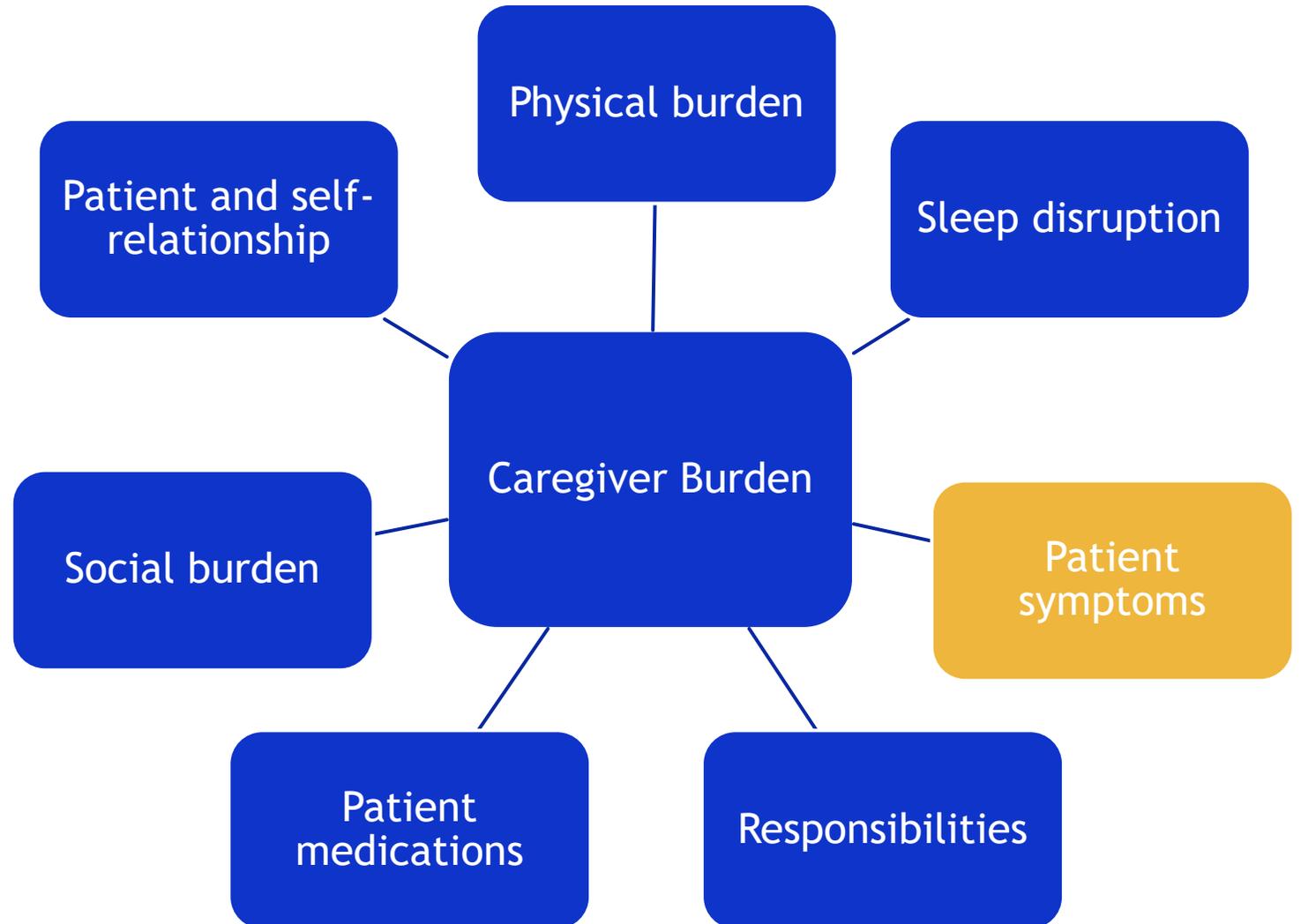
Caregiver Burden in Parkinson's Disease

- I feel annoyed or frustrated because my sleep is disturbed by him/her at night.
- I think I get enough sleep at night, and I feel awake during the day.



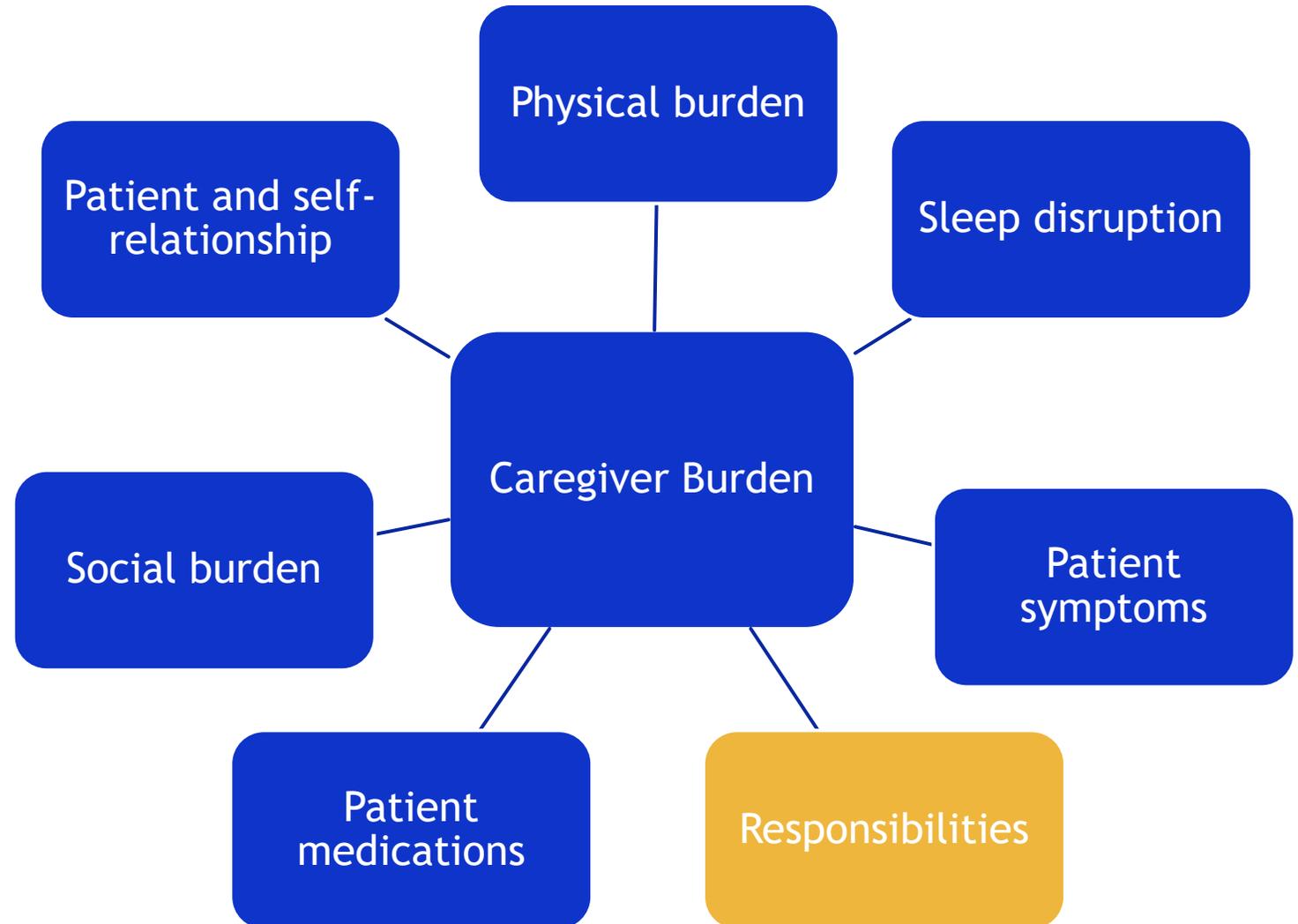
Caregiver Burden in Parkinson's Disease

- Dealing with the day-to-day unpredictability of symptoms makes it frustrating and difficult.
- I am fine with how slowly he/she moves and does things.
- He/she has trouble with urinary urgency, and helping with toileting is very difficult for me.
- I have had trouble coping with his/her compulsive behaviours (such as gambling, sexual hyperactivity, hobbies, and hoarding).
- I feel anxious or confused because I am unsure whether he/she is suffering from depression.



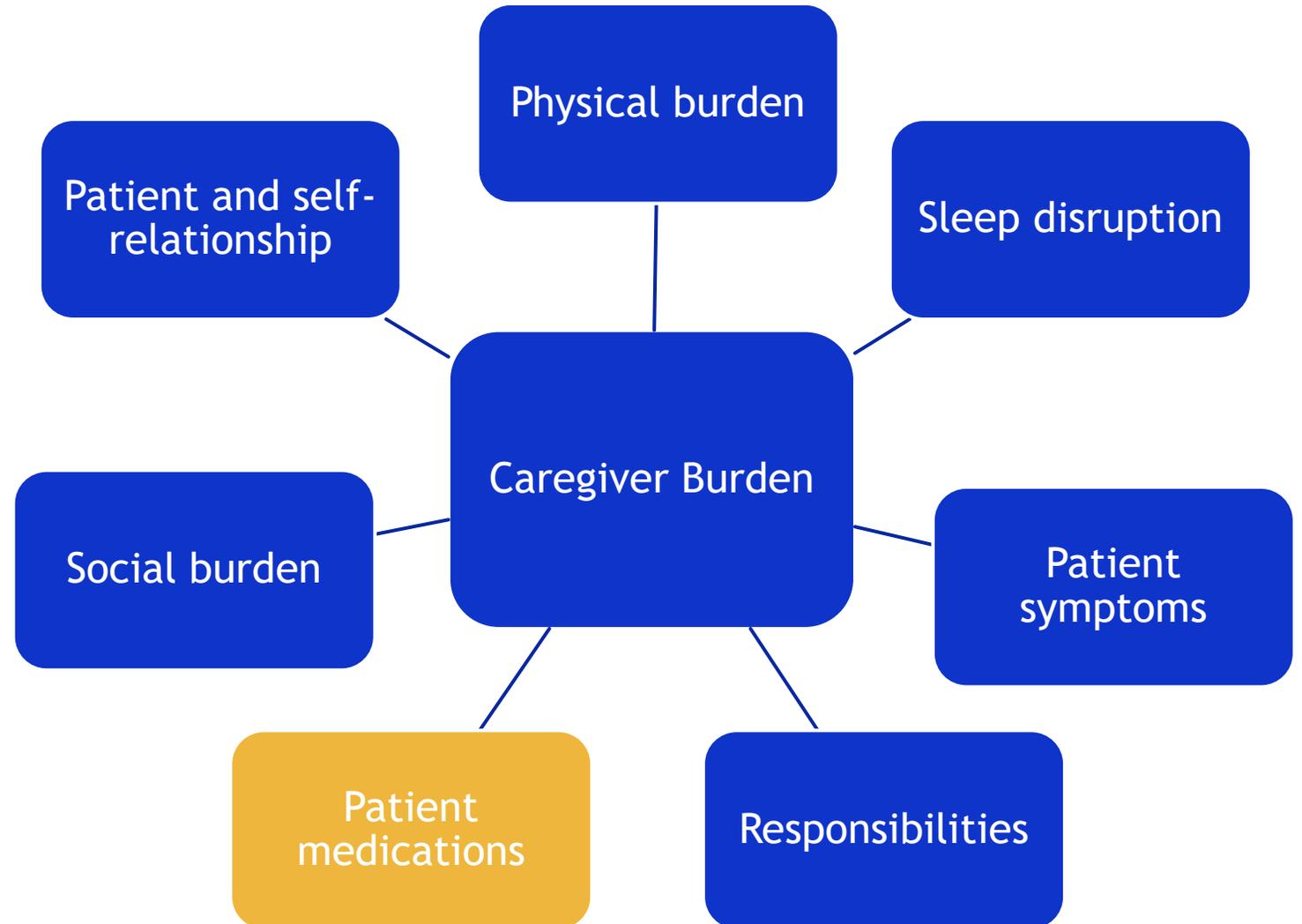
Caregiver Burden in Parkinson's Disease

- I am okay with having to take care of our responsibilities, such as decision making, chores and appointments.
- I get upset because it seems he/she can't be bothered to take responsibility of his/her health.
- I feel anxious because I need to be aware of what he/she is doing all the time.



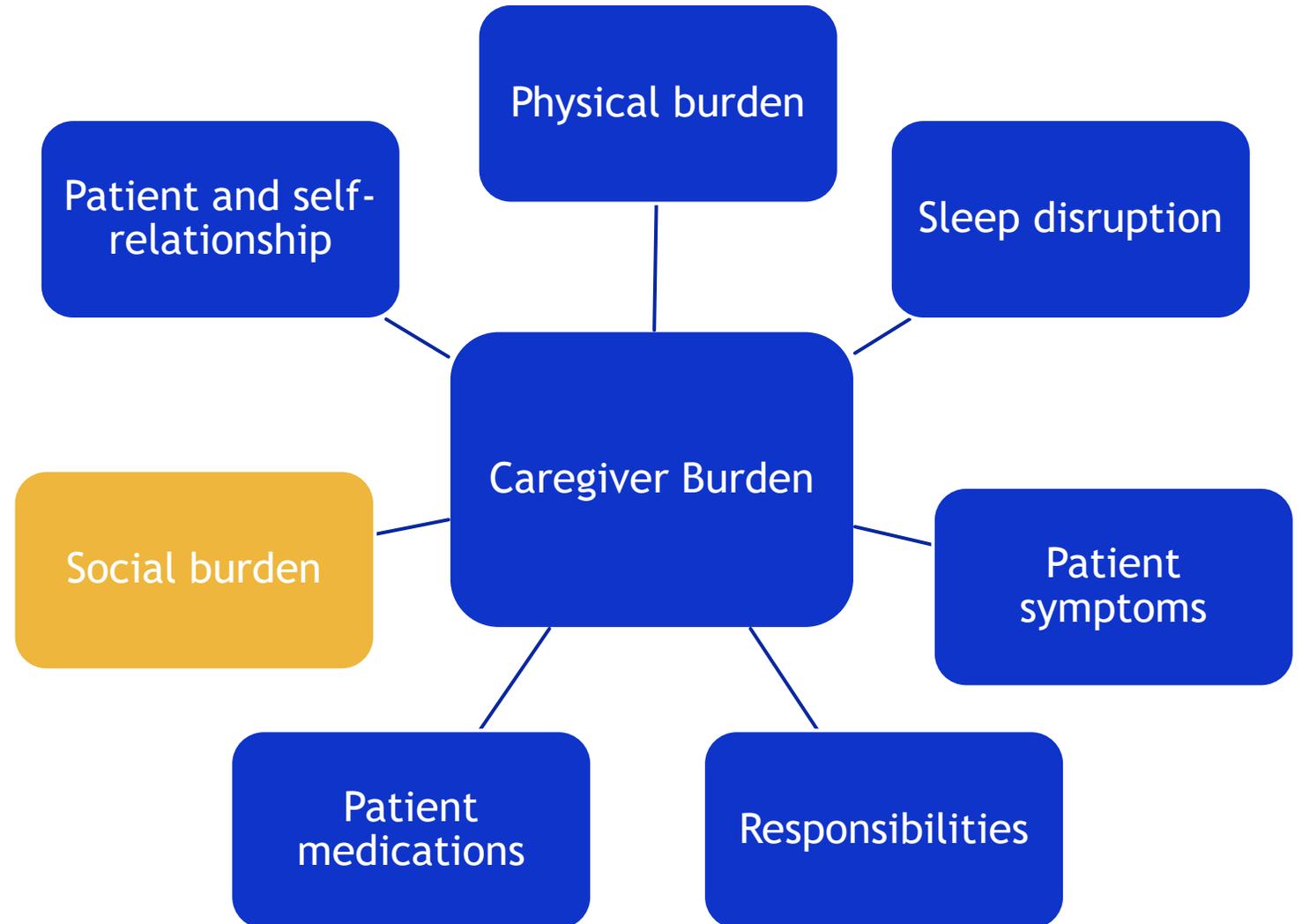
Caregiver Burden in Parkinson's Disease

- I am worried when he/she wants to take more Parkinson's medicine than the doctor prescribed.
- I find it very easy to deal with his/her medications.



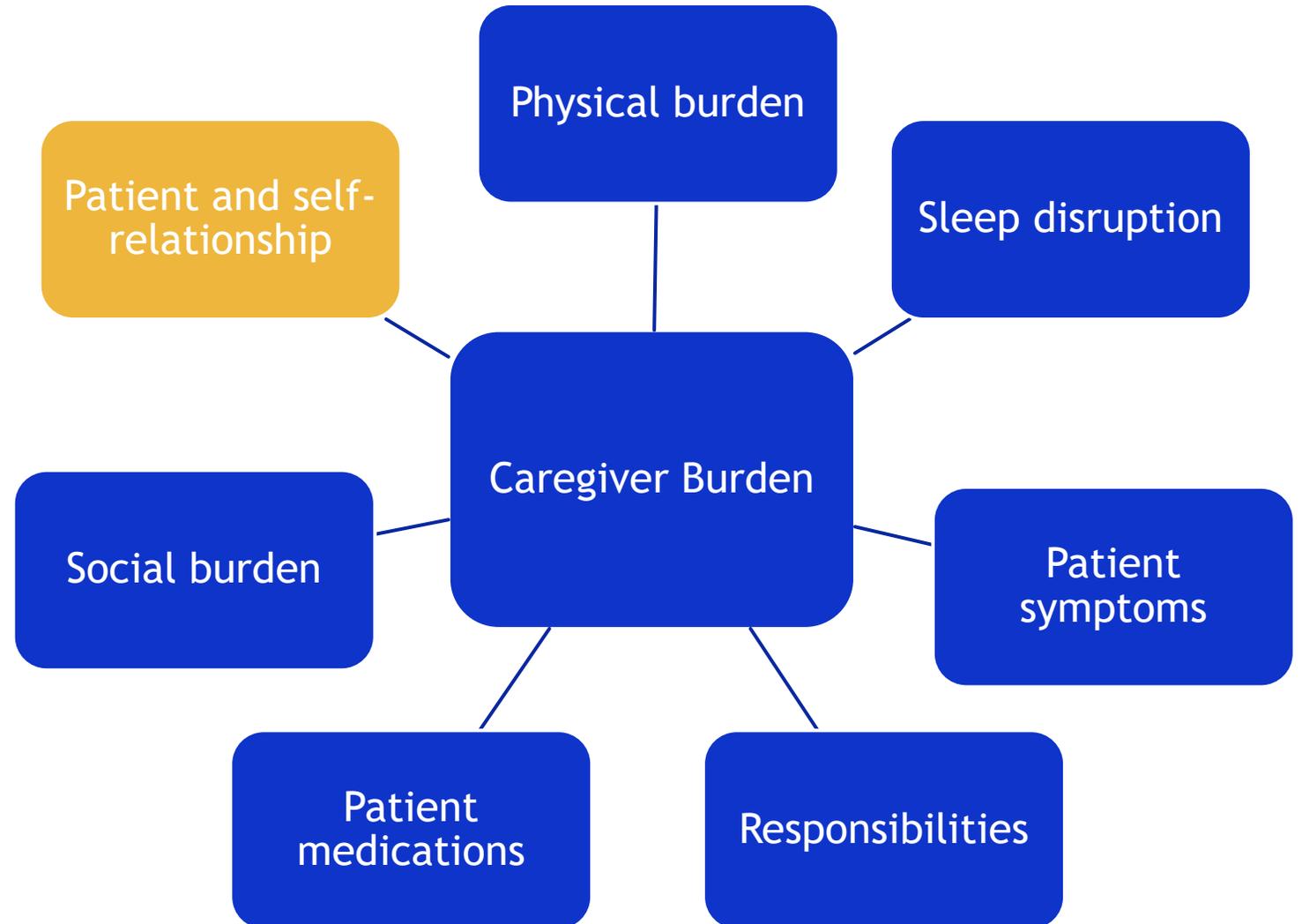
Caregiver Burden in Parkinson's Disease

- I feel embarrassed because of his/her behaviours or comments.
- I am comfortable going out with him/her.
- I don't like it when people notice his/her tremor or dyskinesia (abnormal involuntary movements).



Caregiver Burden in Parkinson's Disease

- I feel that he/she is still my friend.
- I miss the good times we used to have together.
- I am still able to make plans for the future, or to pursue my dreams.

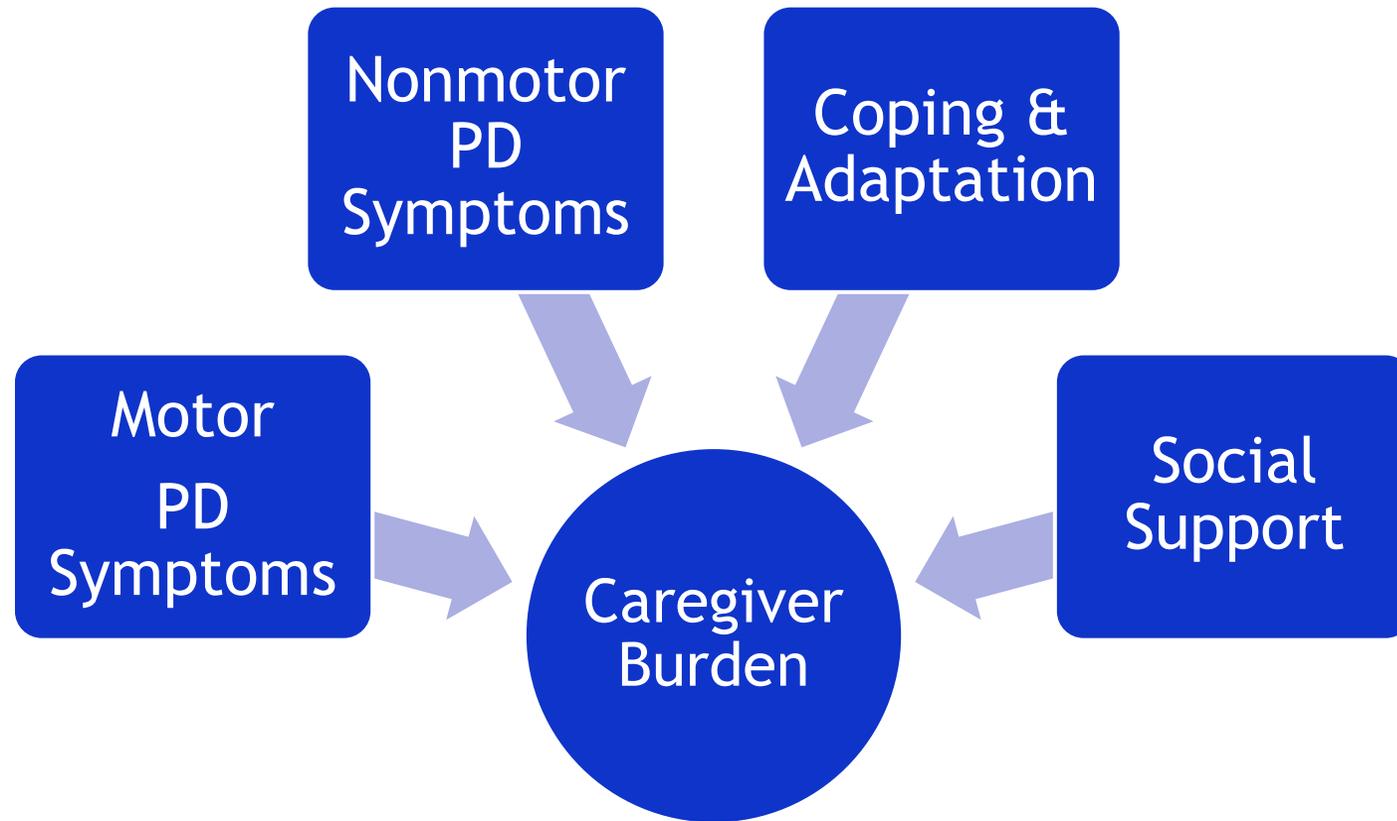


Care Partner Perspectives

- ▶ “We do not have any usual days now.” *Female caregiver of spouse with PD for 6 years*
- ▶ “I've been wanting to go on a cruise and we actually had one plan for 2020. But because of COVID it got canceled, but now I'm concerned that we may never go on it because of his situation with crowds, he can't handle crowds now. Right? It's so it's a definite, a huge lifestyle change. We're pretty much home bodies now, aren't we? Yeah. I mean, we very rarely go out.” *Female caregiver of spouse with PD for 8 years*
- ▶ “It's a lot of caregiving at a point in my life, but I thought, you know, that I would be free of that. Some. And instead, I think I'm going to have more. And I don't know how I'm going to handle that on the road this year is going to be really interesting.” *Female caregiver of spouse with PD for 6 years*

What symptoms in PD are the greatest predictors of burden/strain?

Predictors of Caregiver Burden



Motor Symptoms



Motor Complications

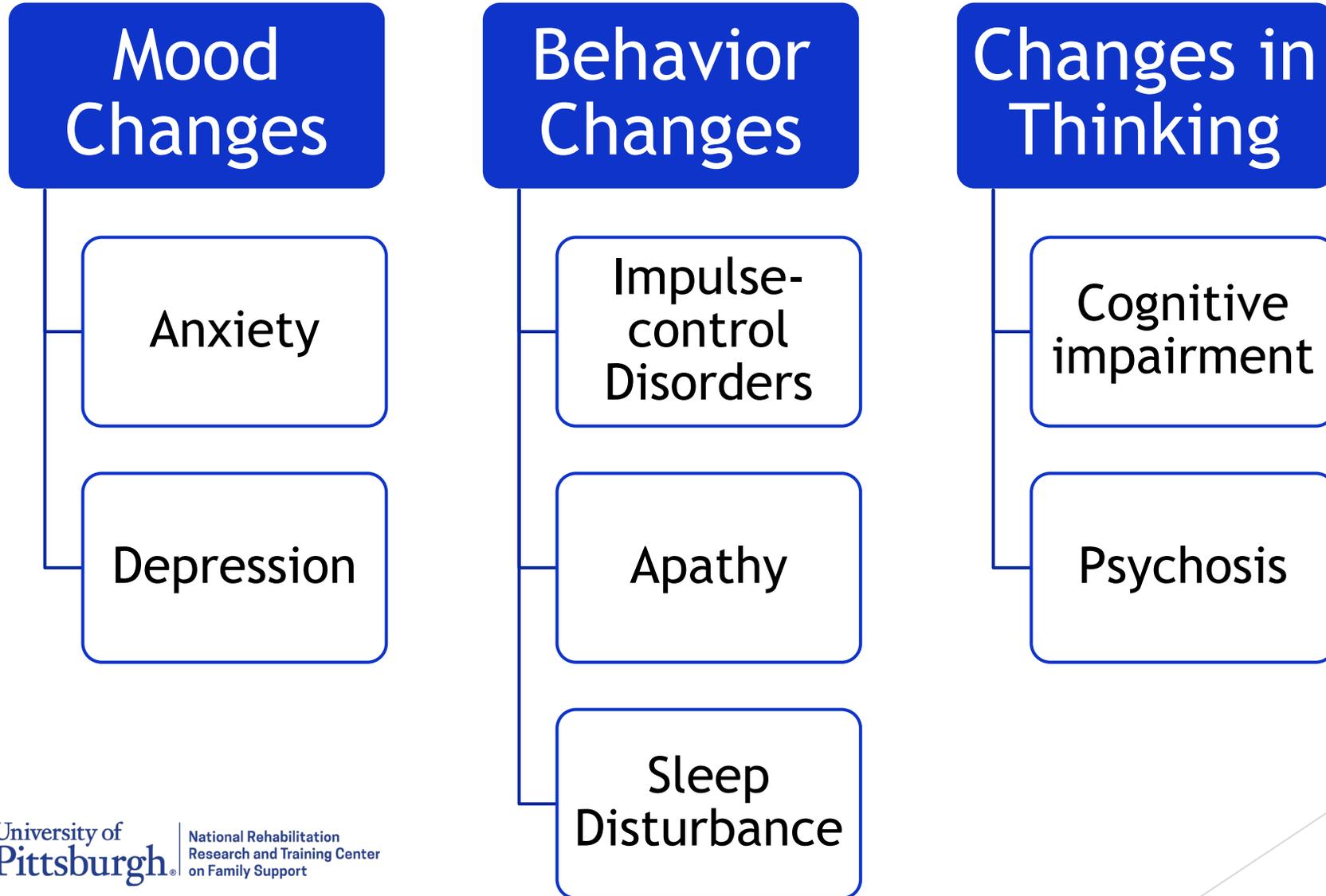
- Onset of motor fluctuations
- Increased time in the “off state”
- Dyskinesias



Balance

- Gait dysfunction
- Fall risk

Non-motor Symptoms

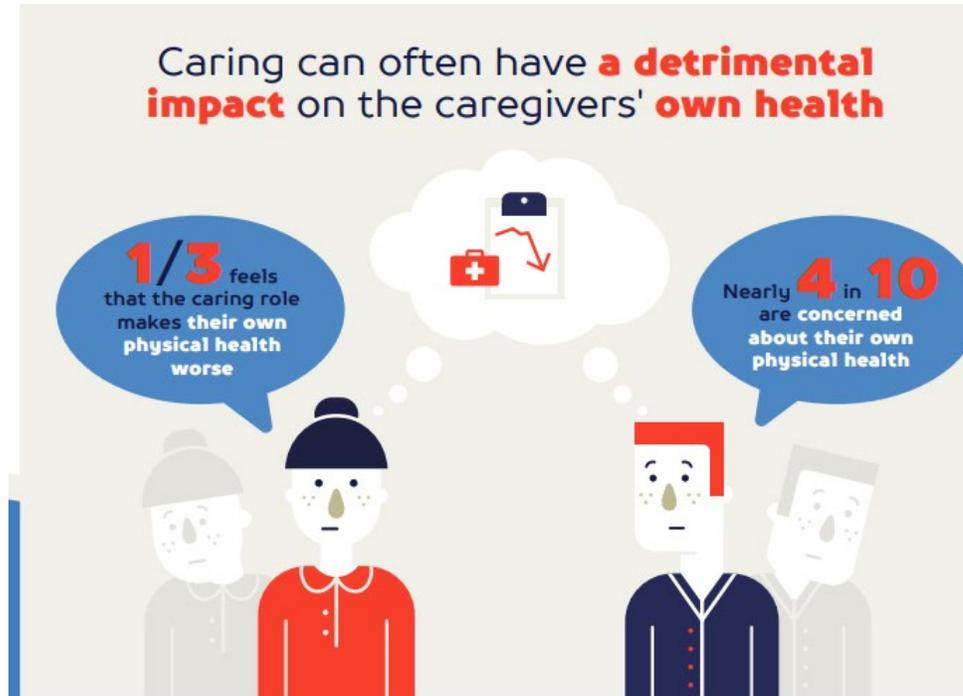


How is the physical health of care partners impacted?

Impact of Caregiving on Physical Health

- ▶ Increased pain affecting daily activities
- ▶ Higher levels of cortisol
- ▶ Worse sleep quality
- ▶ Higher injury risk
- ▶ Increased risk of all-cause mortality

“Don't miss your regular health checkup or neglect your health just because you are busy taking care of your loved one with Parkinson.”



Experiences of Caregivers

- ▶ “I’m worried that I will fall sick. I cannot get sick because I’m a caregiver... the main thing I’m really worried about is my health. I have to keep fit and continue to work. We have very little savings. That is the only thing; I cannot retire.” *Female caregiver of spouse*
- ▶ “My own health could be a barrier [to caregiving]. I’m going through my own health things. And sometimes I’m tired, or I have to do my own doctor appointments.” *Female caregiver of spouse with PD for 15 years*
- ▶ “I just feel like it’s cutting into my lifespan because you know, all the stress and everything else can’t be good for me so I and I worry about the future all the time I worry about you know, having to plan things when something happens to him.” *Female caregiver of spouse with PD for 19 years*

What are some barriers to building a support system?

Barriers to Finding Support

Concern/guilt related to burdening others

“I don't want to dump on them and have them worry about me or him. So I try not to I guess that's the wrong thing to do. I don't know if you're supposed to let everything out.”

“I can talk to my friends about what's going on, but none of them are in the same situation. I don't want it to become the only topic of conversation...I mean, I could talk for days.”

Challenges finding the right support

“I started going to support groups looking for help. And I found that really discouraging. It wasn't a good experience...I think that the onus is on me to just keep trying different groups.”

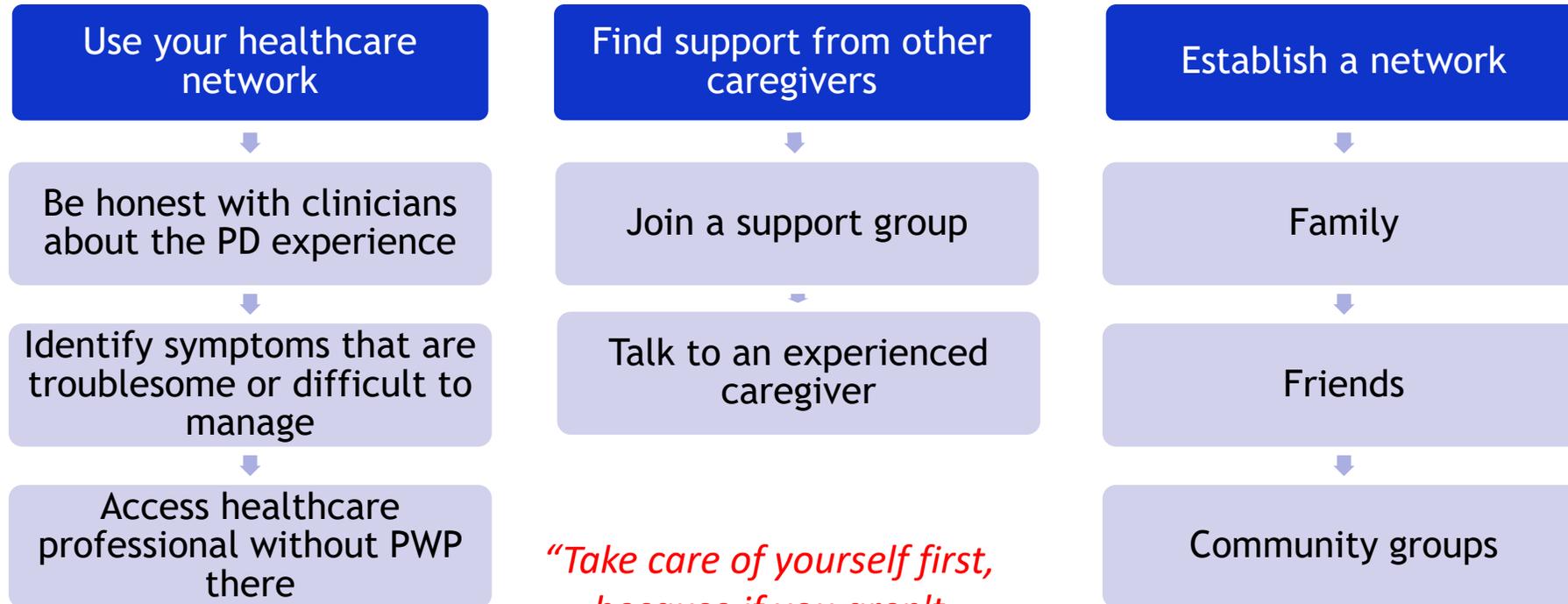
“Dealing with other people around the disease, its not contagious, just because he's got some problems, he's not a bumbling idiot. He still has a lot to offer in every aspect of his life. So, that's a challenge and for me.”

Desire to keep diagnosis secret

“We told some family members, but everyone was sworn to secrecy. I didn't want kids that our kids have to answer questions or, you know, worry about things.”

“I try not to just because I don't want to, I don't want to dump on them and have them worry about me or him...I guess that's the wrong thing to do. I don't know if you're supposed to let everything out.”

What can care partners do if they don't have support around them now?



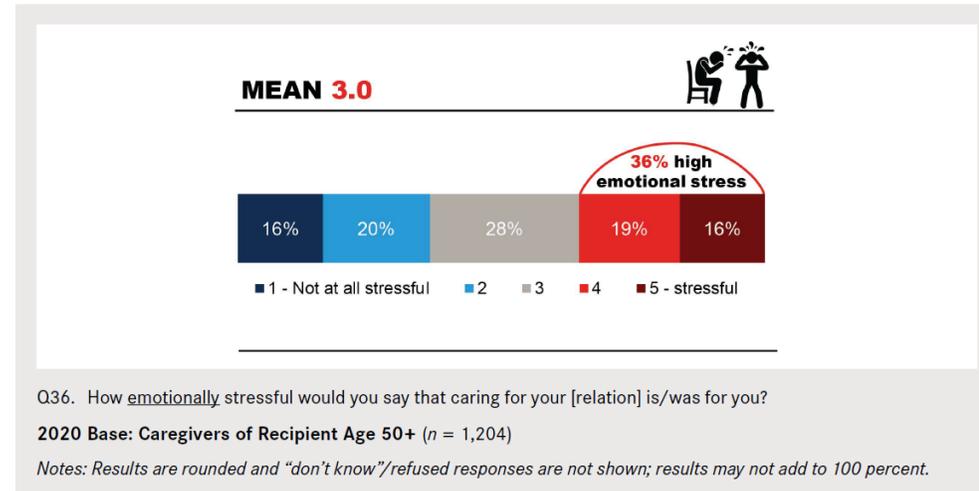
“Take care of yourself first, because if you aren't healthy, who will take care of them?”

How does caregiving impact mental and emotional health?

Impact on Emotional and Mental Health

- ▶ Higher prevalence of depressive symptoms
- ▶ Lower mental health scores
- ▶ Higher anxiety prevalence
- ▶ Decreased socialization with is linked to cognitive impairment

Figure 40. Emotional Stress of Caregiving

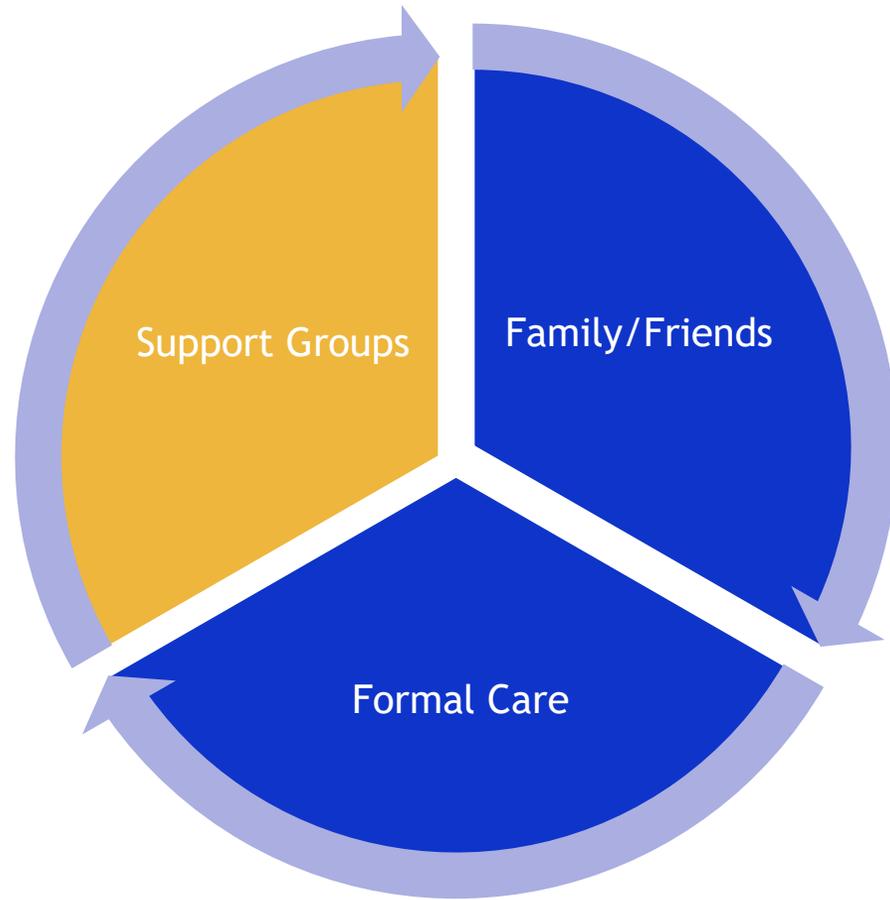


Care Partner Perspective

- ▶ “I suppose they make me feel a little bit depressed at times because I feel as if I’m losing him a bit.” *Female caregiver of spouse with PD*
- ▶ “I feel like I’ve lost my partner, he’s become very self-absorbed, it feels like life revolves around him now, it feels like he’s living so much in a bubble that he has stopped noticing how things impact on me completely... I actually just feel really lonely . . . I can’t quite find the words to describe how much it’s changed our relationship really, I feel like I’ve lost him in lots of ways (Crying).” *Female caregiver of spouse with PD*
- ▶ “And I learned that last year when he was having all those issues, you know, do I have to do what he needs, right? [...] I’m finding it impacts my own executive function that I’m having a lot more trouble focusing and following through and remembering what I’m doing and all that kind of thing.” *Female caregiver of spouse with PD*

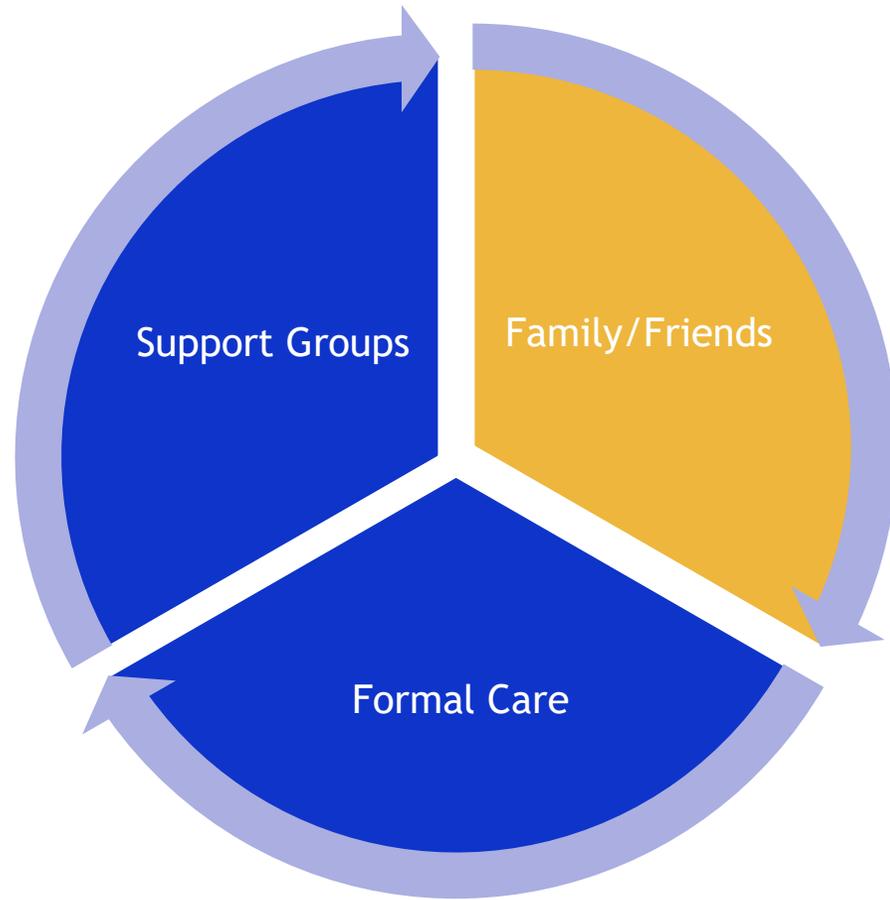
How does a support system impact caregivers?

Positive Influence of a Support System



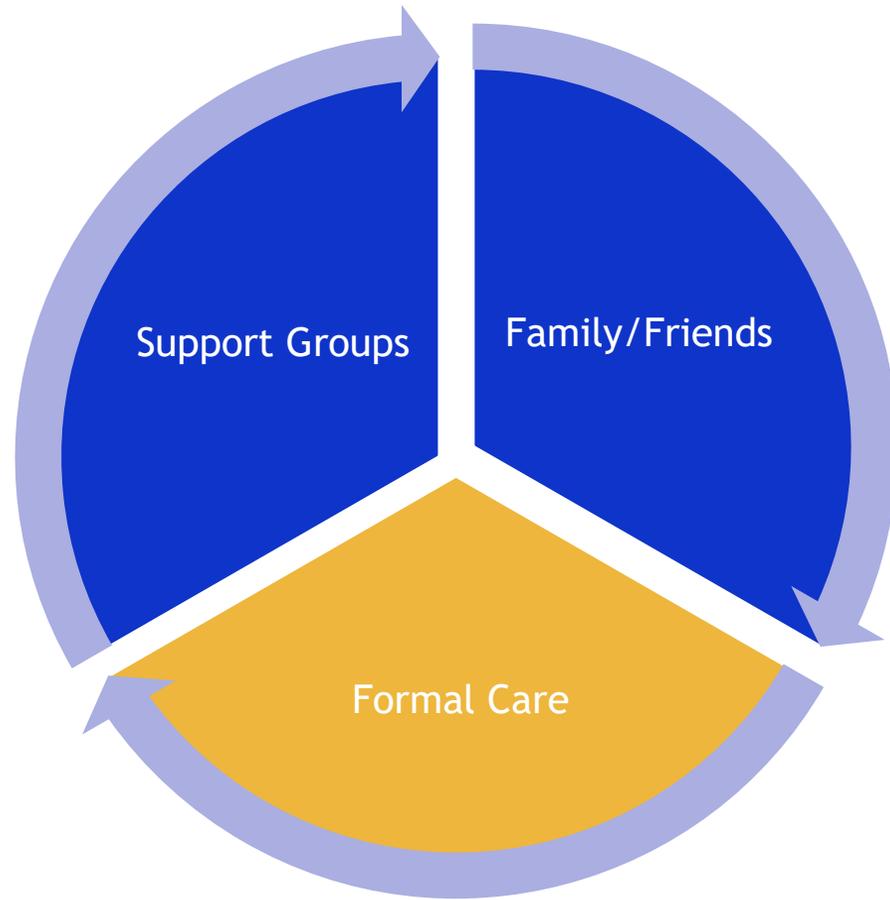
- ▶ Commonality among members
- ▶ Education, information
- ▶ Learning to adjust to diagnosis
- ▶ Practical techniques
- ▶ Feeling understood
- ▶ Reducing stigma
- ▶ Socialization and friendships

Positive Influence of a Support System



- ▶ People who can serve as a back-up when you have other obligations or need respite
- ▶ Time to address personal health
- ▶ Reduced risk of burnout
- ▶ Better outcomes for care recipients with increased socialization

Positive Influence of a Support System



- ▶ Paid caregiver
- ▶ Area Agency on Aging
- ▶ City or County public assistance office
- ▶ Faith-based organizations
- ▶ Volunteers

Care Partner Perspective

- ▶ “The thing with Parkinson's and with him in particular, he's, you know, he's had it since 2020. And you know, he's better now in some ways than he was before. And then things that are huge problem go away, and then there's something different.... things that are huge problems might go away. So do I react or do I wait and see?” *Female caregiver of spouse with PD*
- ▶ “When I have to go away one day this month from work. I will ask my son to come over and stay with him. Just in case he has an episode while I'm gone, you know, I just feel comfortable if somebody is here with him, you know he can he has issues sometimes when he chokes and so I want somebody here with him.” *Female caregiver of spouse with PD*

Ambiguous Loss

“I've lost my partner, my friend, my lover, my confidant, everything and this other person is living here now. I still love him. But he's not the same person. And he's not aware that he's not the same person. He doesn't understand why I'm upset. He honestly has no idea what this has done to my life or our lives.” *Female caregiver of spouse with PD for 15 years*

“I know we've still got a wonderful relationship we've always had a great relationship, sometimes I feel, oh it sounds horrible, as if I'm love, living with an old man which has never been [my husband], so I do get depressed over it yes.” *Female caregiver of spouse with PD*

“It's very difficult and sad to watch your loved one deteriorate and not be able to function independently.”