

THE EMOTIONAL TOLL OF CAREGIVING

Kate Perepezko, PhD, MSPH
Postdoctoral Associate



University of
Pittsburgh®

National Rehabilitation
Research and Training Center
on Family Support

OUTLINE

- Emotional vs. mental health
- Coping with PD
- Relationship changes
- Mental health challenges
- Predictors of caregiver burden/strain
- Physical health challenges
- Practicing self-care (barriers & strategies)



**IMPORTANCE OF
ADDRESSING
MENTAL HEALTH**

BENEFITS OF ADDRESSING MENTAL HEALTH

Reduced anxiety

Think more clearly

Improved relationships

Increased self-esteem

Better productivity

Ability to cope with stress

Better physical health

Improved mood

(Tanji, Anderson et al. 2008)(Smith, Perrin et al. 2019)

MENTAL HEALTH AND THE CAREGIVING JOURNEY

Early PD

- Growing into the caregiving role.
- Learning about PD.
- Managing new routines.

Mid-Stage PD

- Treatment management.
- Symptom progression.
- Complications of therapy.

Late-Stage PD

- Medical decision-making.
- Higher risk of psychiatric complications (dementia, psychosis).



**EMOTIONAL
HEALTH VS.
MENTAL HEALTH**

EMOTIONAL VS. MENTAL HEALTH

Emotional Health

- Ability to cope with and regulate emotions
- Ability to foster positive relationships
- Can be practiced and improved

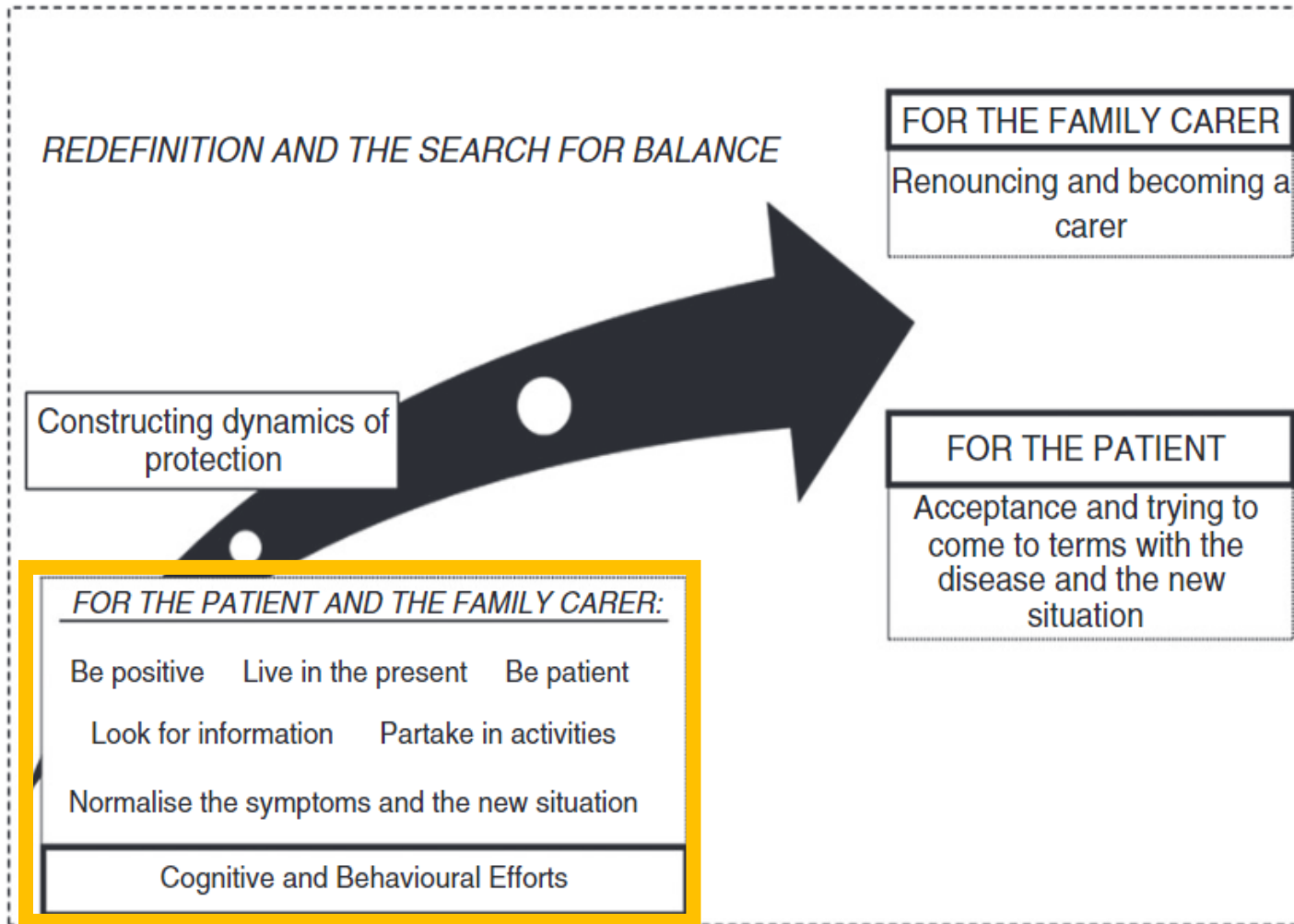
Mental Health

- Ability to think clearly
- Issues can result from trauma and/or chemical imbalances
- Can be treated with medication and/or therapy

The background features abstract geometric shapes in shades of teal and blue. On the left, there is a large teal triangle pointing towards the center. In the middle, a large, light teal circle is partially visible. On the right, a thick blue ring is partially shown, overlapping the circle. The overall design is clean and modern.

COPING WITH A DIAGNOSIS

COPING WITH A PD DIAGNOSIS



“You have to accept the disease, that’s crucial, and if you don’t you’re fooling yourself and making it complicated for the person you are looking after” (F5, male, 68 years old, retired, husband of a woman with PD since 8 years ago)

(Navarta-Sánchez, Caparrós et al. 2017)

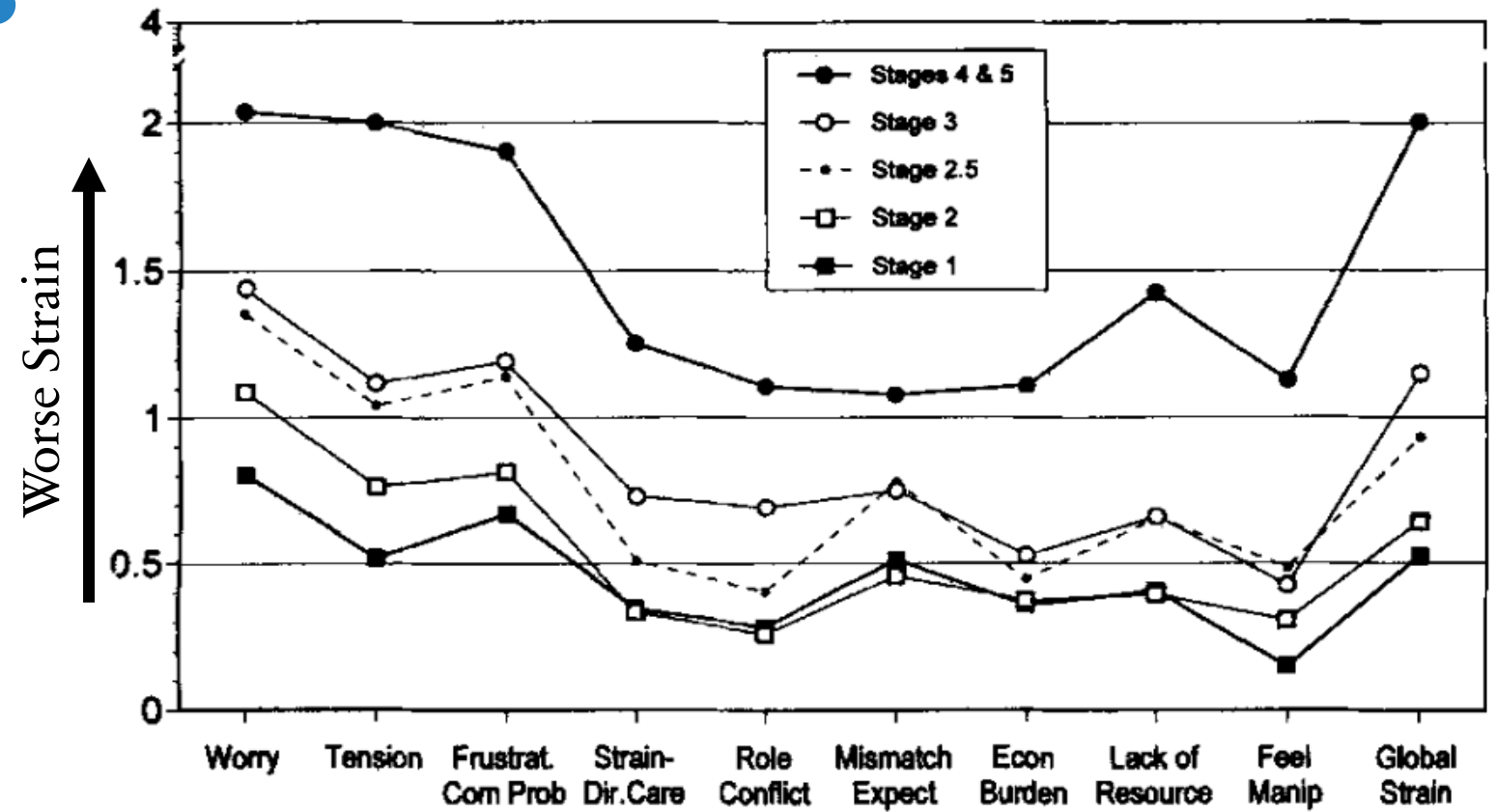
The image features a white background with several abstract geometric shapes. On the left, there is a large teal triangle pointing towards the center. In the middle, a large, light blue rounded shape contains the text. On the right, a thick ring is partially visible, with a teal segment on the left and a darker blue segment on the right. The text 'ROLE CHANGES' is centered within the light blue shape.

ROLE CHANGES

ROLE CHANGES

- Increased role strain with disease severity.
- Increased responsibility
- Changing roles
- Impact on relationship satisfaction:
 - Communication
 - Attention
 - Sexual functioning
 - Shared activities

Role Strain by Disease Stage



CHANGES WITH CAREGIVING

Relationship Changes	Caregiver Sacrifices	Caregiving Tasks	Feelings about Role
<p>“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.” Care Partner 10</p>	<p>“If we do plan to do something, we always have to have an out...if we want to go somewhere, for a little vacation, and we're going with friends, well, we know we also have to drive separately. So then when [PWP8] goes down, we can have an out we can take him back somewhere to a hotel, to the camper, something like that.” Care Partner 8</p>	<p>“I'm just like taking care of things around the house that I didn't ordinarily. I have to shovel the snow, he does a little bit of that, which I don't want him to because of the fall risk. Just dealing with anything to do with billing, his appointments, picking up his prescriptions, just things like that.” Care Partner 1</p>	<p>“Hardest part is watching his physical deterioration...and feeling pain for his perspective on the disease of being able to deal with that.” Care Partner 5</p>

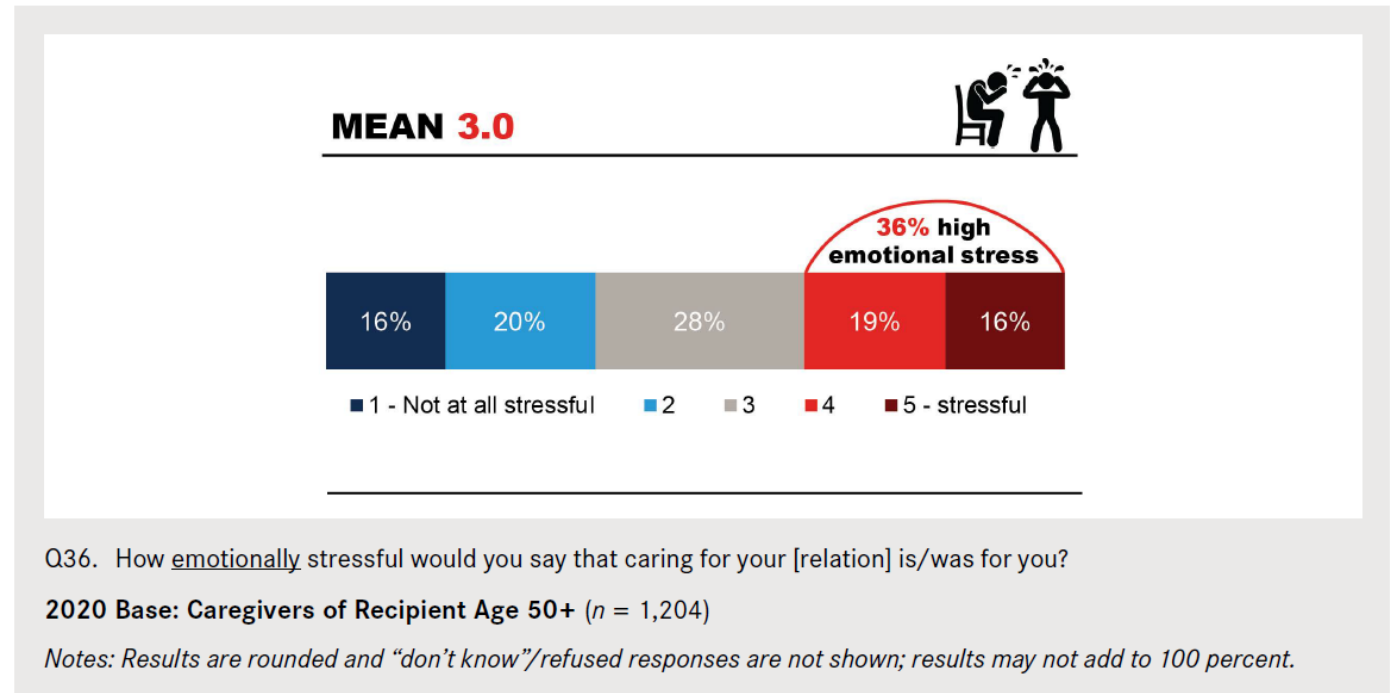


**CAREGIVER
MENTAL HEALTH**

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

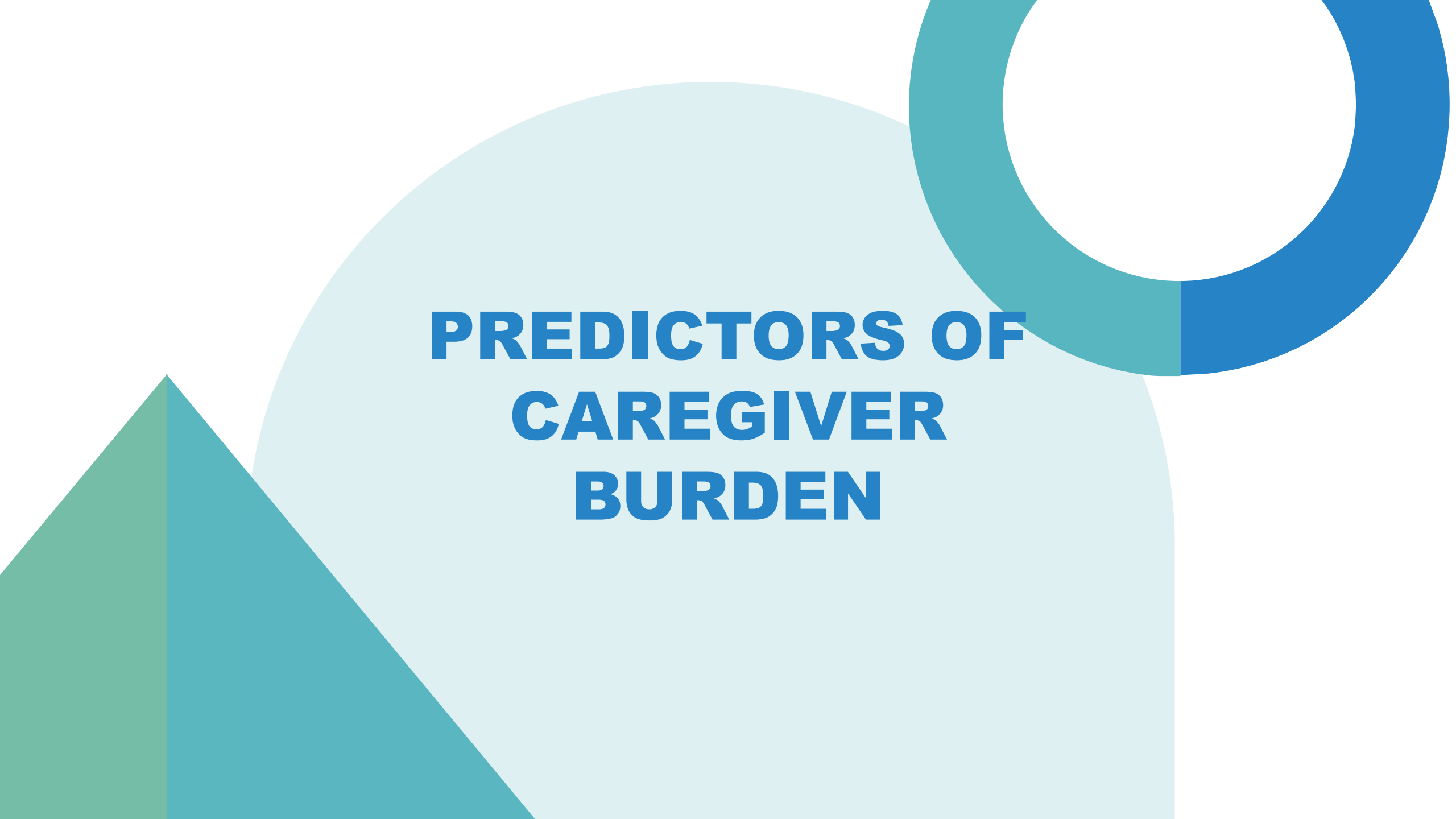
Figure 40. Emotional Stress of Caregiving



Nielson et al. (2014); Hulshoff et al. (2021)

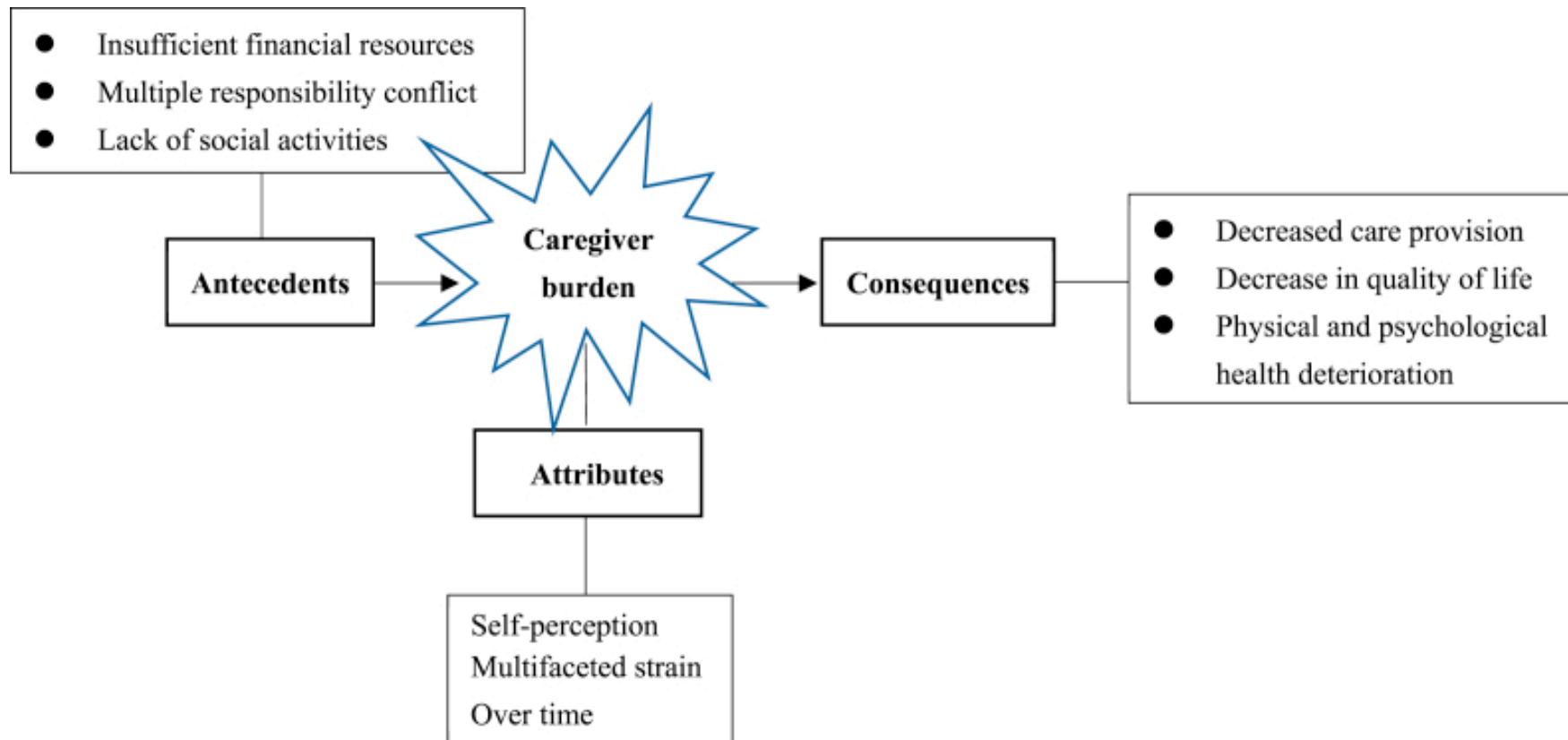
CARE PARTNER PERSPECTIVE

- “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 away? [...] 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*



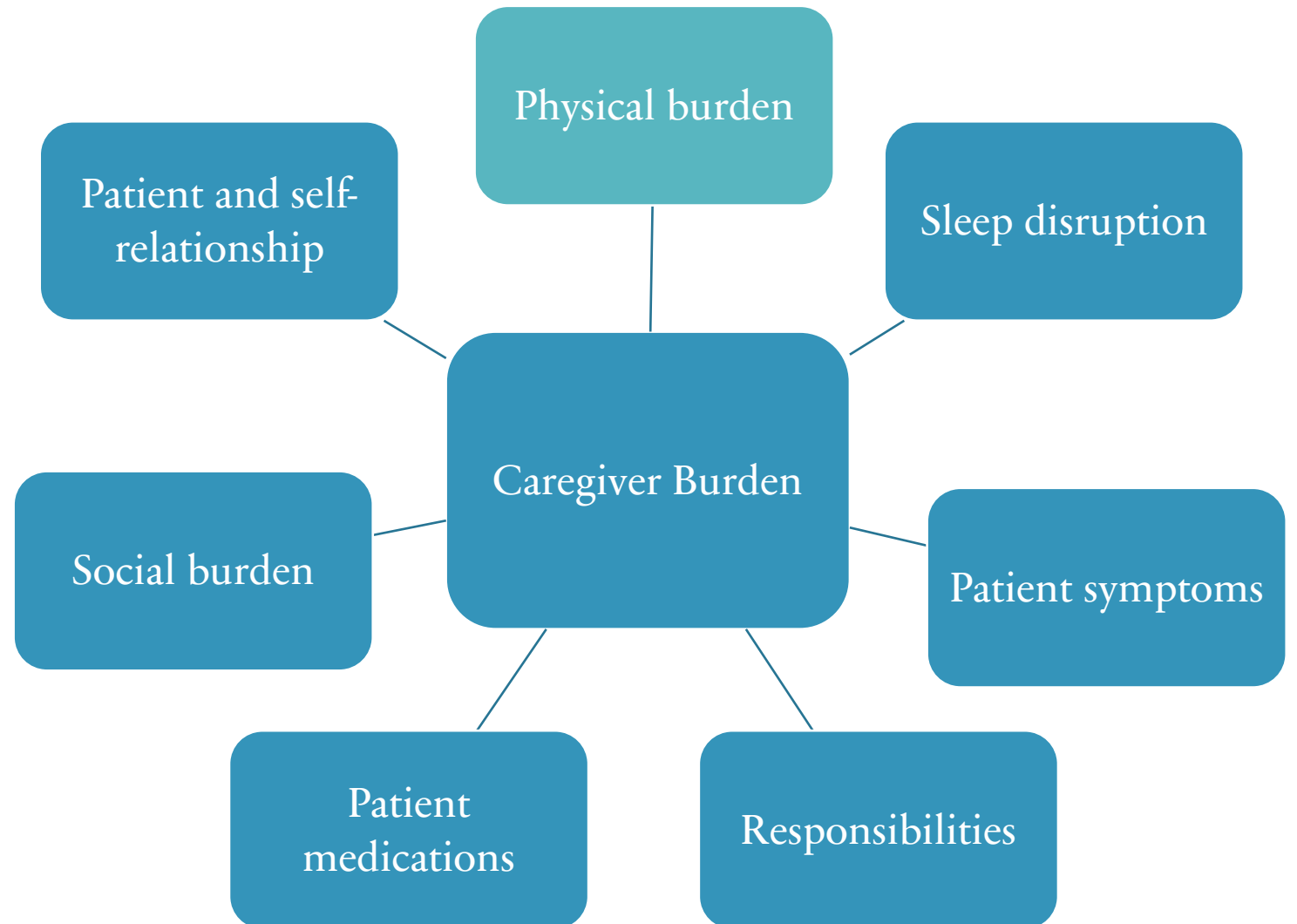
PREDICTORS OF CAREGIVER BURDEN

CAREGIVER BURDEN



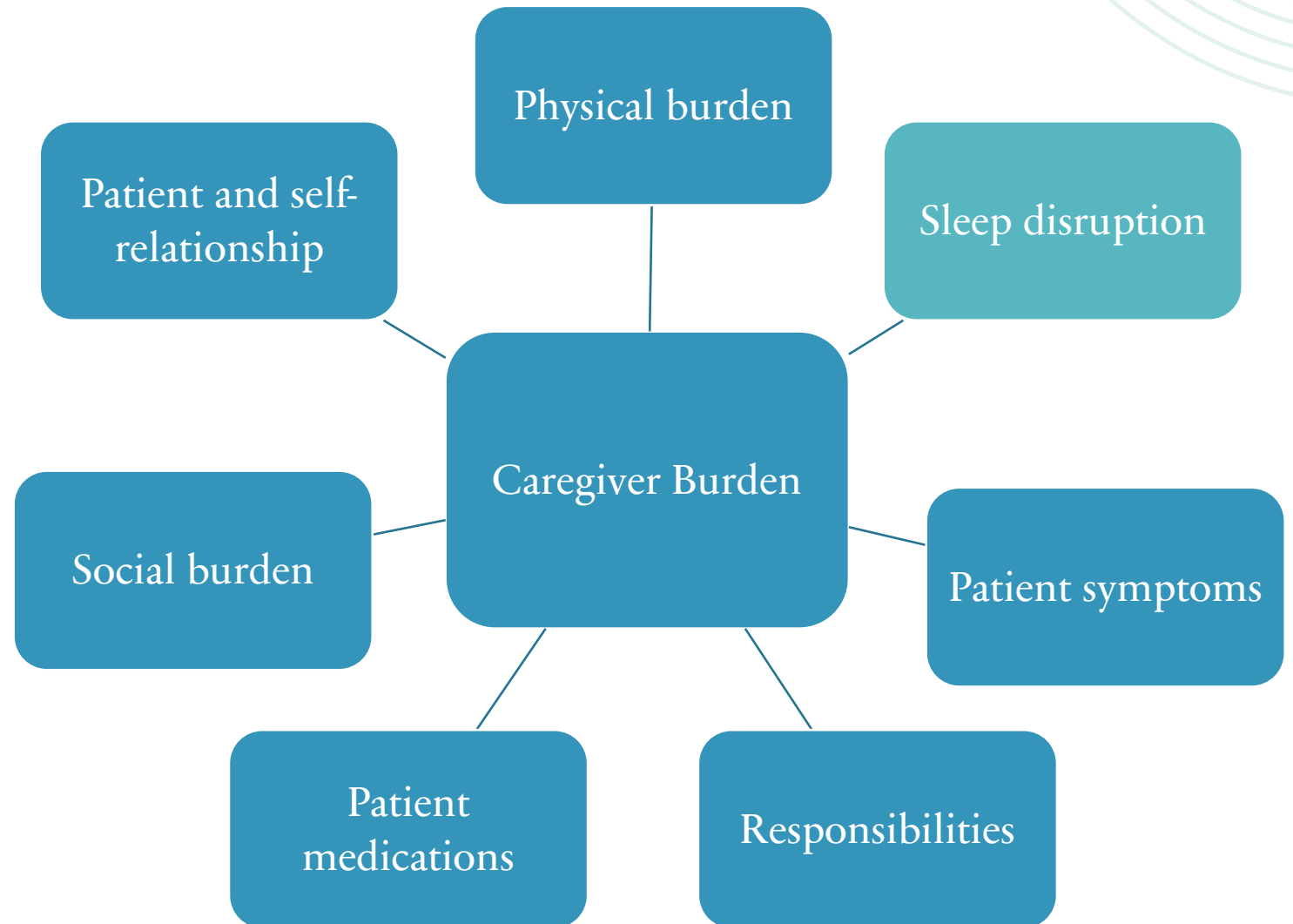
CAREGIVER BURDEN IN PD

- 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.



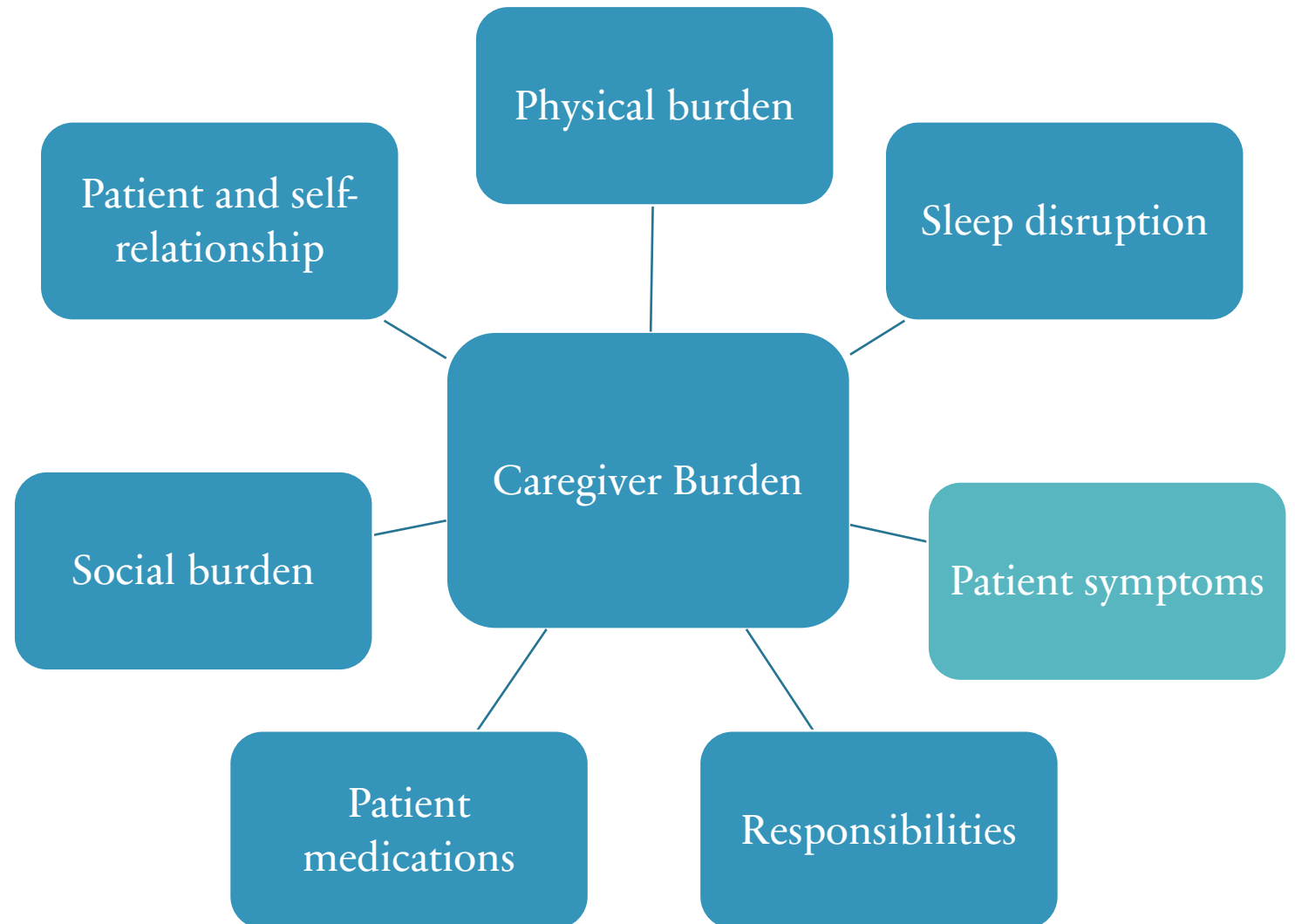
CAREGIVER BURDEN IN PD

- 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.



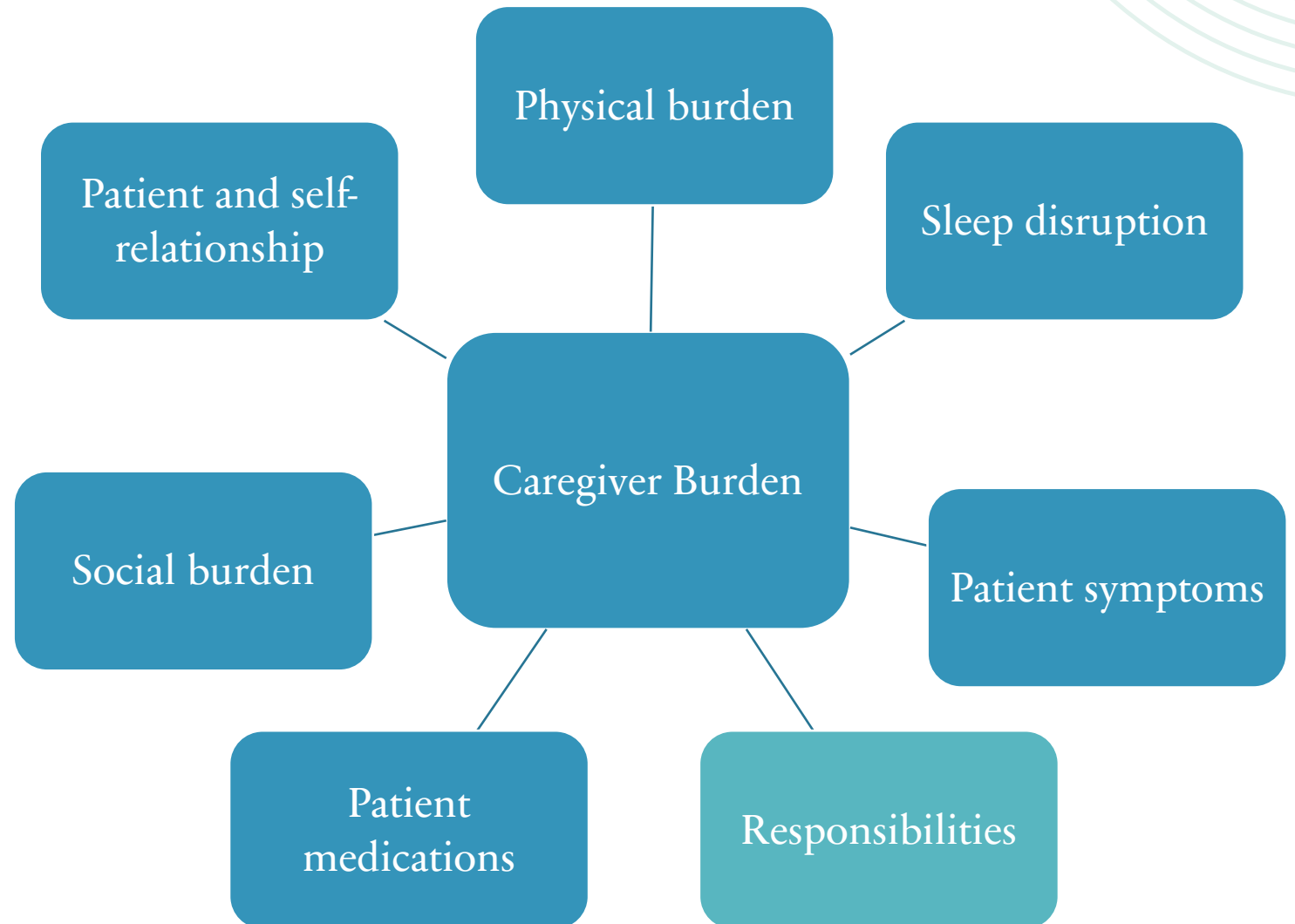
CAREGIVER BURDEN IN PD

- 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.



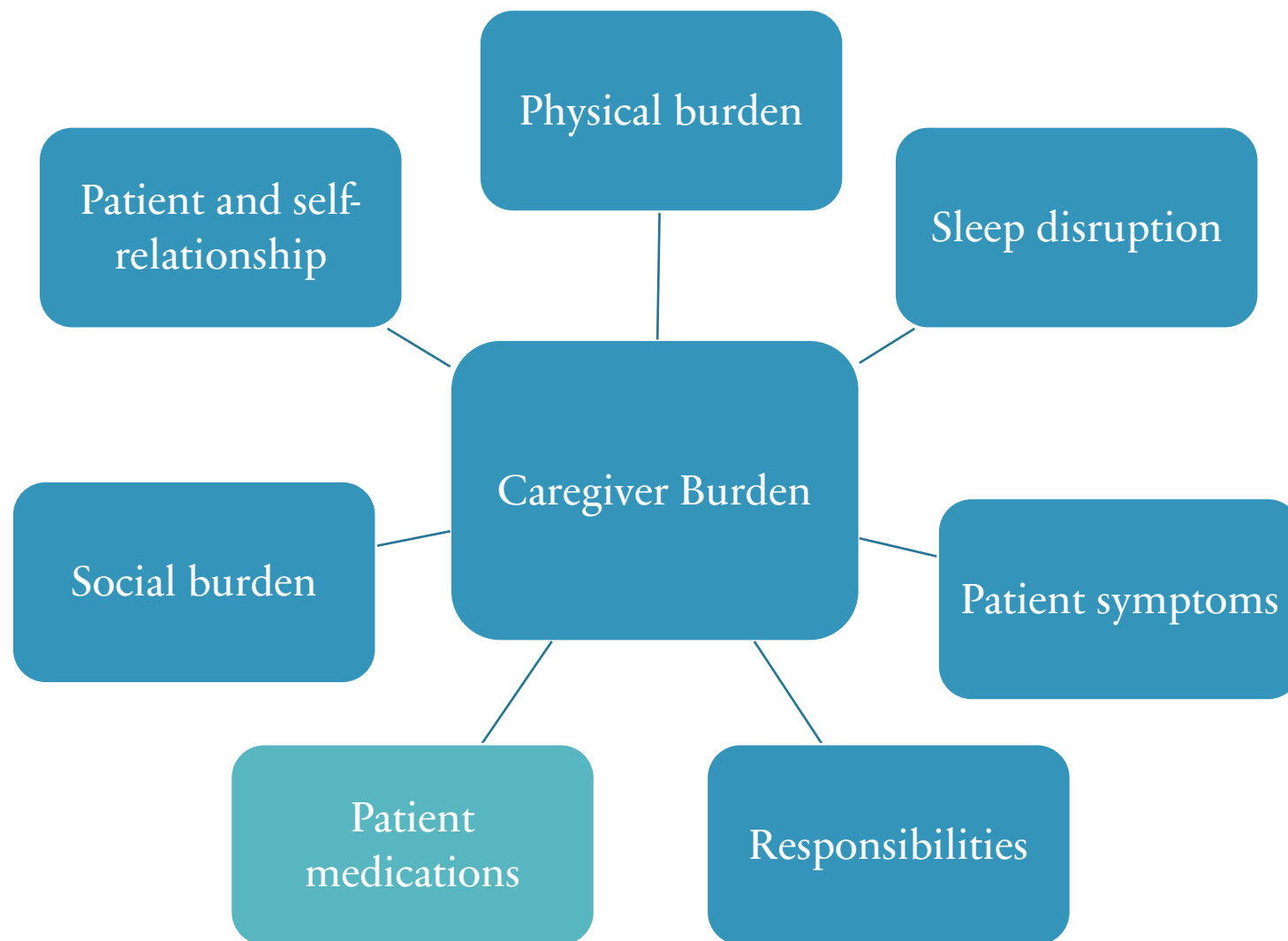
CAREGIVER BURDEN IN PD

- 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.



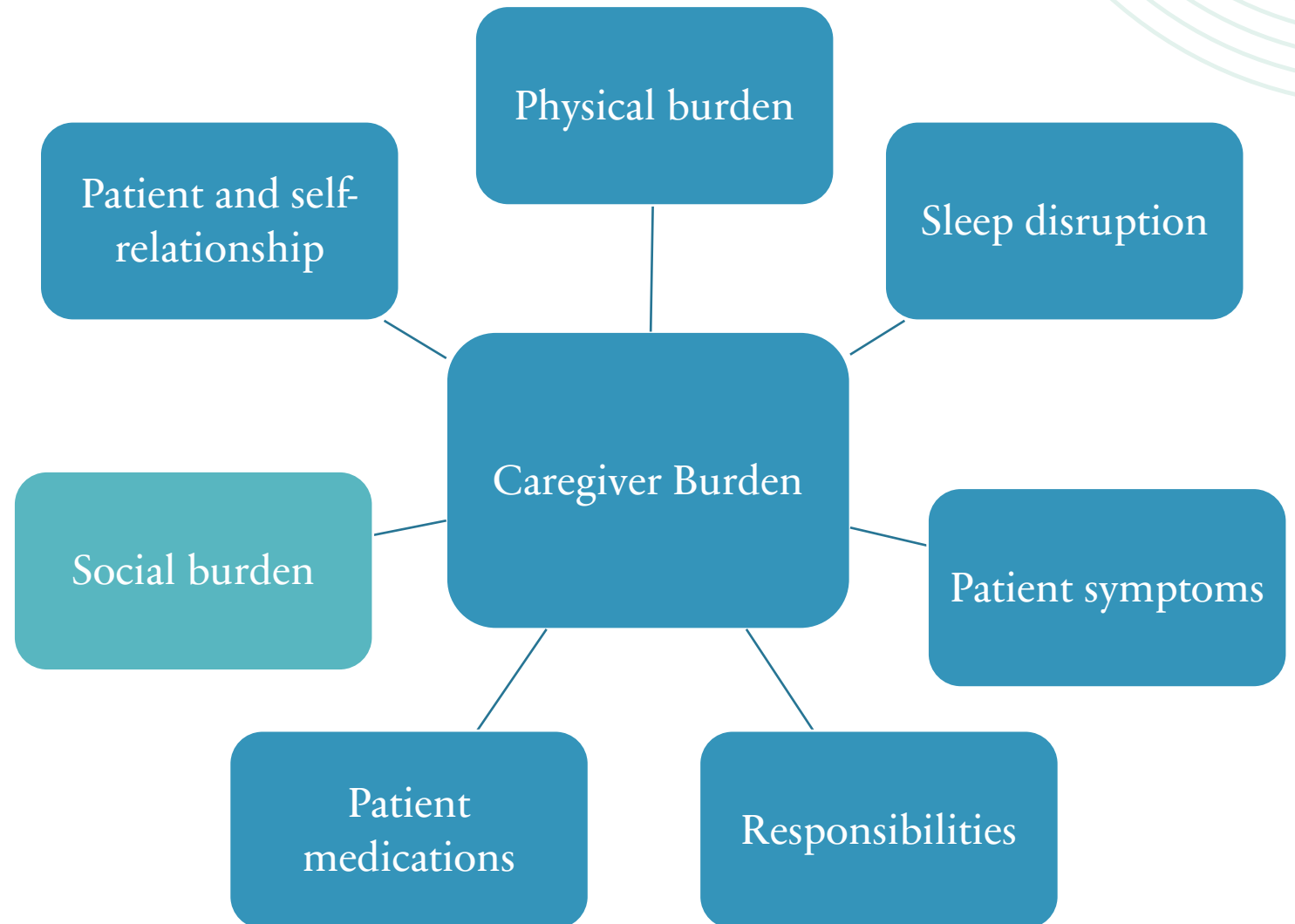
CAREGIVER BURDEN IN PD

- 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.



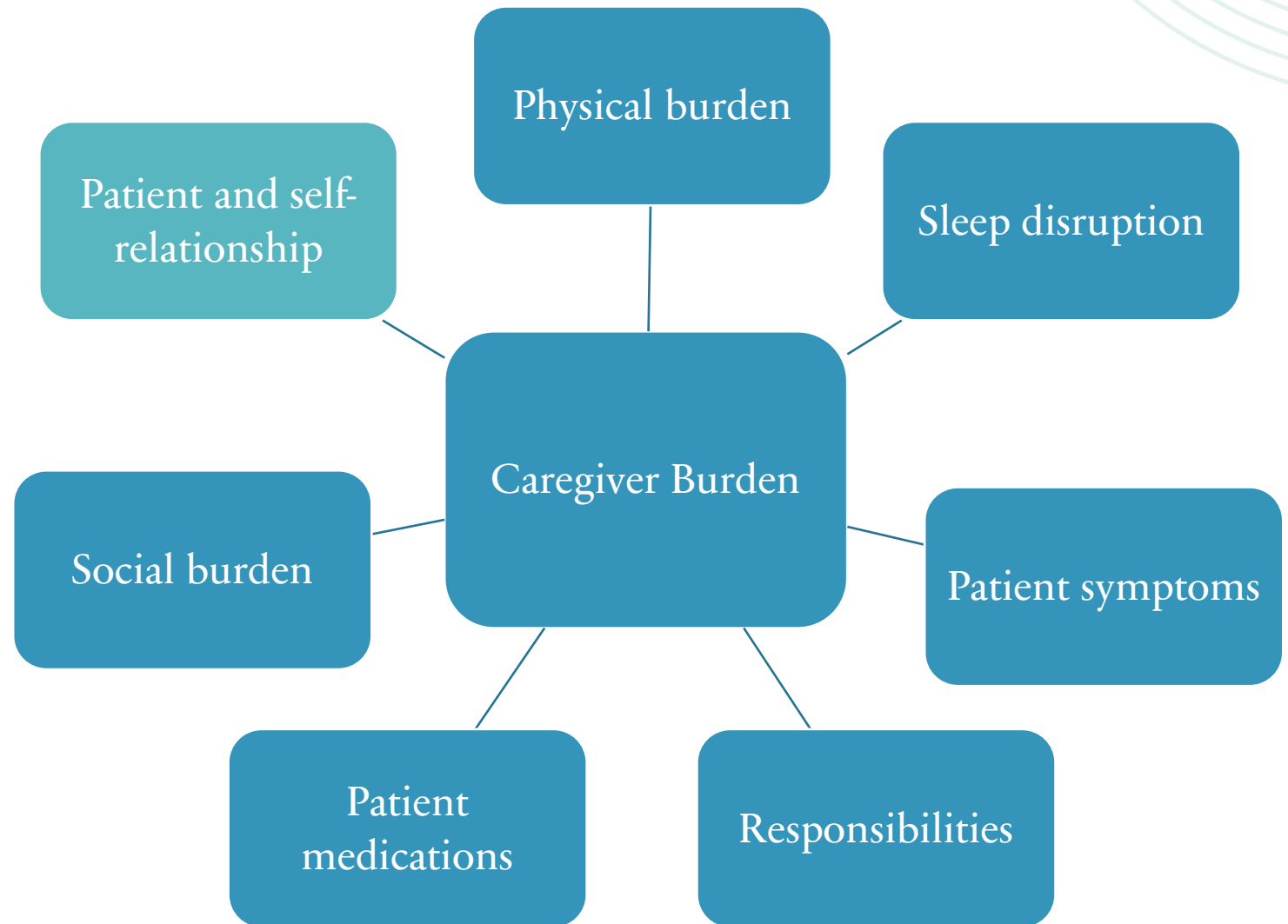
CAREGIVER BURDEN IN PD

- 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).



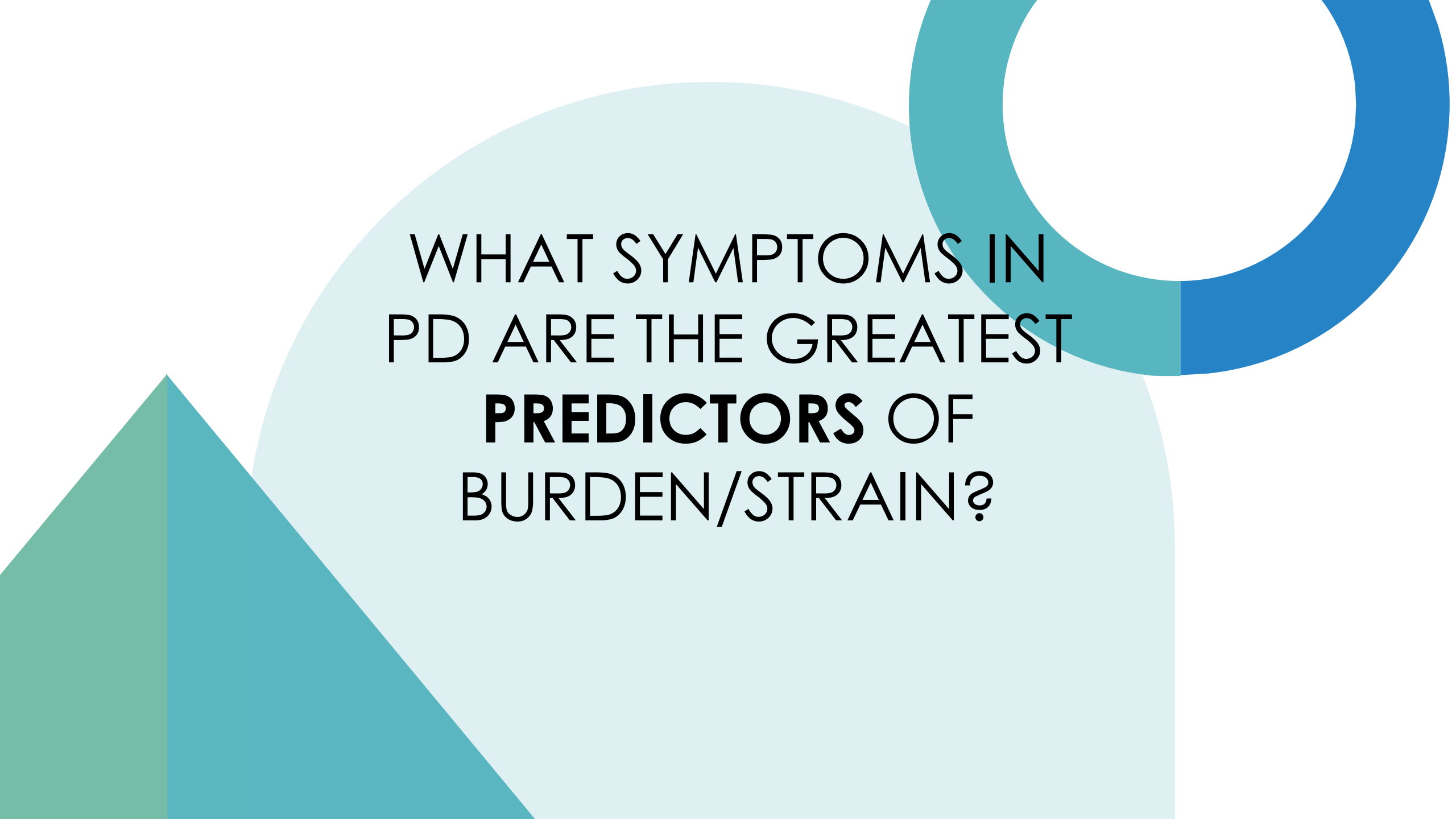
CAREGIVER BURDEN IN PD

- 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.



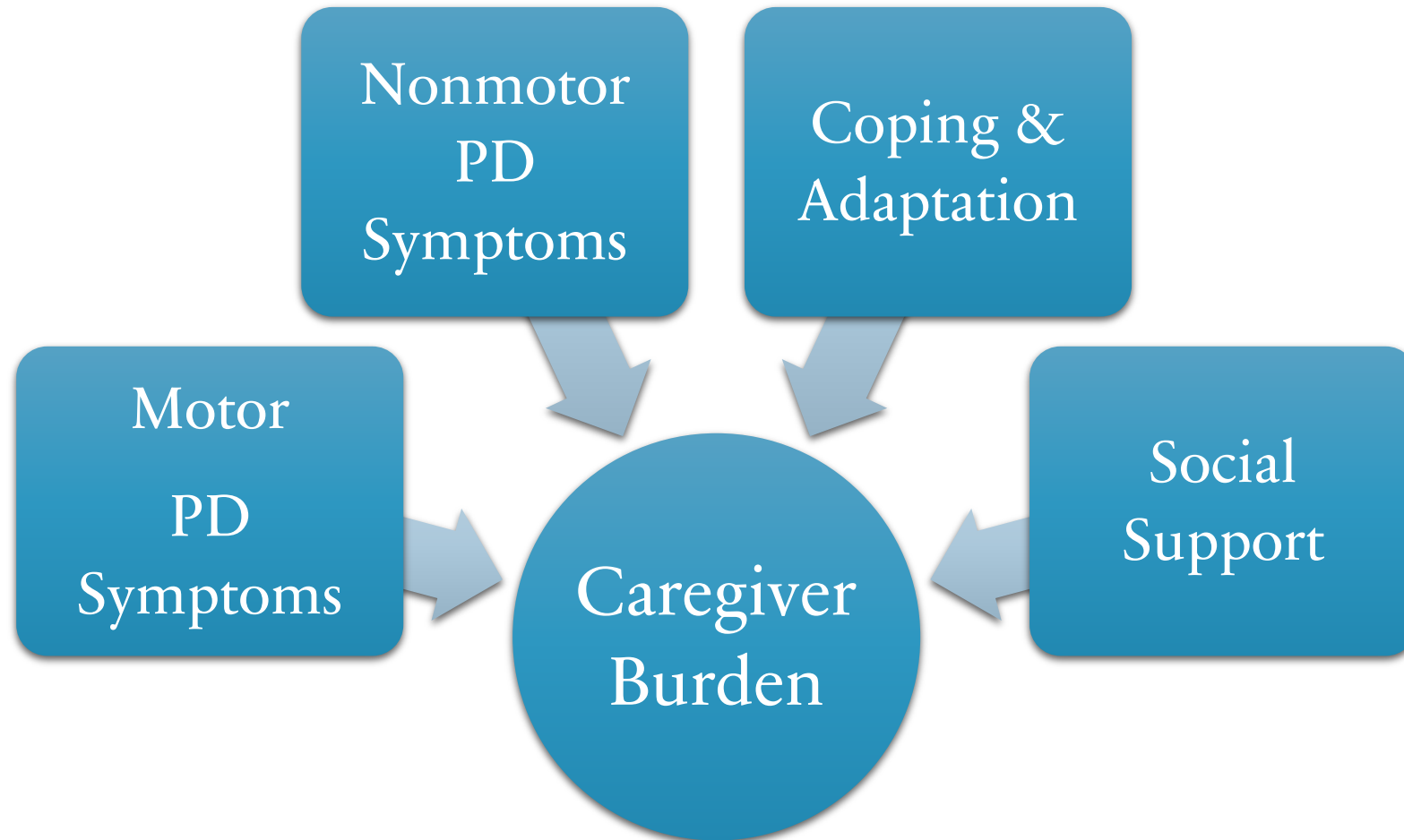
CARE PARTNER PERSPECTIVES

- “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 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*

The background features abstract geometric shapes in shades of teal and blue. On the left, there is a teal triangle pointing upwards. In the center, a large, light teal circle is partially visible. On the right, a thick blue ring is partially shown, overlapping the light teal circle.

WHAT SYMPTOMS IN
PD ARE THE GREATEST
PREDICTORS OF
BURDEN/STRAIN?

PREDICTORS OF CAREGIVER BURDEN



MOTOR SYMPTOMS



Motor Complications

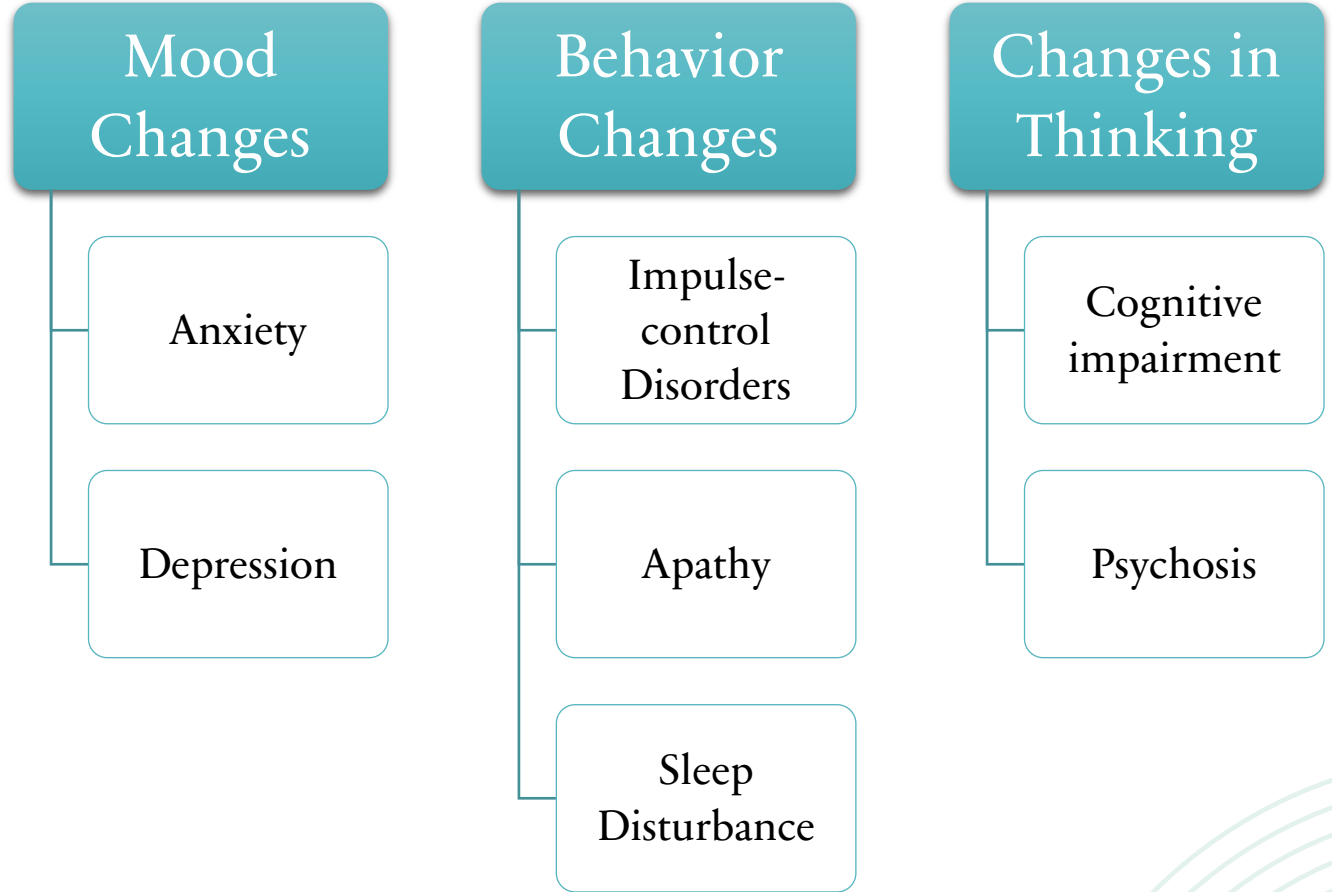
- Onset of motor fluctuations
- Increased time in the “off state”
- Dyskinesias



Balance

- Gait dysfunction
- Fall risk

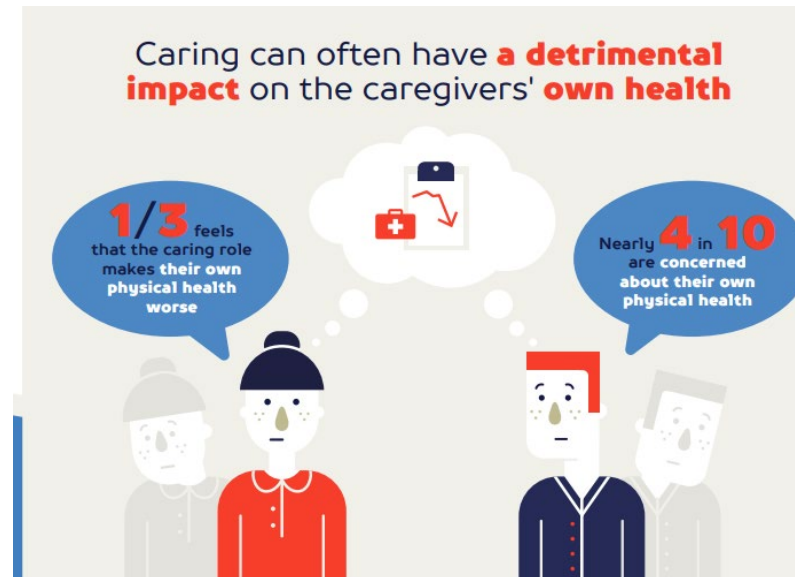
NON-MOTOR SYMPTOMS





**IMPACT ON
PHYSICAL HEALTH**

IMPACT OF CAREGIVING ON PHYSICAL HEALTH



“DON'T MISS YOUR REGULAR HEALTH CHECKUP OR NEGLECT YOUR HEALTH JUST BECAUSE YOU ARE BUSY TAKING CARE OF YOUR LOVED ONE WITH PARKINSON.”

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

EXPERIENCES OF CAREGIVERS

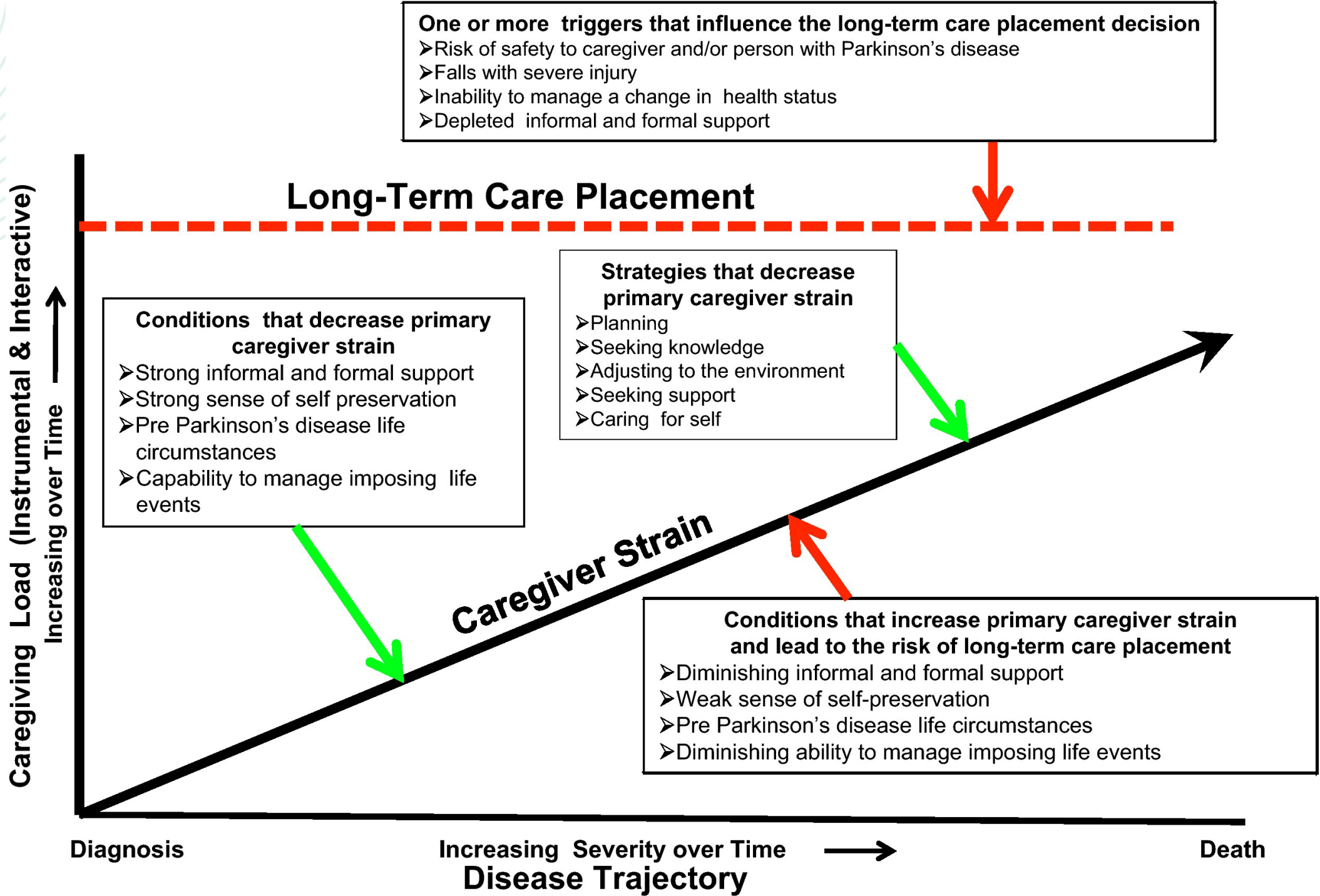
“I’m worried that I will fall sick. I cannot get sick because I’m a caregiver... the main thing I’m really worried about is my health. I have to keep fit and continue to work. We have very little savings. That is the only thing; I cannot retire.” *Female caregiver of spouse*

“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*



**CORRELATES TO
LONG TERM CARE
PLACEMENT**



PD SYMPTOMS AND LTC

Functional Limitations

Cognitive Impairment

Neuropsychiatric Symptoms

Behavioral Disorder

Psychosis

Age



BARRIERS TO SELF-CARE



BARRIERS TO SELF-CARE

QUESTIONS TO CONSIDER

- Do you think you are being selfish if you put your needs first?
- Is it frightening to think of your own needs? What is the fear about?
- Do you have trouble asking for what you need? Do you feel inadequate if you ask for help?
- Do you feel you have to prove that you are worthy of the care recipient's affection? Do you do too much as a result?

COMMON MISCONCEPTIONS

- I am responsible for my parent/spouse/friend's health.
- If I don't do it, no one will.
- If I do it right, I will get the love, attention, and respect I deserve.
- Our family always takes care of their own.
- I promised that I would always take care of my [care recipient].

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[person with PD].”

“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.”

The background features several abstract geometric shapes. A large, light teal circle is centered behind the text. To its right, a thick teal ring is partially visible, with a dark blue segment on its right side. In the bottom-left corner, there is a teal triangle with a green-to-teal gradient. The overall color palette is composed of various shades of teal and blue.

STRATEGIES FOR PRACTICING SELF- CARE

Rate each item below from 1 (almost always) to 5 (never) according to how much of the time each statement applies to you. Write the date above so you can track your wellbeing over time.

1 = ALMOST ALWAYS
2 = FREQUENTLY
3 = OCCASIONALLY
4 = RARELY
5 = NEVER

1. I exercise on a regular basis.	① ② ③ ④ ⑤
2. I make and keep preventive and necessary medical and dental appointments.	① ② ③ ④ ⑤
3. I have a job or regular volunteer activity that is gratifying.	① ② ③ ④ ⑤
4. I do not use tobacco products.	① ② ③ ④ ⑤
5. I do not use alcohol or drugs.	① ② ③ ④ ⑤
6. I get an adequate amount of sleep each day.	① ② ③ ④ ⑤
7. I have a hobby or recreational activity I enjoy and spend time doing.	① ② ③ ④ ⑤
8. I eat at least two to three balanced meals a day.	① ② ③ ④ ⑤
9. I have at least one person in whom I can confide (tell my problems, discuss my successes).	① ② ③ ④ ⑤
10. I take time to do things that are important to me (e.g., church, garden, read, spend time alone).	① ② ③ ④ ⑤
11. I do not have problems with sleeplessness or anxiety.	① ② ③ ④ ⑤
12. I have personal goals and am taking steps to achieve them.	① ② ③ ④ ⑤

INTERPRETATION:

- 12–24** You are doing an excellent job taking care of yourself.
- 25–36** You have room for improvement. Examine the areas where you struggle, and seek help from family, friends or healthcare professionals to make some changes.
- 37–48** You are doing a poor job taking care of yourself and are at moderate risk for personal health problems. Talk to your healthcare provider or others who can help you create and stick to a plan to take better care of yourself.
- 48–60** You are at extremely high risk for personal health problems. It is important for you to talk to your personal healthcare provider as soon as possible. Remember, you can only provide good care for someone else if you take good care of yourself.

SELF-CARE

1. Identify your concerns according to the categories in this section.
2. Place your needs and concerns in priority order.
3. Consider and write down “action steps” that you can take.
4. Discuss your ideas with others.
5. Devise a step-by-step plan.
6. Implement the steps with help from others as needed.



SELF-CARE PRACTICES



**MAINTAIN HOBBIES
AND REGULAR
ACTIVITIES**



EXERCISE



**EAT A BALANCED,
NUTRITIOUS DIET**



DRINK WATER



**GET ENOUGH REST.
TAKE TIME TO
RELAX**



**GET REGULAR CHECK-UPS
AND KEEP YOUR OWN
MEDICAL APPOINTMENTS**



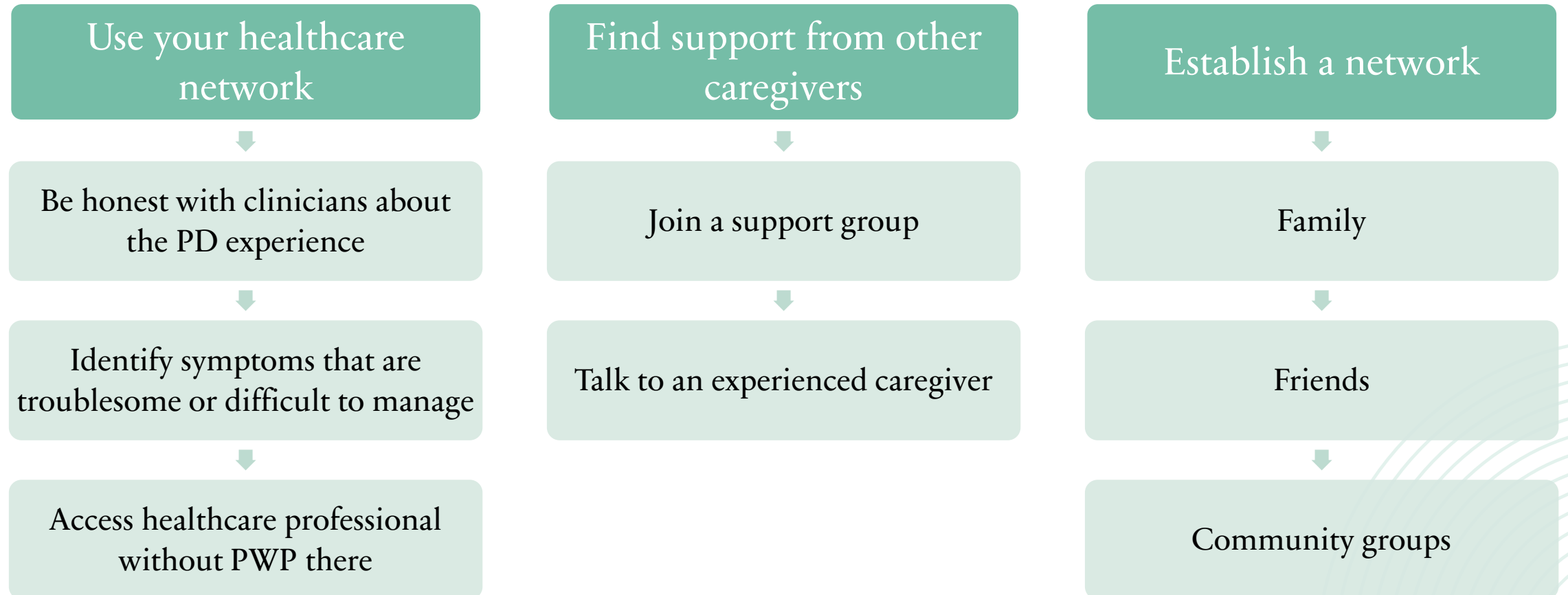
**THINK ABOUT YOUR FUTURE. WHAT
GOALS DO YOU HOPE TO ACHIEVE,
AND HOW CAN YOU ACHIEVE THEM?
CAN YOUR LOVED ONE HELP YOU
ACHIEVE THEM?**



**SET LIMITS AND STICK TO
THEM. BRING IN OUTSIDE
HELP (FAMILY OR PAID
WORKER)**

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

BUILDING SUPPORT NETWORK





THANK YOU!

Kate Perepezko, PhD, MSPH

kmp222@pitt.edu