

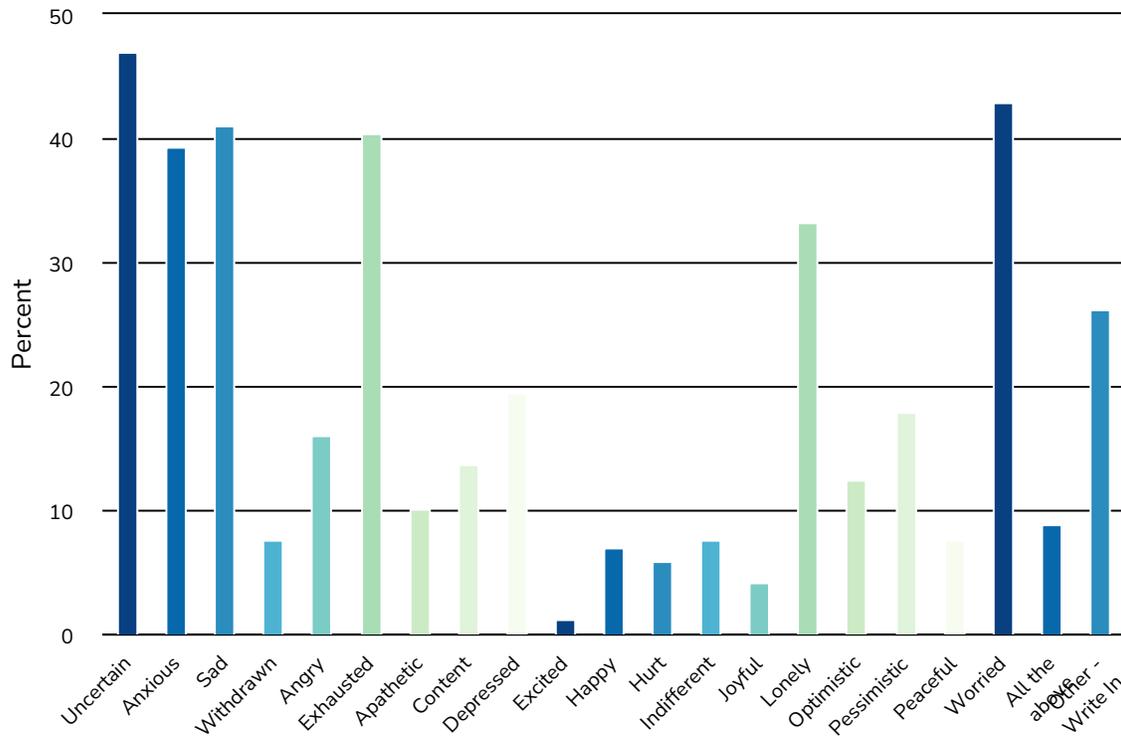
Report for Living Well as a Parkinson's Care Partner

Response Counts



Totals: 170

1. How are you feeling right now? Choose all that apply.



Value	Percent	Responses
Uncertain	47.0%	79
Anxious	39.3%	66
Sad	41.1%	69
Withdrawn	7.7%	13
Angry	16.1%	27
Exhausted	40.5%	68
Apathetic	10.1%	17
Content	13.7%	23
Depressed	19.6%	33

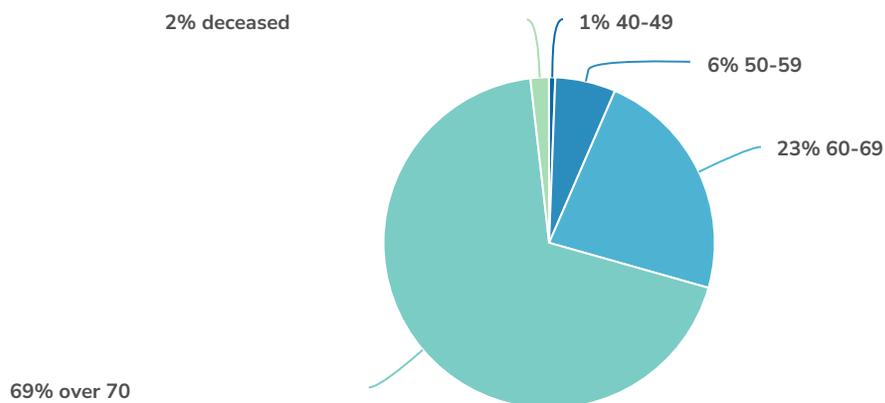
Value	Percent	Responses
Happy	7.1%	12
Hurt	6.0%	10
Indifferent	7.7%	13
Joyful	4.2%	7
Lonely	33.3%	56
Optimistic	12.5%	21
Pessimistic	17.9%	30
Peaceful	7.7%	13
Worried	42.9%	72
All the above	8.9%	15
Other - Write In	26.2%	44
Excited		1.2% 2

Other - Write In	Count
Grateful	2
frustrated	2
overwhelmed	2
Alone	1
Both husband and myself have Parkinson's. Having trouble with coping, and very emotional.	1
Challenged	1
Totals	44

Other - Write In	Count
Current and anticipatory grief.	1
Desperate to feel peace through this journey if so much grief.	1
Extreme frustration with the current medical industry's approach with PD	1
Frustrated	1
Frustrated & Supportive	1
Grateful	1
Grateful for what we do have	1
Grateful to still be partners with my spouse of 60 years	1
Hopeful	1
Husb has now passed as of Christmas 20221	1
I go between all of these emotions. Fortunately my partner is taking good care of himself physically.	1
I'm away from home right now on travel and have my brother at the house staying there in case my wife has a problem. So I am relieved being away and yet still having her watched over.	1
Just depends on the day	1
Learning	1
Loss of a future. Not making any plans.	1
Numb	1
Okay despite concern about future	1
On red alert 24/7, resentful	1
Overwhelmed with compassion	1
Relaxed	1
Resentful, exasperated	1
Resigned and fearful	1
Totals	44

Other - Write In	Count
So incredibly busy all the time doing everything	1
ageism	1
confused	1
depressed	1
in grief	1
isolated	1
lost freedom	1
neutral to avoid feeling bad	1
optimistic based on reality	1
overworked/ undervalued	1
resigned	1
sleepy	1
unsupported by family	1
Totals	44

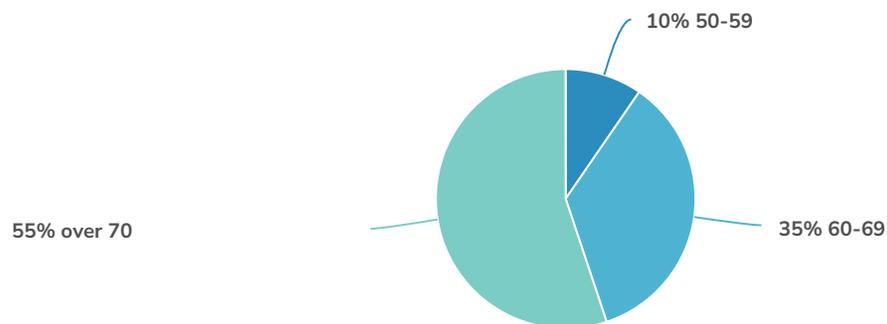
2. My person with Parkinson's is...



Value	Percent	Responses
40-49	0.6%	1
50-59	5.9%	10
60-69	22.9%	39
over 70	68.8%	117
deceased	1.8%	3

Totals: 170

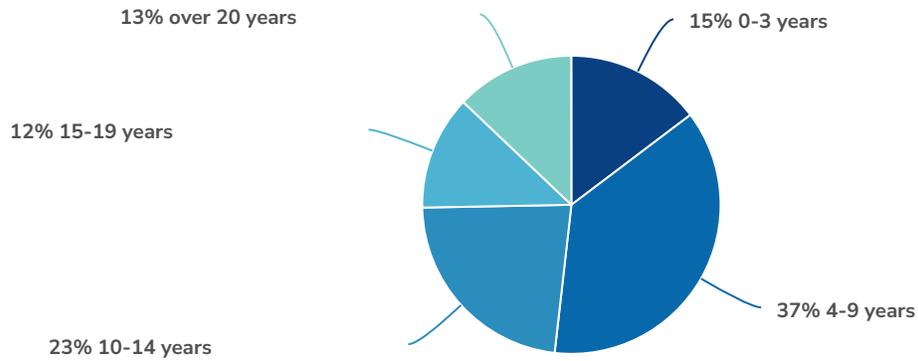
3. I am...



Value	Percent	Responses
50-59	9.6%	16
60-69	35.3%	59
over 70	55.1%	92

Totals: 167

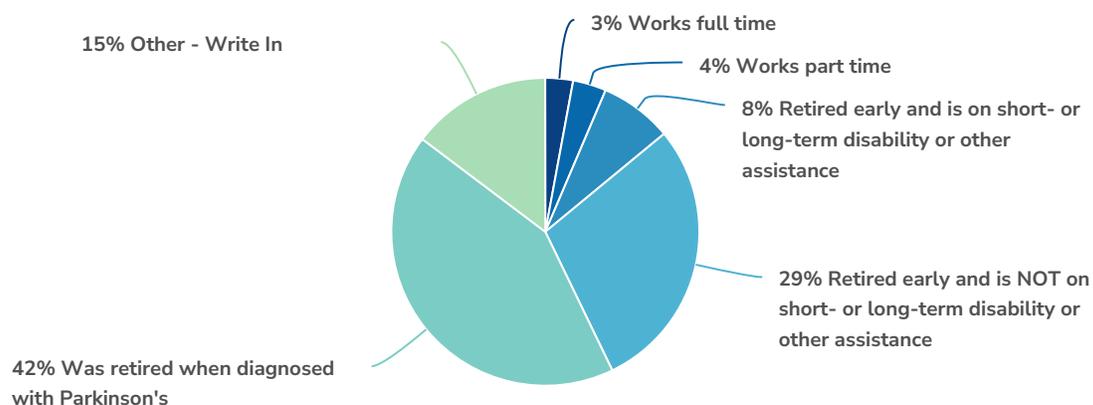
4. My person with Parkinson's has been living with Parkinson's for...



Value	Percent	Responses
0-3 years	14.7%	25
4-9 years	37.1%	63
10-14 years	22.9%	39
15-19 years	12.4%	21
over 20 years	12.9%	22

Totals: 170

5. My person with Parkinson's...



Value	Percent	Responses
Works full time	2.9%	5
Works part time	3.5%	6
Retired early and is on short- or long-term disability or other assistance	7.6%	13
Retired early and is NOT on short- or long-term disability or other assistance	28.8%	49
Was retired when diagnosed with Parkinson's	42.4%	72
Other - Write In	14.7%	25

Totals: 170

Other - Write In	Count
Is retired	1
Totals	25

Other - Write In	Count
Lost his job because of Parkinson's	1
On medical leave from full time job at costco	1
Retired	1
Retired 1998 but won't exercise or walk with me.	1
Retired after Parkinson's diagnosis	1
Retired and working 3rd career teaching math	1
Retired at 65 , good pension	1
Retired at appropriate age before diagnosis	1
Retired now going through the process of receiving disability	1
Retired shortly after diagnosis, but at normal retirement age.	1
Semi retired	1
Timing is an estimate. He had Parkinson's long before diagnosis.	1
UTI sent him to hospital	1
Was of retirement age and continued to work as long as possible	1
Worked 2 yrs before retiring after being diagnosed	1
gradually retired with PD	1
just switched his medical practice to 100%...works part time which is new.	1
retired at 65	1
retired at 67 years old Was eligible for medicare. Retired because working was getting harder	1
retired early and died a few years later	1
retired early and is now beyond age of retirement	1
retired from part-time position due to PD. Gets VA disability	1
retired on disability that now is on regular social security	1
Totals	25

Other - Write In**Count**

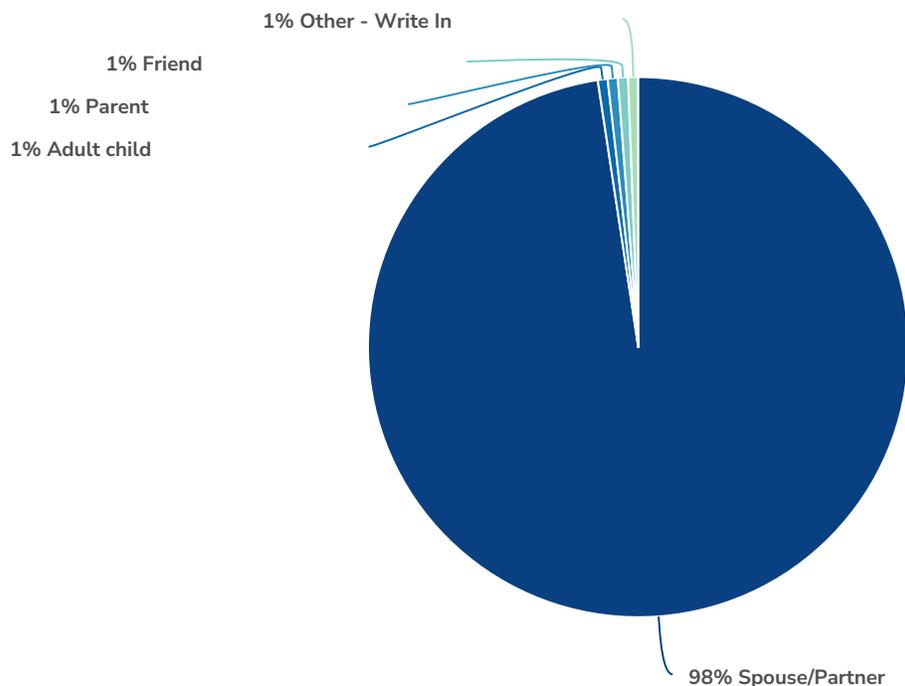
retired using long term care insurance

1

Totals

25

6. My person with Parkinson's is my...

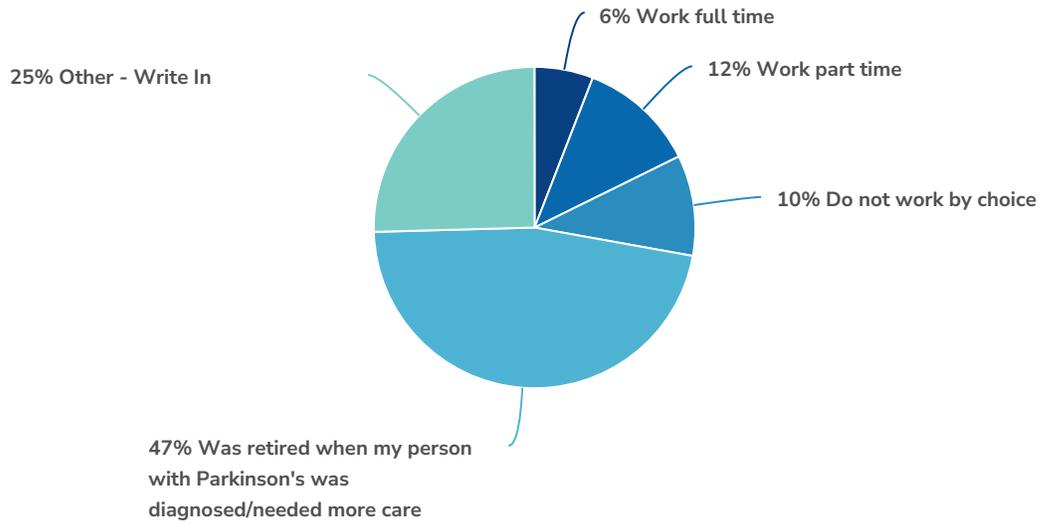


Value	Percent	Responses
Spouse/Partner	97.6%	166
Adult child	0.6%	1
Parent	0.6%	1
Friend	0.6%	1
Other - Write In	0.6%	1

Totals: 170

Other - Write In	Count
Ex-spouse	1
Totals	1

7. I...



Value	Percent	Responses
Work full time	5.9%	10
Work part time	11.8%	20
Do not work by choice	10.1%	17
Was retired when my person with Parkinson's was diagnosed/needed more care	46.7%	79
Other - Write In	25.4%	43

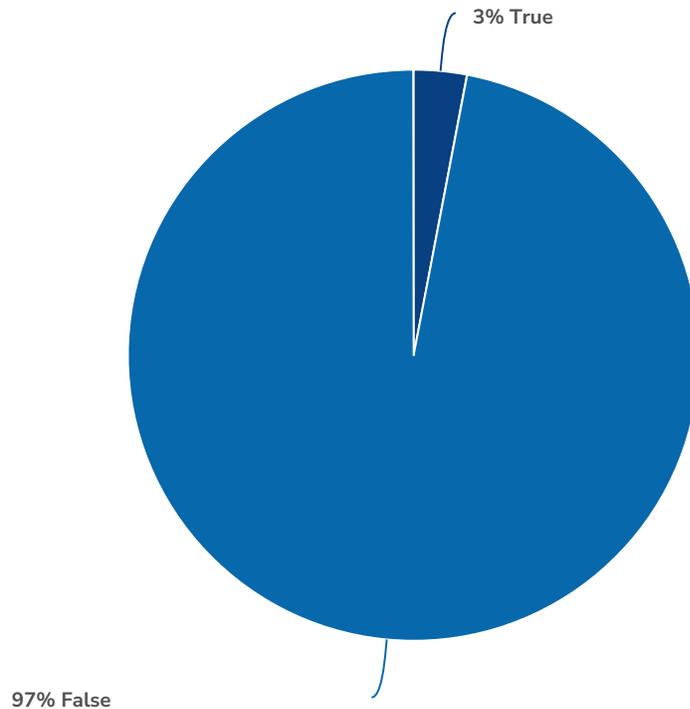
Totals: 169

Other - Write In	Count
Retired	4
retired	3
I am looking for job and I cant find it. I live in Peru	1
Totals	43

Other - Write In	Count
I stopped working 5years after diagnosis, but didn't retire until later	1
Recently retired to provide needed care	1
Retire in 2010 because my husband's parkinson was getting worse, so I retired at age 62.	1
Retired 5 years ago to become my LO full time carepartner.	1
Retired after diagnosis	1
Retired after my person was diagnosed with PD	1
Retired at appropriate time (before diagnosis)	1
Retired before diagnosis but it doesn't seem like retirement with weight of all work on me	1
Retired before my partner was diagnosed	1
Retired by choice	1
Retired early after my PWP was diagnosed.	1
Retired early due to my own health conditions and to be a care giver	1
Retired for many years	1
Retired from work/career a bit early to spend quality time with my spouse who has PD	1
Retired in 2012	1
Retired on my normally planned retirement 4 years ago, about 4 years after she was diagnosed. She didn't experience significant symptoms at the time of my retirement.	1
Retired shortly after my husband's diagnosis so that we could travel. I was at normal retirement age.	1
Retired when I planned to	1
Retired when she was diagnosed	1
Retired with my pwp	1
Self-employed	1
Shortly after retirement	1
Totals	43

Other - Write In	Count
Stopped working when it was clear he needed me full time	1
Was joyfully helping to care for grandchildren when my spouse with Parkinson's needed more care	1
Was working and retired early to care for him	1
Was working when diagnosed but retired early to travel while we still could	1
Worked when he was diagnosed but retired last year and became a caregiver.	1
did not work to care for partner	1
had to give up my job when I also was diagnosed with health issues. Needed full time at home to care for spouse with PD and myself	1
reired a couple years early when started needed more help	1
retired	1
retired 2 years after the diagnosis	1
retired at my full retirement age	1
retired same time he did	1
was not retired when my spouse was diagnosed. I am now retired.	1
Totals	43

8. I am a person with Parkinson's, and I am also the primary care partner or caregiver of someone else. (For example, I have Parkinson's, and I am the care partner to my husband with Alzheimer's/cancer/dementia/etc. I have Parkinson's, and I'm caring for my adult child who is ill. Or, I have Parkinson's, and I am a grandparent who is raising my grandchild(ren).)



Value	Percent	Responses
True	3.0%	5
False	97.0%	161

Totals: 166

9. If the previous statement is true, and you would like to tell us more about your situation, please do.

ResponseID Response

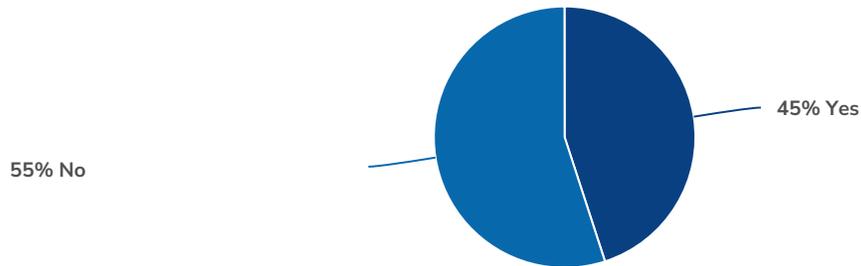
31 Have vascular Parkinsons and husband with pd is in memory care but still needs more than that

47 I was diagnosed in 2019 and my husband tries to take good care of me. He needs considerable help himself because of several different problems: gout, heart problems (had a quadruple by-pass, etc.)

83 Both of us have Parkinson's so we help each other.

90 I am always worried because he falls a lot. Take care of the house and taking care of my husband. It's taking a toll on me. I feel I am stuck. I have no life. I am on duty 24/7. My mind is always racing, what I am doing next. This is hardest time in my life. I love him, feel so sorry for him. I am getting very tired lately.

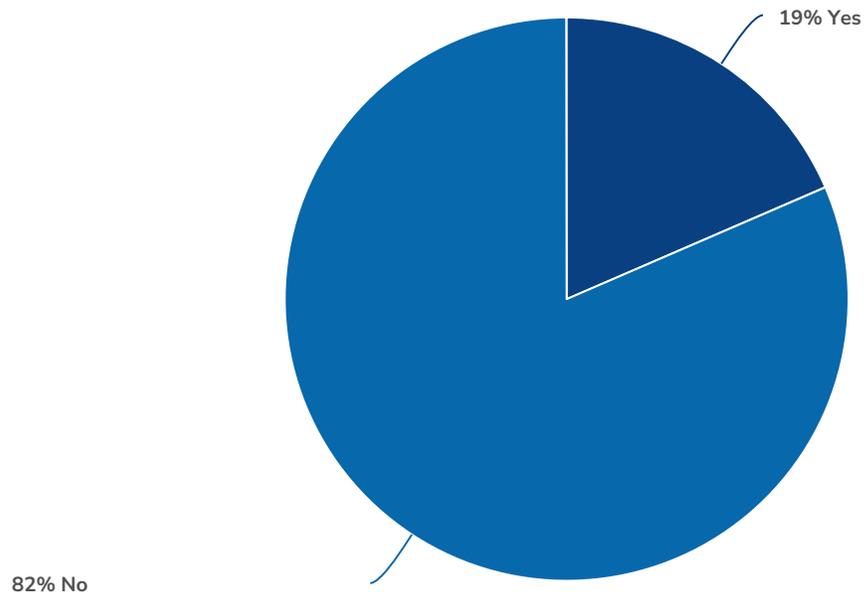
10. I attend a virtual care partner support group regularly.



Value	Percent	Responses
Yes	45.0%	76
No	55.0%	93

Totals: 169

11. I attend an in-person care partner support group regularly.



Value	Percent	Responses
Yes	18.5%	31
No	81.5%	137

Totals: 168

12. One of the things I like MOST about participating in care partner support groups is...

ResponseID	Response
1	Knowing that other people are going through the same experience.
3	Listening to the stories and getting advice
5	Sharing with others going through similar challenges. Ability to share feelings with others who will not judge you because they are going through similar challenges also
8	Resources
9	My periodic irregular attendance is accepted and I always feel welcomed and nourished
10	Useful tips, sense of community.
11	Ideas about how we as care partners can care for ourselves. Tips for coping and even thriving. Insights into how we can cultivate hope and optimism and avoid pessimism, despair, and depression.
13	Just hearing what others are going thru and how they handle it. I love the honesty about the feelings and info that are shared.
14	I don't feel alone. That somebody out there cares and understands my difficulties.
15	I get that my experience is hard and not unique. It helps that others are working with similar challenges.
16	The friends I've met and the sharing of ideas, experiences, etc.
17	N/A
19	They understand and share experiences
20	the resources, and knowing I am not alone
21	hearing other's experiences and paths. Mine is not too bad right now so I want to prepare.
22	I haven't participated yet in a group just for care partners except briefly about 5 years ago before we moved to another state.
23	New ideas, validation of feelings
24	N/A

ResponseID Response

25	I'm still hoping I can find an in person or virtual care partner support group that meets my needs. So far none of them have. I believe the best group for me would be a social group for spouses of Parkinson's. The focus would be social activities, with Parkinson's issues only coming up naturally in conversation instead of a "group therapy" atmosphere.
26	Sharing and supporting. Learning.
28	Knowing I am not the only one
29	We have become friends, now on our own, and enjoy our monthly coffee. We used to meet with our partners as well, but ParkinsonCanada no longer supports care groups, for PD folks or caregivers.
31	Sharing experirnces
32	Share & receive tips from other care partners. Also knowing I'm not the only person going thru care giver issues.
33	learning about: (1) local support agencies and exercise options that others use; (2) strategies for travel with my partner, hiring care givers, etc; (3) the progression of PD for different individuals and what the future might hold for my partner and, thus, me
34	I share my insights, I share my reflection based on my experience. I share information I find it valuable. I enjoy cheering people in my group, it gives me meaning.
35	I feel that I'm not alone in this journey and I get ideas from others that will help my spouse.
36	Taking an hour for myself with others who get how hard this is.
37	The kindness/tenderness yet professionalism of Connie and the panel members
38	My situation makes support groups redundant. My PWP doesn't want to know anything about PD. Doesn't know what medicine he takes. Does nothing to help with his diagnoses. Does nothing but watch tv. I've been to support groups and no one has been in my situation. The people there have partners that participate in their illness.
39	Getting problem solving ideas. Finding out I am not the only one having these thoughts, emotions, problems etc when dealing with my PWP
40	Tips for caretaking, and being with others who understand the struggle and challenges of care taking.
41	Ideas and suggestions for dealing with various aspects of Parkinson's. Tips (or hacks) for everyday situations.
43	Knowing that I am not alone, getting resources from others' experiences.

ResponseID Response

44	suggestions from panel and resources posted by others in chat
46	Do not attend one
47	Mostly people understand what you are talking about. Say constipation and I know the pain. You don't have to explain that PD is an inside/outside problem. For every muscle that twitches outside there are many more conditions wearing you down from the inside.
48	Hearing suggestions about how to prepare for and handle situations. For example the last care partner support group was timely as we are currently traveling in the UK and there were many tips and ideas plus encouragement to continue to travel together. Thank you!!
49	Other people understand and I get useful information.
51	Reading how care givers cope
52	Sharing
54	I learned about new things I can use to help my person with Parkinson's.
55	I sometimes find webinars you have taped and watch them. I find them interesting and educational.
56	Understanding people who are experiencing what you are who share tips and lessons learned.
57	I find helpful suggestions and a sense that I am not alone.
58	Hearing people talk who understand what I'm going through
59	Learning different ways of managing symptoms.
60	When I attended. .knowing there are others going through similar situations .hearing new ideas
61	connecting with/hearing other peoples' stories
62	feeling like there really is support.
63	I have only had time to attend one or two of the care giver support groups. For the little bit I tired it was helpful to hear others with the same concerns and frustrations, plus helpful hints on care
64	Hearing good words to fall back on as well ad hearing that I am doing a good job.

ResponseID Response

66	When my husband was alive I did participate and found it helpful. My husband and I, with another couple, lead a support group which had both people with Parkinsons and their care partners. The in-person support and sharing of information and help was very important.
68	Knowing I'm not alone
69	Learning from others
71	I believe , if I was in a support group, I would feel less impatient and feel more supported.
72	We had various presenters come and speak
73	no opinion
74	Resources and tips to deal with PWP and support for caregiving.
76	Each month before I go, I reflect on the prior month and what observation/feeling I might choose to share with the group.
78	hearing how other care partner's cope and listening to experts
79	Knowing others understand, and learning new information. It's still so new to us.
80	Ideas to manage my PWP Uplifting to hear about self-care Travel tips good Enjoy having a medical/social work on calls too
81	sharing of information and experiences, and always find something to laugh about even if we are all having bad day(s)
82	Hearing about other caretakers information and or problems..
85	Everyone is having a similar experience so they all get it. It's an hour for ME! So much fabulous information
87	I don't know since I don't have a support group.
88	The friendships I have made with wonderful, remarkable women! I learn so much! Help, medications, etc.
89	Sharing time with others who understand my situation and are so supportive of each other, helps a lot.
90	I was attending virtual care partners meeting. They are in person now. I can't leave him by himself.
91	Not sure that I like it. Participants are often overwhelmed and that makes me anxious for our future.

ResponseID Response

92	Information Coping strategies Ideas for managing
93	the honest sharing, advice, help, resources
94	Helpful info
95	I'm always looking for optimism. I can share my thoughts as we have been living well with Parkinson's for 25 years.
96	Learning new ideas of caring and support of others going through the same thing.
97	Hearing about what can be helpful for my pwp. What others do to stay positive
99	In the past I was able to attend zoom care partner support groups. Then, my person with PD got worse and needs more of my attention and I can't seem to find the time to get on with the support group any longer. I enjoyed hearing from others that we all had similar experiences and hearing what others did to cope.
100	I have been unable to participate in support groups, but I watch videos and recordings for care partners. I can't explain specifically what I like or exactly how it helps... it just does.
101	Feeling supported, less alone, understood. I often learn something valuable from someone else.
102	Meeting people
103	I can say any truth, without giving background or needing to explain myself.
104	validating feelings I am experiencing. learning new resources.
105	Not feeling alone
106	It is Cathartic to be able to talk with others who are experiencing similar difficulties. I receive many practical suggestions and hear about valuable recourses. Thank heavens for support groups.
107	Never been to one.
108	Learning I am not alone
109	Haven't started participating but am looking forward to it.
110	knowing I am not alone

ResponseID Response

111	Learning how PD has changed other care partners' lives (e.g., career changes, lifestyle changes), and learning what other care-partners do to get a reprieve from PD.
113	N/A
114	Easing the loneliness felt in this journey and giving and receiving advice on caring for a person with PD.
115	Learning from others Tips to make caring easier Tips to make life easier for my PWP
116	Information provided..
117	The open discussion of negative as well as positive feelings about the caregiving role
118	Information about how others treat various difficult symptoms
119	I don't feel so alone.
120	Hearing from other people going through the same experiences. It's great to share experiences and hear how other people deal with challenges. It helps me to think I am not crazy!
121	Learning from others
122	support! Learning so much from Davis Phinney care partners zoom meeting and from this website and other websites that offer information
123	Honest I am so busy trying to keep up that often forget the meetings even if they are on my calendar. It is hard to assume the role of both spouses in a marriage. I appreciate Davis Phinney Foundation and your efforts. I am trying to acheive better attendance. Email Reminders a week prior help!
126	Hearing about other means of dealing with the symptoms of PD and Lewy-Body dementia.
127	Hearing stories similar to mine centers me; I don't feel alone or crazy.
129	laughter
131	finding others who care for those with PD having the same symptoms, concerns, and who are also new to this
132	The sharing of feelings, symptoms our person with PD experiences and being able to talk about possible care solutions.
133	I always come away with helpful information. I feel supported. I don't feel as lonely.

ResponseID Response

134	The opportunity to share resources and hear about people's experience with neurosurgical procedures such as focused ultrasound and DBS.
135	Hearing of other people's similar experiences and not feeling so alone. I haven't been able to participate in these meetings in a while because I'm just too busy tending to my husband and I feel overwhelmed - there's just not enough time in the day....
136	Knowing others are experiencing some of the same issues I'm dealing with
137	I can share stories with other care partners
138	just hearing that others have the same issues helps, ideas for dealing with them .
139	Learning from each other.
141	hearing information about being a care partner, what to expect as the disease progresses, knowing there are others dealing with the emotions you are experiencing
142	Knowing that life goes on. It is comforting to see the care partners talk about regular life too and not just the Parkinson's impact.
144	Knowing I'm not alone
145	Knowing I am not alone
146	real time chat, I've only been able to attend one live event and I loved it! I have watched some of the videos on the sight
147	Bouncing questions to others and sharing experiences. Getting good answers.
149	I don't feel as alone or overwhelmed. I learn from those who walk before me.
150	Simply connecting, hearing from others caring for a PWP
151	Hearing other people's stories and experiences and how they deal with it. Up to present my partner has been fairly self sufficient. I wasn't too interested in care giver info. Now the PD is taking a greater toll and I am more interested now
152	Nothing in particular, poss. it scared me like I was in for in our future
153	Hear tips to cope from people who have been through it
154	You get a chance to talk about how you honestly feel
156	I usually learn one new thing about PD or one new way to handle something that I might not have known if I wasn't listening to Connie & the others.

ResponseID Response

157 That I'm not alone with the challenges in caregiving without much help from family members.. do 24/7 care & others have it worse, hearing specialist confront the mental health & cognition issues that neurologists don't address.

158 Sharing stories

159 Hearing other care partner experiences and stories.

161 Na

162 Hearing that I am not alone in this struggle.

163 Suggestions of other care partners about things I struggle with that they also deal with.

164 You learn what others are going through and don't feel alone.

165 Na

166 I feel less desperate

167 Common concerns

168 I like that I can attend them virtually. Some groups record the meeting so I am able to listen to the recording when it works for me.

169 Affirmation that I am not alone in my frustrations. Learning how others deal with PD.

170 I feel less isolated, more connected

13. One of the things I like LEAST about participating in care partner support groups is...

ResponseID	Response
3	The time it takes!
5	We don't have an expert in the group
8	Zoom is SO impersonal
9	Meeting during Covid outdoors with my uncomfortable travel chair I liked least.
10	Reminders of how hard it can be. Not being able to support others due to the load I am carrying.
11	Too much talk about how to provide something for our partners and too much talk about "my PwP is experiencing x, is this normal?"
13	Sometimes certain participants talk too much and don't let others share.
14	Sometimes get busy and cannot log in
15	Sometimes I feel that our situation is worse than others especially since we had to move my PWP to a care home a few months ago.
16	The reminder of how things might be in the future.
17	When I have looked into and in person groups I am turned off by all the prayer.
20	It's very scary to hear in-person descriptions of how much my PWP's health can deteriorate
21	I have nothing to say about this.
23	More talk verses personal support
25	1. Conversations that are disrespectful to spouses with Parkinsons. 2. "Poor me" discussions. 3. Lack of resources/groups that address needs specific to a spouse. 4. Lack of attention to dealing with loneliness, loss and grief due to personality changes and communication problems of spouses due to Parkinson's. 5. Assumption that issues of children, friends etc. are the same as spouses. 6. Assumption that busy working care partners are available in the middle of the day. 7. Most groups/videos etc. seem to focus on teaching the care partner how to improve their caretaking, instead of focusing on the needs of the care partner herself.
26	Being called out when I don't actively participate.
28	When someone is really negative.

ResponseID Response

29	I also attend an Alzheimer Care Partners group, because my PD partner has advanced dementia, and I don't like the Alzheimer "Now it's your turn to tell us about your life" approach as we make our way around the circle. The PD approach that we used was and now is much less "formal" and much more comfortable and enjoyable
32	Interruptions constantly from my husband with PD.
33	hearing about the progression of the disease in other PD individuals, while helpful, is distressing and makes me pessimistic for the futures of both my husband and me
34	Leadership in support groups has the challenge to be adaptive.
36	Spending an hour on issues not relevant to me or our situation.
38	See above. I also don't like virtual support groups. They feel impersonal.
39	There is nothing I don't like!
40	Like most of it....sometimes someone going on at length with something that is not relatable to me.
41	When everyone is allowed to participate, there are always one or two participants who seem to dominate the hour. ,
42	Driving to the meeting. Or arranging time to attend virtual.
43	When newly-diagnosed, it was hard to see what was coming down the line. Now I am glad that I was prepared.
44	no opinion - I miss many of the meetings (as I'm sure other care partners) because my loved one's immediate needs come first.
45	Depressed people venting - or remaining silent. Little that is practical and much that is discouraging. They make me want to weep.
46	Not applicable
47	I am a slow talker and most people cannot hear me because my family is nearly 100% soft slow southern talking. People get tired of straining to hear me and cut me off.
48	Hearing about possible situations I may find myself in the future. But, that doesn't mean it isn't good for me to hear about them, just scary
49	Depressing
51	I'm new to this so I really can't answer
54	There's nothing negative for me.

ResponseID Response

55	I wish I could tune into the Live Care Partner webinar, but it airs at 2PM Eastern time and I'm working then. There was one webinar I tuned into not provided by your foundation and I found it too depressing. Yours tend to be most educational.
56	People who complain but do nothing to change their reality
57	The fact that I can't always make them and there are no replays.
58	I need to find one in Los Angeles so I have no complaints yet
59	Trying to schedule time in between work, school, and kids.
61	when emotion is squelched
62	I usually don't have time.
63	no comment
64	The whiners....there are always a few.
66	There are no longer any local in-person support groups.
67	my spouse with Parkinson's does not like support groups
68	Hearing the stories of what's to come. Feeling overwhelmed
69	Absorbing others complaints
72	Some people dominating the group
73	no opinion
74	None
75	It seems all of the care partners do not have a spouse as advanced in Parkinsons as mine is.
76	Hard at times to be away from my partner.
79	Really nothing. I can scare myself with 'what if' on my own, seeing how well care partners deal with this disease gives me hope.
80	Nothing - it's all Positive

ResponseID Response

81	tried virtual, however, my spouse within hearing distance did not allow me to speak freely as i can at in-person group
85	wish we were all together in person
87	Not sure! I will have to work on that.
88	My group is all women. We have lost two husbands in the last six months.
89	You see what may be coming by hearing from those further along in the disease process. It can be sad and depressing.
90	I get depressed listening to people's hardships and sad stories.
91	Same as my previous answer and I also don't care for the push toward mindfulness. It feels very new age.
92	The time it takes. The need to find someone to be w my partner. With limited free time I don't want robust it focusing on PD
93	can be a little depressing
95	Sad, depressing, selfish stories.
96	Want to discuss not be lectured to
97	Can't think of anything
99	Frankly, some people seemed to be handling things so much better than I was that it made me feel guilty. No one else's problem - just mine. :)
102	Can't find the time, I am a 24/7 caregiver.
103	Some personalities may taje over, when others have more pressing needs.
104	concern about my future based on situations expressed by others
105	Learning more about what will likely be my partners demise.
106	Hmmmm. Most of the online sessions have been very helpful. I feel better after the sessions even though we have discussed the many problems that may come with PD.
107	N/A
108	Depending on a particular meeting, not helpful so becomes a waste of valuable time
109	N/a

ResponseID Response

110	mixed company, would prefer being able to share more openly with other wives caring for husbands
111	Getting overwhelmed with PD information that tends to be generalized (e.g., sales pitchy); whereas, PD is quite unique from person to person and specific treatment effectiveness varies from person to person.
114	The fact that it is necessary in the first place.
116	Seeing the progression of others in more advanced disease
117	The unfortunate reminders that my role will inevitably become more difficult
118	Learning about more difficult symptoms that may be coming in the future
119	It's virtual vs. in person
121	The set times do not work well with our varied schedule - ie Dr. appts etc.
122	I love everything! When the zoom meeting is over I'm so grateful for the meeting! I learn so much.
123	Some of the virtual meetings I have attended are really helpful when they cover topics I am dealing with. But some of them are overly upbeat and positive which only makes me feel more isolated. I need to hear truthful discussions of serious issues like Parkinson's Dementia and Behavior Disturbances. I don't want to be overly negative or scare others. But hearing overly positive discussion is not real for me.
127	N/A
128	Listening to what others are going thru and knowing that I may be facing the same thing. Find it depressing
129	I don't have a "least"
131	being with those who have been caregivers for a long time and PD is movement. I need help with cognitive newly diagnosed.
133	I don't attend the care partner support group which is a sub-group of our support group for PwPs. Mainly because it can be really depressing. We're there to listen, but I don't feel supported by this group.

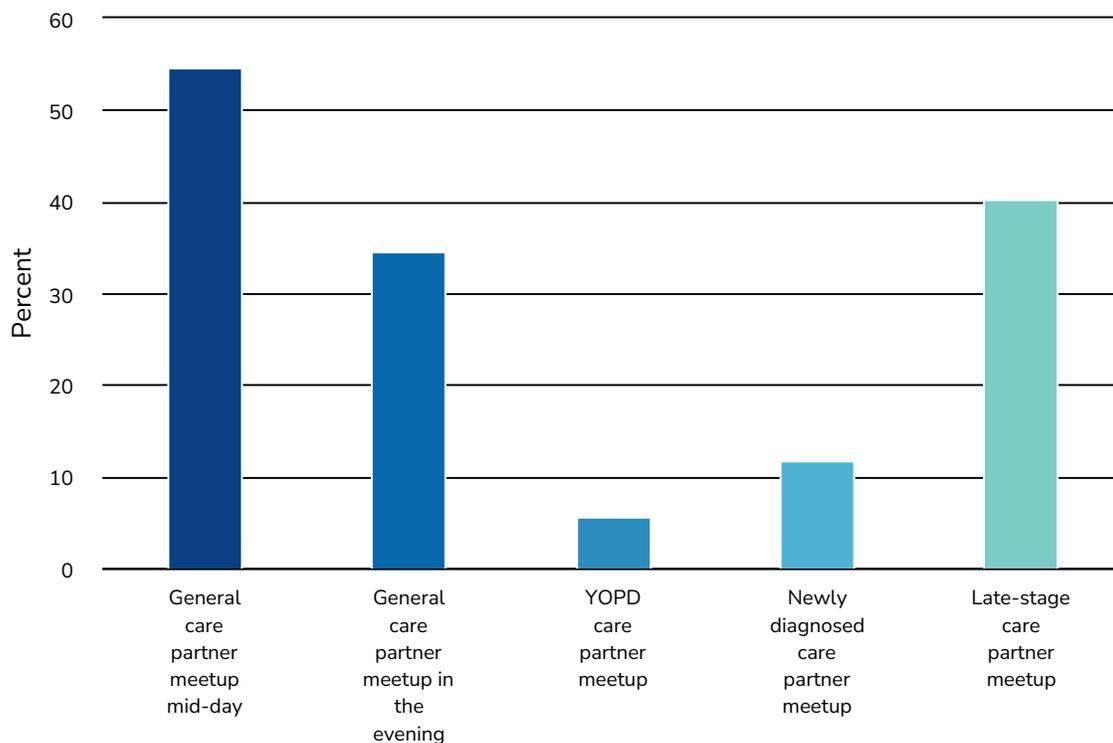
ResponseID Response

134	The large amount of clinical misinformation and misunderstandings among caregivers—and sadly, in the only Caregiver support online group (from the Davis Phinney Foundation!) I have attended so far, several participating caregivers themselves were extremely dismissive of the person they were "caregiver" for making ANY decisions or being involved in any decisions related to their care. While I understand that there may be some limitations for those with severe cognitive deficits, the impression I got was that that was not necessarily the case. This is the opposite of what I would want if I had a neurodegenerative disease, and it made me reluctant to participate in ANY Parkinson caregiver support groups. I strongly recommend that support groups be facilitated by a team with social work and clinical expertise. Without this, support groups may inadvertently do more harm than good.
135	The time that it takes
136	Hearing how others have family members to help them
137	Planning meetings and getting more to attend.
138	I'm not always available when sessions are on
139	Some members are irritating.
141	so far the in person groups I have tried were older individuals and at a different stage of life and Parkinson's so wasn't a fit for what I am experiencing
142	When the conversation veers toward people who have had Parkinson's for a long time or whose symptoms are much more extreme than my husband's. Sometimes it is too much to think about down the road.
144	I'm often unavailable when the meetings take place
145	I can't think of anything
146	time of day
147	Some people talk too much
149	Having to face the future of my spouse's progression and preparing for it.
151	The over sharing and dramatics.
152	Scary, sad, no hope for me (selfish?), quick progression. We were planning to move from CO to my home in Maine, so we sold our home, Ken had to give up his publishing company, loss of writing skills, start of tremors. No support group that we were of, esp that we weren't aware it was Parkinsons not stress with the upcoming move. I did most of the crosscountry driving and my dental hygiene classmate diagnosed him long before we got an MD. Oh my!

ResponseID Response

153	Thinking about how hard it's going to get
154	Nothing
156	Sometimes the topic is something I have heard before so my mind may start to wander. Then I remember that each time you hear a reading from the Bible it says something different because you are different than the last time you heard it.
157	When people judge caregivers for their brave honest venting... it's something I'm not brave enough to share ,
158	Sharing stories
159	Wish there was more chances to meet in person.
161	NA
162	To get to one is too far away,. And I don't have the energy to start one in my area.
163	Participants who have so many problems and spend an inordinate amount of meeting time describing them. The facilitator doesn't reign them in, and they can't get out of their own way, so to speak.
167	Nothing
168	I really don't have anything negative to say. They are all helpful.
169	The DPF sessions are not long enough!
170	planning for interruptions

14. If we were to offer the following virtual care partner meetups, which one(s) would you likely join?



Value	Percent	Responses
General care partner meetup mid-day	54.7%	87
General care partner meetup in the evening	34.6%	55
YOPD care partner meetup	5.7%	9
Newly diagnosed care partner meetup	11.9%	19
Late-stage care partner meetup	40.3%	64

15. Here's what I think Parkinson's organizations get CORRECT about care partners.

ResponseID	Response
1	That it is an exhausting and frustrating experience.
3	They come in all stages and categories
5	That it is challenging and exhausting
7	We are struggling with the burdens of care and the loss of the person as we once knew them
8	The need for more awareness of the difficulties faced by family caregivers
9	Lots! Thanks. I'm looking forward to reading the new EVC Manual for Care Partners
10	We are under-served but valuable which means, hey keep doing a good job but don't expect much support.
11	That we're an essential component of the PwP's care team.
13	Having website resources to look up as needed. Providing experienced care partners to share information. Providing a synopsis of the discussion and resources after the meeting. I really love this about the DPF care partner support group.
15	Parkinson's affects so many different aspects, physical, psychological, emotional and so much more.
16	Care partners are all different and have different needs.
20	That we need help too, and offer lots of support and resources
21	Lifestyle/living with PD information, experienced advice, etc.
22	We need support too!
23	Need for support
24	Every one is different. Every PD person has different needs, as do their care partners. Makes everything harder.
25	Some of them do try to help people find resources they may need. Many of them are trying their best but actually do lack the expertise to help.
26	Knowing they can be overwhelmed
27	There is not as much support as needed

ResponseID Response

28	It is a very hard job both physically and mentally.
29	Canada (Ottawa) stopped funding us and so we're adrift from them. They worked well with skilled facilitators. The virtual meetings did not work well. No facilitator now available [volunteers] The care givers one has disbanded in favour of our monthly coffee.
30	not much, except this one comes close.
31	Hard job
32	So thankful they support us caregivers! They also supply so much valuable info
33	an understanding of our emotional state and exhaustion, of our needs
34	Parkinsons organization do a very important work, giving support to us. We are supposed to have the strength, the knowledge and the resources to sustain our love ones an ourselves. These societal expectations can become too high for ourselves. I believe we need a different care partner vision, one which relies in affirming our inner resources while sharing community resources. An ecosystem for care partners of pwpcd may give some clue. Thanks for the great work you do.
36	That it's hard, that all our PWP's are having their own individual experiences and therefore so are we, that we need to take care of ourselves but sometimes it's all but impossible. (Still it's good to be reminded.)
38	They acknowledge the role is difficult.
39	We feel guilty, unappreciated and worn out
40	Only another caretaker can fully understand what you are going through.
41	We are all struggling in one way or another
42	Caregivers need support. Caregivers need help from other caregivers. Sharing experience is immensely helpful.
43	We have a lot on our plates
45	They acknowledge (on paper) that it is overwhelmingly difficult: life-sucking.
46	That caregivers matter and OD is unique
47	By and large I like the Davis Phinney group of ambassadors. Different people bring different points of view., different experience.
48	Support and giving us a chance to know that we are not alone. Very helpful to be given a place to talk about how stressful it can be without having to feel guilty.

ResponseID Response

49	Not much
50	It's frustrating
51	They do need an outlet
52	The need to care for themselves, so they can do the best for the one they care for.
54	They understand what we're going through.
55	It's different for everyone.
56	All PD patients are different and prepare your world for a long haul.
57	We need help
58	They recognize us
59	Understanding the challenges especially with people who aren't close to retirement and navigating the health care system (non-Medicare).
62	Especially since Connie Phinney KNOWS personally the challenges, DP Fndn offers a lot of information.
63	I think this one truly gets what it is like to be a care partner
64	We do it all!
66	How important they are and that they need support. Without my care I am sure my husband would not have lived his 30 years with Parkinsons.
68	That we need support. We need resources
69	That we need more support and access to respite care
72	Recognizing how difficult the work is and the need for self care
73	no opinion
74	All the emotions and support needed in caregiving.
75	They have a big job.
78	It's exhausting and all consuming
79	I love the term. We're in this together. I love the focus on practicalities. And how to live well with really resonates with me.

ResponseID Response

80	Everyone progresses differently
82	Everybody is different, its hard to Jo get correct answers.
83	Learn ideas that maybe not familiar with.
85	Your Parkinson organization gets pretty much everything right about care partners and you give us a nice mix of one discussion forums and planned topics-also you are very welcoming and appropriate for Canadian participants.
86	Not sure they provide much help
87	I am usually not a group joiner, so i have no idea what they do for me.
88	They know it's a hard job with burnout potential everywhere.
89	DPF gets a lot of things rights because Connie Carpenter is so involved and she has lived the care partner experience.
90	Information about how to deal with the disease and how to face different situations.
91	Acknowledging the extreme challenge.
92	Need for respite. Managing realistic expectations
93	there it is normal to feel irritable and frustrated, we're doing the best we can
95	We get tired. We like an ear that listens and understands. We know what we are talking about.
96	The toll it takes and emphasis on self care but need solutions to find time for self care.
97	Everyone must take care of themselves in addition to their pwp.
98	Recognizing we need support a place to share our struggles and our feelings of helplessness and hopelessness
99	That we all need support, but feel as if we're hanging out there alone. I think we all know that we aren't really, but day to day that can be hard to keep in perspective.
100	Understanding that support is needed.
101	We need Education and community and they provide them.
102	Need resources
103	They know we have fears, exhaustion, needs, love, sarcasm, desperation, hope and tears.

ResponseID Response

104 support in sharing and validating feelings

105 How difficult it is to be in a position where your partner is dying and there is little or nothing you can do to prolong their life.

106 I am always appreciative of the reminders of the resources that are available.

107 Look to address their needs.

108 They help me learn more about the disease when they bring in speakers or the group discusses some real life issues

110 they are important

111 They share information on the disease of PD and the current treatment options.

113 They try to offer helpful information. Virtual webinars are most beneficial.

114 The importance of self-care for care partners.

115 Care partners are overwhelmed and overworked

116 The support we need

117 Connecting caregivers to discuss their circumstances, and offer helpful ideas is very rewarding.. Feeling isolated is almost inevitable when the PD person cannot be left alone and other support possibilities are not readily available. Covid still presents a danger, so virtual connections are vital. No carer wants their PD person exposed to the possible post Covid decline in cognitive, and physical, abilities, and therefore must avoid contagion themselves.

118 We need each other for support! You do a fantastic job!

119 Education, communication and general support

120 We are all a part of Parkinsons. It's not just our partner's disease so we all need to be informed and supported.

121 We are full time - often exhausted

122 the stress, frustration a care partner goes through. How care partners need to take care and take time for themselves.

123 I am grateful that you are there. Please keep the noon caregiver meetings but may be add some late stage and some dementia oriented meetings for some of us.

124 Not familiar with other other organizations info on care partners. I do enjoy and get a LOT of value out of Connie's (DPF) monthly care-givers meetup.

ResponseID Response

127	An understanding PD effects all aspects of life for the PWP and the care partner.
129	we need places to share and get support
131	Too new to this to know
133	I think they have a complete picture of our lives and what we have to deal with on a day-to-day basis. They are also tuned into our fears and anxiety.
134	That the needs of Parkinson's patients from caregivers increase greatly over time, as does the exhaustion. And that the unrelenting progressive nature of a neurodegenerative disease is especially challenging. It is hard to remain hopeful as quality of life slips away day by day.
135	Just being available for people with people with Parkinson and their care partners is a wonderful thing.
136	Needing connections and need for knowledge of the disease
137	We need support.
138	It's a very difficult journey, help is limited
139	Providing someone that understands.
141	letting care partners know it's ok to have bad days also and you are doing the best you can
142	Fear, worry, grief of old relationship, struggles in intimacy
144	They get it
145	They understand the importance of including us as active partners in care.
146	most everything this is a thankless job
147	We are exhausted and have huge hurdles
149	That we need support!
150	Sharing info on P progression, i.e. what to expect; and resource references is helpful
151	Emphasis on self care

ResponseID Response

152	To know just how huge the disease can be widespread..
153	That they need help and shouldn't be afraid to ask; love all the resources on the website
154	They understand just how difficult it is
156	You tell us we are doing a good job and that it is a hard job sometimes.
157	They understand that the caregivers are living with the disease as well .. caregivers are stressing & Parkinson's are suffering.
158	They know it is a difficult situation
159	They understand the challenges and variety of experiences that care partners experience have.
161	It's tough and scary and most people's just don't get it
162	I think the support you give to care partners is amazing. I look forward to every month when Connie etc talk about various challenges and suggestions.
164	I think they try to address as many issues as possible.
166	That we need help just as the person with Parkinson's does
167	They need support
168	They get right the fact that we need support and safe places to vent our frustrations. We need to care for ourselves and sharing with others in the same circumstances is very helpful. They help you feel not so alone and offer help in dealing with problems you may be experiencing.
169	We are under a lot of stress.
170	They realize everyone's experience is different, but with many similarities

16. Here's what I think Parkinson's organizations get WRONG about care partners.

ResponseID	Response
3	Nothing comes to my mind that you get wrong.
7	Just telling care partners to take care of themselves isn't enough. We know it, but it's very hard to actually do in this demanding situation
8	That persons with Parkinson's are willing to try things to improve.
10	Failure to pay attention to educating the care population and helping the care population to find community. False optimism.
11	I think most focus on the physical strains and don't focus enough on the mental and psychological. They need to focus on developing traits and resources for care partners to be more resilient and have more self efficacy (glad to see PD SELF being merged into Davis Phinney programming).
13	If the support group is not lead by an experienced facilitator, the meeting may not be as inclusive as possible. A number of the care partner support groups I participate in do not provide written follow-up.
15	I think grouping people at similar stages will be helpful
16	I'm not sure if I've seen anything really "wrong."
17	Religion
20	Not spending much time on the economics of care, and how to cope with/plan for limited financial resources
21	Not sure yet....
22	Lots of differences between care partners with PWP's recently diagnosed and those living with it a long time.
23	Actual time spent caregiving and constant interruptions that happen when care partner trying to get things done (i.e. interrupted x 5 when trying to do monthly online banking)
25	Most of it I listed above, but generally I think it's least helpful for me to sit around in groups listening to "poor me" conversations, or negativity about partners. I also don't get much from hand picked people just talking about their own experiences on video without a two way conversation.
26	N/a
28	I don't know

ResponseID Response

- 29 See the above. The former format when we were funded worked well. Once a month we met as a total group for 2 hours with 2 facilitators and usually a speaker or topic. After an hour we split into 2 groups, care givers and PD folks, and we each had our own facilitator.
- 30 at some point a care partner becomes a caregiver and we need to acknowledge that. and we don't need to be talked down to.
- 32 Some organizations just give basic caregiving info ; like it's not such a big deal.
- 33 too much is virtual and too little in person; personal meetings are important for bonding and support
- 34 Care partners are alike and at the same time so different one from another. This diversity brings energy within a group. . We need virtual and in person spaces to talk by ourselves. Its time to use break out groups intensively with agile methodology. People need to voice their voices, this heals and is a vehicle to recreate a healthy story of oneself. I suggest Parkinson organizations would enhance their information gathering with federal agencies to take in depth questionairs and interviews to gather quality information about what care partners needs are. I once heard a family doctor approach: What ´s needed here?
- 37 There is a real draining away of hope of anything better when the disease progresses over decades..life is over for a caregiver who might still be vital
- 38 They assume every caregiver has family and friends to help them. I am doing this totally on my own. NO SUPPORT from anyone. There are no free resources such as respite care, help with cooking/cleaning/shopping, help with bathing person with PD, etc. for care partners
- 39 Telling me how important it is to take of myself when I can hardly keep our clothes and house clean and meals on the table. There is no time or energy left over.
- 41 How truly unsure we are about being able to handle future declines in our loved one.
- 43 We're not all saints
- 44 it is easy to describe the importance of respite care for the care partner - yet it is very difficult in practice to ask friends to come sit with my LO while I take off for some private time.
- 45 They 'get' that it is an unending burden - on paper - but to tell the caregiver to 'take care of yourself' and 'take breaks' and other platitudes denies the reality for the partner - so, they 'don't really get it' -
- 46 Often the approach is falsely optimistic. The truth is not happy.

ResponseID Response

47	Nothing leaps out at me as being wrong. Each age and stage needs to be discussed as well as impact of different remedies/ experiences. Then you can chose what you need to listen to.
48	Never with Davis Phinney but with others I have experienced being in group settings and not ever having an oppportunity to be separated from our partners so it didn't give us the freedom or opportunity to really talk about our experiences or get to know the other care partners
49	Allot
51	Don't know
54	Not enough is said about the ongoing grief as we move through the stages with our Parkinson's person. It's very scary to see my husband get worse. It's also hard to know if something is Parkinson's related, old age related, or whatever related.
56	Their ability to put together a functional health care team. Most of us do not have access to university based research teams, health insurance and financial resources to support the care needs of our PD person or ourselves.
57	Don't know
58	They don't realize how much we need help to find meetings that we can attend Or There's not enough options in case I can't make the one monthly virtual one on Fridays due to my husband's PT
59	I can't think of anything
62	That we just have so little time.
63	other groups don't focus on care partners as much
64	We are burdened.
68	We need more tips and tricks and action items we can take away after the meeting. We can start using these things with our PWP right away
72	Not sure
73	no opinion
78	support networks are difficult to find in rural communities
79	I haven't seen anything yet.

ResponseID Response

83	Not really knowing how the person with Parkinson's feel. That's more my problem I suppose. See people with Parkinson's doing well, and I still have Trouble with the reality because we both have it.
85	can't think of anything
87	See last submission
88	Our time is the most valuable thing we have everyday!
89	No sure - I don't have experience with PD organizations other than DPF and Parkinsons Association of the Rockies. (My virtual care partner support group is run by volunteers in our community. The two leads both lost their husbands to PD.
90	Some people take over and you get tired of listening to them, you can't ask what you are facing
91	Offering suggestions that aren't helpful, i.e. "there are other ways to be intimate", when the PWP has ED. The devastation of no longer being able to have intercourse needs to be recognized. It took a year for us to finally find a doctor who would even discuss it with us, let alone having the discussion in a support group!
92	Not experienced enough to know. I feel I'm steeped in PD and need time away fro it as focus.
93	don't truly understand how difficult it is to get good help such as CNA's, especially at night, and also respite care
95	We need advice on aging, late stage Parkinson's and preparing for death. We are all aging. We know what's coming.
96	That we don't acknowledge burnout
98	Nothing you all get it
99	I'm not sure that the Parkinson's organizations actually get this wrong, but sometimes I feel like they think we are all alike so there can be cookie cutter solutions.
103	?
104	not sure
105	We need more training on how to deal with the despair of watching your partners decline.
106	I have always found the session moderators to be considerate and useful
108	That caregivers have easy access to the necessary providers

ResponseID Response

111	Care partners' situations differ from person to person; just like PD differs from person to person. My situation as a PD care partner is likely completely different from another care partners situation. The difference isn't just with PD symptoms, but rather with our life situation and decisions I made because of my spouse's PD (e.g., leaving a successful working career early). I think PD organizations get the mental health impacts from PD wrong with care-partners.
113	Not sure
114	A better understanding of the difficulties faced by care partners for PD patients in the latter stages of the disease.
115	They assume care partners are trained in caregiving
116	Not much
117	Most participants are reasonably well off, it appears, and unfortunately we have little idea of how caring for a PD person without resources for mobility aids, home adaptations, technical support, etc., would unfold. Middle class people connecting with each other. Extremely useful, but leaves out a huge population, I suspect. I have no remedy to offer, but it is a tragedy.
118	Often have to miss the mid day meetings. So frustrating that one treatment doesn't work for everyone and physicians often don't have any suggestions.
119	Nothing. It seems like they're trying really hard to get it right
122	Can't think of anything wrong right now.
123	With medical care in this country today it is hard to build a support team. Our HMO (Kaiser), for example, has had only one Parkinsons doctor in the entire area until just recently. Last time I checked, there is now a 2nd doctor. Ours is overworked and an hour away. Care consists of an annual visit. We wait months and months for an appointment. When we had a mental emergency last year it took 2 months to even get a phone call visit with our neurologist; Then another 2 months for an office visit . The doctor adjusted medication which has helped and recommended accupunture, exercise, speech therapy etc. But the idea of a team of partners? it does not exist within our HMO Kaiser.
127	???
129	my needs as a care partner for a person with PD dementia are much different than if he didn't have dementia.
133	Can't think of anything just now.
134	That they can easily adapt to the nature of the Parkinson's beast.
136	That the PD partners is doing everything they can to help themselves. Time availablity.

ResponseID Response

137	Nothing
138	I'd like to know more about to deal with the negative behaviors that accompany my husbands Parkinson's. Bad moods, constantly changing clothes, cleanliness paranoia
139	Not enough information on tools and techniques to help with managing disease progression.
141	more hands on assistance to help care partners find counseling that understands/specializes in Parkinson's. I have tried to use the "links" provided and wasn't able to find a therapist, felt like trying to find a needle in the haystack
142	It's not all doom and gloom. Some of us are very fortunate to have a good support system. And also, I am thankful that I get to help take care of my person.
144	Not sure how to answer
145	They tend to connect with us through our PwPs rather than directly.
148	Resources are sparse. They are mostly addressed to the person who has it
149	N/A I've just started joining the virtual DPF monthly meet up. Don't have any other experience with others
151	?
152	Scared me
154	?
156	Question 13 -- I wouldn't have the time to join every day. The once a month support group is enough at this stage of our journey. What would you talk about if you were presenting day after day?
157	Most times they leave us out of the equation. as Parkensons care does not exist without a caregiver. Educating caregivers how to advocate in the medical system would be a game changer. Hospitals can be the worst to care for Parkensons patients. Caregivers know more about the patient & are rarely acknowledged as cognitive & dementia is not addressed
159	Not sure due to the lack of experiences with organization that deal with the care partner experience.
161	There's lits of hype about what is available but not much meat in the presentations. Taking up valuable time with poor reward
162	NO Clue

ResponseID Response

165 They need to meet separately from their partners, so they can talk authentically, and not just talk about the next "cure" down the road.

166 There is a lot of encouragement and optimism, and there is a place for those sentiments, but sometimes they don't acknowledge what we are really dealing with

167 Not sure

168 Nothing that I can think of now.

169 We have flexible schedules.

17. What is most pressing for me right now regarding my role as a care partner is...

ResponseID	Response
1	need for more caregivers, especially at night.
3	End of life options
4	Adequate energy.
5	To have a support group
7	I feel alone and that my own life is being overwhelmed by the care role
8	Dealing with falls.
9	Fostering independence as we work with our health care team vs how much to lean on care givers vs how much I should be doing myself to help him
10	Staying healthy and always vigilant.
11	Cultivating my own neuroplasticity to be more optimistic. As PD progresses, my own resilience and rewiring my brain to be more self-efficacious needs to outpace the progression of PD.
13	Living in the present while preparing for the future.
14	There seems to be no end
15	My partner's cognition is failing
16	I am concerned about how to keep help after our long term care insurance runs out.
17	My husband's need for spine surgery
19	Protecting my own health
20	Knowing that my PWP's health is likely to worsen but not knowing any kind of timeline; struggling with talking to my PWP about their condition when I perceive some new challenges; how to keep living my best life as well
21	Not sure....too early, and my PWP is highly functioning and positive, and solution based...
22	What the future may bring— how much I will be able to handle and when I will need help. AND, will my husband accept help from others?
23	Delusions and poor mobility

ResponseID Response

24	Finding options for keeping him moving and as "normal" as possible for as long as I can.
25	1. Grief. I've almost never heard this addressed in any care partner group. But Parkinson's comes with losses day by day and anticipation of future loss. 2. Loneliness due to husband's personality changes and difficulty communicating due to speech and processing changes.
26	What will happen when I can't care for him
27	Managing the anxiety and depression of my PD spouse
28	Anxiety about him falling and mental acuity
29	staying sane! We are on a 3-4 year wait list for long term care. When we signed last year it was to be a 1 to 2 year wait (which was ideal for us). When I checked this month (after 12 months) to see where we are on the list, I find that the wait has become 3-4 years. How does this happen?
30	now that he has passed, i feel a need to share (in social media as well as in person) that he would have loved something or remind people what he had done.
31	Finding more cate
32	Free time for myself
33	dealing with my spouse's developing dementia
34	To secure income to support my family, my husband with 12 years of Parkinson's, with no pension-he was a catholic priest for 20 years in shanty towns in Perú, and my teenage children. Peru is undergoing a very difficult political and economical situation. I am 56 years old. I am applying to different jobs but I havent get one yet. I am in the process of crafting my own job. Thanks for asking this question. Open questions are key.
35	I have to do almost everything, ie, I have to think of most things that need to be done financially, in the house and outside in the yard. I have hired one of our grandsons to cut the grass and help in the yard. A lot of things that my husband helps with takes so much time for him and usually ends up by making more work for me.
36	Figuring out the transition to hospice and/or accessing Death-with-dignity option while my struggling PWP still has the cognitive ability to make her own decisions.
37	Finding the mental energy for my own care and keeping up my own interests..I have given up so much because I need to simplify to be present in a good way for my pwp
38	My mental and physical health.
39	My health problems are preventing me from being the care partners I need to be

ResponseID Response

40	How will it end? We are getting close and started hospice.
41	Time management. Keeping up with everyday chores and paperwork and still have time for myself. Seems it's one or the other.
42	Lack of communication. Dementia has removed partner's ability to think or share original ideas.
43	Trying to plan financially for the future
44	I can't seem to find time to exercise or to bicycle as my LO has very limited mobility and lacks balance. In other words, as all our friends tell me to "don't forget about taking care of yourself" - easier said than done.
45	Exhaustion:emotionally and physically. Isolation. Stultification. Loss of companionship/freedom/pleasure.
46	The fact that the future could be long, very difficult , unrelenting and exhausting. The fact that there are many non mobility issues especially in our case, both PD and dementia.
47	having a snarly spouse.
48	Trying to get him to retire. This holiday has been amazing but the months leading up to it were extremely stressful as he was trying to prepare for being away from work and didn't have any energy left to be part of planning the trip so it all fell to me and then he complained about me taking over everything and deciding what we would do and planning everything.
49	How to figure out the future
50	To get support. In house care
51	The uncertainty
52	Fear, patience
54	I don't know how quickly my person will get worse. I have a place reserved for us to go to, but I don't know when we will need to do so.
55	Trying to motivate my partner to read books, magazines, real papers, take a course, socialize more, get off of his phone and stop watching mindless things. He has learned fly fishing and does Sudoku for his mental acuity.
56	Feeling satisfied with my own life as I navigate getting my husband what he needs while pushing him to want more for himself. Apathy is disheartening.
57	Finding time for outside activities. Sometimes I feel like I am disappearing.

ResponseID Response

58 Help and support

59 How do I raise my young children and hold down full time job.

60 Helping my partner see there can still be good moments in his life. Get him through depression and thoughts of suicide.

62 Staying centered and peaceful when he is so touchy and snarky.

63 Are the changes in mental status happening due to parkinson's or dementia or do all people with parkinson's lose mental focus?

64 Maintaining my patience and speaking succinctly to my PWP.

67 my spouse with Parkinson's has other health issues unrelated to PD

68 Dealing with PWP depression and anxiety.

69 Adapting to anticipatory grief

70 Trying to access ongoing support for my partner (exercise, etc.)

71 Most pressing is for my husband to enter a respite care situation for 3 or 4 days a month. I need to get some sleep.

72 Finding respite care so I can go away for a few days

73 getting help WHEN I NEED it without blowing up MY OWN financial future.

74 Sleep. Helping PWP during the night several times.

75 not getting help

76 I have always been a planner and with PD it sure is hard to plan!

78 Finding time for me

79 Learning how and when to help, without taking independence away. And getting access to a movement disorder specialist. We have to travel for that.

80 Keeping my strength up to lift my PWP if he falls I go to PT to help with my body & eating right

81 trying to keep up with disease progress and try disease management in various ways until we find one that works. example: spouse was previously able to do 2 week med sort, now unable to do. This puts all med issues to me, for 2 week sort, nightly, daily and morning meds. It's all on me.

ResponseID Response

82	Trying to stay patient and continue my role as caretaker.
83	How difficult this may become. I would imagine we are an unusual case with both having it
85	just staying on top of everything and easing out of some of my least favourite personal activities
86	Taking care of PD spouse as well as taking care of myself. Little time for me beyond regular Dr appointments
87	The emptiness, of my life!!!
88	Keeping my husband safe. Falls are deadly.
89	I will be traveling alone out of the country for a couple weeks in the fall. My husband is fairly independent, but does need help with a number of things. Trying to figure out how to plan for his needs while I am gone is the most pressing thing.
90	How can I make my life easy. So we can enjoy this journey with nasty disease.
91	Accepting that my husband is becoming more feeble with each passing day. Missing my very athletic, highly intelligent, sexy husband.
92	Anticipatory grief- the fading away of a partner. I've become a "helper"
93	I have a chronic disability and am also taking care of my husband with 18 yrs of PD. Have some help, but don't know how much longer I can do this.
94	Helping my partner make wise decisions regarding health matters everyday (water, going to bed on time, etc). Deciding about dbs
95	I have issues with giving my parkinson's person freedom.
96	Finding and having bandwidth to find an affordable caregiver for the first time after spouse in hospital 73 days and we returning home with me not leaving his side in the whole hospitalization. .
97	Staying healthy.
98	How will I be able to sustain this?! What will happen if something happens to me, how will I be able to provide adequate care for my loved one.
99	In the past couple of months, my husband has gotten to the point where I can't leave him for even a short time. It just feels sort of suffocating and isolating.
100	My mental health!

ResponseID Response

101	My psychological well being.
102	Need quality in home care
103	Are we in crisis or is this our new normal? How can I get a therapist who works with care partners with no good positive outcomes for their loved one.
104	learning to deal with my own feelings, and how best to support my person with PD
105	Trying to keep positive
106	Exhaustion. We are both old and I find myself just running out of steam during the day.
107	Finding the right medical professional
108	My person is having non motor symptoms He deals with the motors symptoms as he calls them an inconvenience When he has a new non motor symptom, it's as if it's the end of the world and the mental stress if it affects both of us Right now it's the fatigue He is normally an introvert and this pushes him further into himself
109	-that I may not be able to care for him due to my own health issues -not knowing how to get help for him in the future -fear that he's in denial, not wanting to be the one to tell him he should probably stop driving soon
110	getting my children on board to be more prepared if something happens to me
111	Learning how to reduce expectations on a day to day basis; for both me and my spouse who has PD.
112	The unknown of what is ahead and how to handle it.
113	How to prepare for the future, yet fully embrace living in the moment.
114	Fall risk and orthostatic hypotension. Falls with broken bones have occurred.
115	Trying to understand his needs while his ability to speak loud enough and to complete a thought or sentence is diminishing Getting him ready while trying to get myself ready to get him to all his appointments
116	Getting support from others in family and community. No one seems to understand the non motor symptoms or when explained slough them off
117	Keeping both of us virus free as the world opens up and leaves the vulnerable even more exposed.
118	Not having the patience my spouse deserves!
119	Needing a break and not being able to get it as my person can't really be left alone

ResponseID Response

- 120 MY PWP is still working and capable but I see more decline this year and it is hard to figure out how to support in a way that does not offend him. (with med management, sleep habits, exercise and eating right). My PWP tries to hide his Parkinsons. I struggle with how to tell him what is changing with him, especially what other people see and experience. (cognitive decline along with visible symptoms)
- 121 No free time
- 122 Am I doing all I can do for my husband without him losing his dignity. He can be stubborn but I can remain calm most of the time. And right now my husband wants to see if he a candidate for deep brain stimulation,
- 123 Preparing for care for my partner if I die. Legal preparation, money to last, and day to day help. Simplifying our life in preparation. For example updating estate plans (legal) getting rid of time consuming real estate such as rental properties, or updating and maintaining home etc
- 124 balancing my partners needs along with my needs, expectations and plans for my retirement
- 125 constantly waiting for him to do things.
- 127 Do I help or don't help my PWP. The lack of appreciation for the constant work I do to maintain the house, relationship, PWP's well-being.
- 128 Seems to have more needs on a daily basis. Have little time for myself
- 129 we have had fun the last two days and that is precious but now I am behind and overwhelmed by what need to get done.
- 131 finding people to help me, lend support, and gather resources and information I will need down the line. I hear a lot that there is a lot out there, but living in a new city for a year without a network of support, it has been challenging. I have to trust recommendations of strangers or people I barely know, that's not easy and the same goes for doctors, therapists, and organizations.
- 132 finding patience and slowing down my movements to accommodate my partner.
- 133 The need for family to step up to the plate. I recognize that they need to start now before I REALLY need help. It was a two-hour drive yesterday and today so husband could have an endoscopy. I managed the drive today but hope it's the last time I have to do so when I am super stressed and exhausted. It is not safe for anyone.
- 134 Exploring options and waiting for promised scheduling call backs that never come—barriers to navigating the endless number of appointments and evaluations that need to take place prior to any possible procedures even being scheduled.

ResponseID Response

135	Making sure that I take care of myself and not end up burning out.
136	Keeping my attitude in check when providing help, trying to decide if I need to hire some help and if so how to do that.
137	HWP in rehab after quick decline. Why and will he return to baseline. What happens next?
138	Getting help for diminishing mobility
139	Emotional outlet.
141	dealing with my husband's frustration that he can't do what he used to be able to and getting upset with me when I ask him to talk me through the project so I can do it and learn Also becoming the only decision maker for the family, we always made decisions together
142	Trying to support my partner while he is still 100% able to care for himself and put strategies in place together for when that changes.
144	Not knowing next steps. Am I able to continue having my spouse remain in a family care home, or do I need to start the process to make him Medicaid eligible? I would prefer not to move him but can't cover the costs longterm.
145	Knowing when to ask for help.
146	understanding my emotional reactions and developing coping skills so that i don't develop anger or resentment towards my spouse
148	Getting my spouse to admit he has it and actively seek help. Then following through with key things that would help him, like exercise.
149	Being able to trust my spouse as much as I used to. Physically, mentally, spiritually, socially as his PD progresses. I don't know what behaviors are medically induced, a part of his disease or if he's thinking clearly and "normal".
150	Communicating reality to her siblings and kids; increase their awareness of her increased limitations, reduce their expectations of how she can help them, and inform how they can help her.
151	Increase care and how that will effect my routines.
152	None. Just got a bill from his nursing care facility for pre Christmas "physical therapy" of which there was non. All but comotose, and he was eval by hospice care people twelve hours before he died early the next morn, Christmas day. he's not suffering any longer, a shadow of his former self. He called me good Carole on the good days and Bad Carole when I seemed the nag.

ResponseID Response

153 How to cope with husband's rage; how to motivate him to do exercises and eat right

154 Keeping my partner motivated and engaged

155 Setting limits

156 If my PWP would set an alarm on his phone, then I wouldn't have to ask if he has taken his meds and feel like I am the nagging wife.

157 Agitated, aggressive, angry, meanness depression appears in their loved ones . Not keeping up with my own care doing the work for two . not living the quality of life , feeling like I'm walking on eggshells.. . I get VA help 15 hours a week . I work on being grateful

158 Trying to be student and listen

159 Trying to stay in the moment and enjoying the things we do together. Keeping the perspective of gratefulness and humor going.

160 Being there for my spouse but not being to over bearing

161 Being patient

162 Trying to decide if we should sell our house and find another place to live.

163 Extreme Anxiety. Levidopa off times.

164 Dealing with cognitive issues (some dementia, paranoia, illusions, delusions, hallucinations).

165 The difficulty of communication with her, and seeing her go downhill all the time, and there's nothing I can do but watch it happen

166 Oh, where to start. Its hard for me to have a life, he wants ME to take care of him, and his increasing confusion/dementia are SO exhausting to live with. I have no life.

167 Future care for my spouse.

168 Being able to support my husband as his Parkinson's progresses.

169 Getting adequate sleep and having patience.

170 learning to accept the changes that come with PD dementia.

18. What I am most concerned about when I imagine the next 5-10 years as a care partner is...

ResponseID	Response
1	that my own illness will make care giving almost impossible
3	There won't be 5-10 years.
4	Change of residence to assisted living; learning to assume responsibility for financial matters concerning our household of the two of us.
5	The progression of PD and my own health issues. Big changes coming...
6	Where to find support for failing partner when he has no wish for the future. How to move out of home of 50 years, where to find help with decisions that need to be made.
7	I won't handle it well, and will have emotional or mental health issues
8	My physical and emotional health
9	When he can't stay alone safely
10	Unexpected health consequences for me or my PWP. Needing outside help.
11	My PwP's well-being, health, and happiness.
13	Will I be able to provide my husband with the support he needs or find suitable providers to care for him so I can get some respite?
14	My health is getting affected
15	I don't think my partner will be here even 2 years from now.
16	To tell the truth, I try not to think about it too much because either one of us can die any time. We are in our 80s.
17	Dementia which is already present
19	Whether we can live together or not
20	The potential cost; and quality of life changes for us both
21	That we both work towards shifting house/home responsibilities...again, not sure...
22	See my response to question #16.
23	Loosing myself and my health

ResponseID Response

24	I cared for my mother in Alzheimer's decline. I was mentally and emotionally shot in 9 months. 2 years later I still cannot cook a meal.
25	1. Loss 2. Finding enough practical help.
26	Same as above. What happens to us when I can no longer do this
27	Whether my partner will develop dementia.
28	Can I do it?
29	Staying well enough to care for my partner. We are both in our 80s. My husband has had PD for 1/2 his life.
30	will the toll of the experience shorten my life or leave me sicker than i would have been had he remained healthy.
31	Keeping my husband safe and happy
32	Concerned about my health - what the stress might cause.
33	dealing with my spouse's developing dementia
34	Being able to provide sustainable income to sustain my husband, give him proper care and give education to my kids. My older kid works part time and studies at the university. My younger daughter has intellectual disability, an is not easy to handle the situation at home. I want her to be an independent person. The education in Perú for further studies for people with disabilities is still on its basics. She just finished high school and would like to go to further studies. My husband 's mental health is an issue that worries me. He has always been a thinker person, so for him, being aware of how he is loosing his cognitive assets is very painful for him and for me to. This together with his off moments its difficult. Here the possibility to access to a DBS intervention is very expensive.
35	Having to do more and more by myself.
36	Her decline and death, and the intense suffering along the way. Not getting enough help for her, in spite of a great care team. Current palliative care so far is inadequate.
37	I am shrivelling up mentally, socially, morally
38	Financial issues when I can no longer care for my PWP at home. I also worry about my own health and how that could affect caring for my PWP.
39	Having my husband in a wheelchair, having to help him with bathroom issues
40	Doubt I will be there.
41	My husband becoming totally dependent.

ResponseID Response

42	Taking care of a human body, with a stranger inside. No longer my husband or even a friend.
43	whether I will be able to keep him at home.
44	Will I be emotionally and physically strong enough to properly attend to my loved one's needs as I age? How will we handle the loss of physical intimacy that has been an important and fulfilling part of our relationship and marriage. Also, will we outlive our savings and other resources as my LO progresses to final stages of PD.
45	Care burden is already beyond my reasonable limit - and it will get worse. Continued isolation. I'm getting older (79) and ... His case is increasingly difficult to handle - making it next to impossible to leave him with anyone.
46	A continuing difficult deterioration of my husband and my continuing deterioration of my health and social well-being. For both of us it is a growing prison of isolation.
47	He's only going to get snarlier and not benefit from any exercise or walking
48	Mood swings and anger. Getting exhausted and not having others realize how much I have to change. Currently it's mostly invisible to others but it's definitely becoming more and more of a 'thing' in our lives
49	What's going to happen
50	That my wife will need full time support and how could we afford it
51	The uncertainty
54	I'm most concerned about my husband getting worse and not being able to help him with his emotional issues seeing himself get so bad
55	How things will progress. Losing my beloved partner as I take on a different role in his life. The gradual loss of his independence. Me asking for help and support from others.
56	My own abilities to stay mentally and physically healthy enough to care for my spouse.
57	How bad things will get, The progression of the disease is scary.
58	Just need support then I know we'll be ok
59	The long goodbye part and also, sharing milestones with our young children
61	what to watch for - how to assess parkinson's symptom or something else
62	that my own age and health will make it difficult to be a good care partner.

ResponseID Response

63	my husband will become immobile and i won't be able to care for him. or what if i get sick
64	What surprises will there be that I am not prepared for. What do I need to know about further advanced stages of Parkinson's?
67	cognitive decline/possible dementia
68	Caring for him and what that will look like
69	Increasing physical burden
70	My partner will be wheelchair bound and/or dminished mental capacity
71	The exhaustion level would be thru the roof by that time . Finances as time goes on, will be difficult as the health care for my partner would be costly.
72	I will remain able to manage everything
73	That enough of ME will be left to resume a normal life when I am no longer in this role
74	To know when he will need more assistance than I can physically give him.
75	I don't think I will be able to do it.
76	I want to be sure my health stays good so that I can support my partner as he needs more care.
78	That I won't have time for me with an ever increasing demand
79	How long I can continue to do this. Hoping I stay healthy.
80	Staying on top of my PWP taking Meds on time Concern for falls - How I can handle/manage
81	that I can be strong enough to deal with more changes and challenges as the disease progresses. that I don't die suddenly and have everything unraveled that I have put into place, nor for our family to be burdened with this.
82	How am I going to take care jklof my person with PD and myself.
83	What really is it going to affect our daily living
85	most concerned that I won't be able to do it that I might get sick and we won't have a good enough plan.
86	How bad my PD spouse will get and when it will become too hard to take care of him

ResponseID Response

87	Knowing the time will come when he needs more care then i can handle. We are only married 5 years.
88	Of course, I won't give up on a cure! There are impressive studies coming out of research labs! Otherwise, its one day at a time.
89	Not knowing if we will be able to manage in our condo as the disease progresses or if we should move to a retirement community.
90	He has swallowing problem, speech problem. He can't keep his eyes open, drooling is very bad. I am worried how I am going face life when he can't go to the bathroom by himself. If he can't swallow his pills and food.
91	I can't even go there. It is frightening.
92	Not being certain of my own life span to be here to ensure care.
93	Still being able to take care of my husband
94	Dbx or not
95	That I have the health and strength to be there for him.
96	My health and how we will afford caregiving as needs increase.
97	What lies ahead. Hearing and seeing how the disease will progress. Staying healthy to be able to handle what comes.
98	Will I be able to sustain this emotionally, physically, financially
99	Honestly, I can't even imagine what that looks like.
100	I fear that I will die before he does.
101	Im concerned that I wont be able to maintain good care for my husband. Dealing the anticipatory grief.
102	Will we need to move to nursing care facility
103	What will his decline be? Can I handle it in our new home?
104	that I will be well enough to support him
105	Role will only become more time consuming/costly/difficult.
106	The cost of the assisted living care we are soon going to need.

ResponseID Response

107	The dementia and cognitive impairment that has been going on for years already. Hard to even comprehend how I will cope with this for years to come.
108	That I won't be able to keep up with his care
109	Being overwhelmed and being able to care for him
110	I will need special care or die and my spouse needs not met properly without me to advocate
111	1. The physical limitations for my spouse with PD, and what physical accommodations will be needed 2. what our health insurance will cover in the terms of medication and future PD treatment.
112	I don't think want to think about it. It's depressing. There got to be more to life than for both of us the this. Parkinson has taken over both our lives.
113	What level of care is needed.
114	Whether I can maintain my own health given that I have already been a PD care partner for 24 years. There isn't much left in my tank at this point.
115	Not being able to care for him
116	How are we going to manage if I get ill. I'm now 74
117	The inevitable decline of a progressive disease, and the inch by inch erasure of my beloved partner. A prolonged life of dementia and physical decline is dreadful. We are fortunate to have resources and family support, but nothing could make that existence acceptable.
118	Not having someone to share my hopes and dreams. What will happen if I die first.
119	Finances and my persons mental health
120	Not knowing what's coming Push back from my partner in lending support Can I handle it?
121	What is my next step - live alone in home or move to residential care.
122	Hopefully my husband and I can keep one another going. And hopefully I can stay positive and if I have questions I'll know who to ask.
123	How to maintain my health with the level of stress. Like many people, we got old. It happened before we expected it and other health problems ensued. I am trying to simplify our life to reduce stress and to preserve our nest egg during inflation, and other stressors as simple as who mows the lawn and how long can we stay in our house.

ResponseID Response

124	Can I handle it or can we afford and will she be willing to accept help from someone to come into our house. She is able to take care of herself now but at an extremely slow speed.
125	not having a life of my own
127	Will I remain strong enough to continue carrying for my PWP.
128	If I can mentally cope
129	his increasing dependence on me, physically for sure, but also emotionally.
131	How awful it will be and I already wonder where I am in this. I hear take care of yourself, that gets pushed aside when the focus from multiple doctors and therapists focus on the patient. In an instant my life changed forever with the appearance of symptoms and I try to make a life but less and less is about me. I am totally unprepared now, did not ever know anyone with PD or that it affects the entire body, and cannot imagine my role and what will happen to the one I love.
132	The daily uncertainty of the type of care my husband might need.
133	Being able to do it all and completely losing myself in the process.
134	Will I be able to continue to care for my spouse at home?
135	That my health might be affected to the point that I might no longer be able to take care of my husband.
136	Providing all the help he's going to need, whether it will be at home or in a care facility of some sort.
137	Will he I make the right decisions about his care. Will I know what to do when next decision is required?
138	Will-his next fall totally disable him
139	It getting more and more difficult.
141	copng with the changes in my husband's outlook on life and personality. having the physical strength being to take care of my husband
142	The change in our relationship emotionally. My husband is super high achieving and independent. Having to depend on me in a different way will be challenging for both of us and change our relationship dynamic. I hope we cna continue to stay close emotionally and physically.
144	I think my husband's horizon is much shorter.

ResponseID Response

145	How I will manage as his symptoms increase
146	being alone
148	He will end up in a wheelchair and how I am going to be able to help him like with toilet or even getting into bed.
149	Are we going to be okay financially? Will I be able to handle all that he handles for the family. Do I have what it takes to walk this road?
150	General P progression, potential loss of joint activity e.g. biking, increased care needs
151	Will we be to maintain our active life style and our home life
152	It's done with but it was truly scary for the long run.
153	Burnout
154	Will I be able to physically care for him
156	The physical symptoms I can deal with. If he stops being "him" because of cognitive decline, that will be hard for me to take.
157	I'll die before him
158	How will I be able to stay strong
159	Losing the ability to do the things we enjoy doing together. Keeping a positive outlook. Being able to ask and find the help we need. Not wanting to burden our children.
160	we are very active bike riders and she may not be able to continue riding
161	Who will take care of him if something happens to me
162	While my husband is very sensitive to what I need, he does prefer me above all others. As his PD worsens, I worry I won't be able to cope.
163	Decreasing executive function. Decreasing physical abilities and possible transition to more home care assistance or facility care.
164	How I will deal with the continuing health and cognitive issues and keep my health in check.
165	Can't even think about that. I have to live day to day. One day at a time.
166	Effect of caregiving on MY health, which is declining

ResponseID Response

167 I don't know if I can do it and I don't know if I want to do it.

168 Being able to access and afford in home care for my husband. We have bought a multi-generational home with our son and family. I know they want to be part of his care but when is it time to bring in outside help? Are we being realistic about being able to care for him at home?

169 How I can cope with the dementia issues.

170 Coping with brain changes and will that mean transitioning my care partner from living at home to a care facility.

19. If I could wave a magic wand, here's what I would make available to Parkinson's care partners...

ResponseID	Response
1	More in home care at a reasonable price
3	On the ground help that is free!
5	Support strategies
7	a judge-free zone to tell the truth
8	Paid In home physical therapy and home health aides. A perfect bed for both comfort, safety and a modicum of independence
9	Respite for periodic dependable weekends away...maybe 6x a year?
10	Routine planned respite care More in-home and virtual doctor appointments Mental health checks And why not add free massage :)
11	A zen-like attitude of resilience, peace, and calm.
13	Every physician treating a PwP should involve the care partner in the clinical visit and also offer info about local support groups for the PwP and CP.
14	Extra help so that I can spend some time away from all of this
16	Patience.
17	Is an atheist group
19	Male respite workers for male patients
20	A map of the future detailing what kind of changes will happen when, so I can plan for the changes and ignore the ones that won't happen
21	Emotional support connection. So many people don't have / know about this resource...we are trying to spread the word.
22	Individualized resources for all the varied needs of care partners AND their PwPs. AND, better training for both neurologists & PCPS of the varied needs of both groups.
23	Respite Support
24	Cure

ResponseID Response

25	My perfect support group would be a spouse group that meets around social activities (dinner, lunch, walks in the park, movies, whatever), NOT specifically to talk about Parkinson's. Parkinson's issues would come up organically as people got to know each other better. Periodically the group would invite an expert to discuss important things like assisted living or in home care options, devices, medication options, dBS or whatever the group is interested in. The closest I've come to this is Rock Steady Boxing where the spouses have organized something like this on their own. But they meet infrequently because nobody has time to organize.
26	Knowledge of what to do to help in all situations
27	More personal time without guilt.
28	An affordable knowledgeable aid a few times a week.
29	Funded support programs in Ottawa and wherever else they are not funded
30	?
31	Support
32	A day out for us! Locally go to lunch or meet to get to know each other.
33	availability of more good in-home caregivers to provide a respite from my personal caregiving
34	I love this question. daily health routines based on basic chikung or meditation or what ever needs the person A friend to share the pain and the moments of joy A sustain income to cover the needs and imagine that another way of caring with more ease is possible. Please watch this model developed in the Netherlands: https://www.buurtzorg.com/ (humanity over bureocracy)
35	More help in the home and with outside/yard assistance so that I can have more "me" time.
36	Medicine to reverse it.
37	An engaged pwp
38	Free services like mental health visits for caregiver, respite care, help with daily chores and responsibilities, some one to come in a day or two a week and help PWP with bathing and other personal hygiene tasks.
39	Someone to manage all the information and follow up needed from doctor visits. Medication management, he's having trouble and so am I with preparing the drugs for the upcoming week and getting things renewed no time.
40	DPF has done so much already.

ResponseID Response

41	Affordable help with everyday chores as well as aid workers for my husband
42	Widespread quality-care nursing homes.
43	universal health care including long term care
44	A greater awareness among care partners and their loved ones of the importance and absolute necessity of long-term and end of life planning including having the difficult conversations with children about finances, costs of long term care etc.
45	Management skills. Mandatory respites of longer than a few hours. A magic potion ...
46	More access to resources that are professional in navigation of ALL the facets not just mobility
47	It's very hard to type with even mild shaking, but that's for me. For my husband I would just like to take the pain away.
48	Loving support. Friends and family realizing what it's like, time off knowing they are cared for without it costing a lot and without taking away their dignity. Counseling
49	Crystal ball
50	Low cost support programs every state
51	Answers about future progress, the unknowables
52	Lots of self love ,acknowledging that you are doing the best you can do!!!
54	I would really like to know what the stages are, and how long each stage routinely lasts.
55	A person who would be available to come talk to my partner about the ways he can preserve every brain cell he currently has and instill confidence in him. Maybe a neuropsychologist.
56	Access to PD knowledgeable health care teams for their partner and readily available quality affordable care providers to provide respite.
57	Someone to talk to who understands.
58	More more more virtual meetings Maybe more where people can share rather than just listen I wish you could come up with a program where there were day and evening choices and more than once a month Also.. information to hook us up to any local groups I live in L A
59	Medical coverage for family counseling

ResponseID Response

60	Someone to call at a moments notice to come and help. 24 hour hotline to call. Someone who calls to just check in. I was someone without any support but I am in a good place now.
62	Local coffees every month or two with other care partners. Maybe a website listing of contact info for care partners sorted by zip codes.
63	lol the magic cure pill☺
64	A chef, a housekeeper and a financial planner.
67	the ability to function with less than average sleep
68	A tool box of ideas, tips and trick that we can use right away when needed
69	Respite care
70	More community options for support - exercise classes, respite support, in person support groups, etc.
71	I do not even know. Affordable care that guarantees no harm to my partner.
72	Automatic 48 hour respite every 3 months
73	Guilt and anxiety free time away from it all, sufficient for rejuvenation.
74	Ability to financially get help for PWP anytime the Care Partner needs to get away.
75	All the help and support that is needed. Today all the women are meeting for lunch but of course not me.
78	day care resources
79	A cure first. Second, more informative on some of the lesser known symptoms, concerns. We deal with internal tremors. The lack of information is frustrating.
80	A 1 day or include overnight Fun Outing type Seminar. Comraderie
81	Worry free time. Being away from PD spouse for more than 2 hours is worrisome. I try to do things that I enjoy and some take me away from the house....but it's really not worry-free time. I have to wonder what is going on while I'm gone. Wave that wand and give us TRUE worry free time.
82	Getting help when needed and not feeling guilty when it is needed.
83	Great question. No idea

ResponseID Response

85	ha great question. I would like an administrative assistant.
86	Time for self
87	Relaxing, having time to be happy!
88	Reliable help.
89	To know what resources are available and how to access them at each stage of the disease.
90	More respite time. A place where he can stay overnight so I can have a day without Parkinson's or where I can leave him for a week or so I can get away.
91	Magic wand? Seriously? I pray for strength, patience, kindness, compassion, humility, gentleness and unconditional love. I pray that care partners will be able to see their PWP as God sees them and that they will treat their PWP as they would want to be treated if they had Parkinson's.
92	Respite - alone time not focused on being a better care partner.
93	Lots of good CNA's!!
95	Physical help.
96	Grants for respite care
97	Low or no cost Individual counseling.
98	Legal advice Financial advice and resources Less suffering
99	Hands on, knowledgeable, in-person, inexpensive assistance.
100	More in-person support group opportunities. Webinars at a variety of times.
101	?
103	Support without putting into words
104	not sure
105	A crystal ball that looks 3 and 6 months into the future.
106	More help about how to get more help.
107	Respite care that wasn't so expensive.

ResponseID Response

108 A provider who can direct me to what or who I need next Like a manager Someone I can call and say I need a. Speech therapist near me who knows Parkinson's Or a neurologist closer etc

109 A local friend going through similar situation, respite support so I could take breaks and take care of me

110 more respite care

111 That there was no such thing as PD.

112 Affordable care .., so the care partner could have time to oneself and not worry.

113 How to find or enlist others to help too.

114 Affordable in home PT and home health aides

115 More hours in a day Peace of mind A cure

116 Easily arranged respite

117 Lots of exercise programmes, such as Dancing with Parkinson's, now free in Canada. One area sometimes overlooked is physical strength. Caring requires it, to manage daily life without that partner sharing the load.

118 Maybe a hotline to call when things get especially tough

119 Respite services

120 An in-person support group in the Washington DC area.

122 Support support support from people like Davis Phinney Foundation.

123 Accessibility to doctors and services in our medical system.

124 don't know. something to make her symptoms go away!

125 someone else to care for him

127 Up to a week of respite care to include a person to say with my PWP while I'm gone.

128 Easy to find in home health services

129 a secretary

131 A way forward, some joy, and individual guidance.

ResponseID Response

132	Paid respite to have a weekend or several days break for the everyday care giving duties.
133	A way to make family members really understand the entire picture of life with PD -- both my PwP and me.
134	Empathy. Permission for self-care. Respite.
135	More available help at a reasonable cost.
136	A group that can help make connections with reliable occasional "sitters", repair people, medical professionals (including counseling), and social activities for all levels of PD.
137	A crystal ball to see future.
138	Somebody to talk to, respite care giver
139	A manual of information that includes adaptive aids and information on transfers.
141	a case worker that helps a care partner understand the resources available, and get plugged into a support group and counseling. websites and links to resources are overwhelming and often difficult to find what you need
142	Local resources on how to set up a care team of the right people for all, not just those of us who are in big cities or who have money.
144	A match with someone who's going through the same thing
145	Mandatory respite care twice a week for at least 3 hours.
146	If i had a magic wand, I'd take Parkinson's away from spouse and take it on myself. He just doesn't deserve this - he's a lovely, generous, person. Parky has changed him completely
148	A local support group, or at least a zoom type one.
149	More organized, in person meetups in the South East US
150	I'd focus the magic on a cure
151	Unsure
152	Earlier detection and new meds for all the surrounding side ailments. I miss him but not enough to wish him back to all this.
153	8 hours per day free nursing care for Parkinson's patient

ResponseID Response

154 Actual physical help when needed

156 Every Victory Counts -- I used it often just after diagnosis. Every Victory Counts for Care Partners was nice when that became available. I've never contacted an ambassador, but it's comforting to know that I could if I needed to.

157 Medicare pays for in home caregivers...

158 More assistance

159 A cure for Parkinson. Not sure. More chances to meet in person.

161 A cure

162 I have no idea. It is the hand we have been dealt and there is not much we can do about it.

163 More trained respite help.

164 Have all of the answers.

166 Early on, help caregivers realize don't wait till you are worn out to ask for help, and help caregivers have ways to explain to the person with Parkinson's to accept the help of others

167 Affordable respite care

168 Unlimited, free in home care! I know that is totally unrealistic but I want my husband at home as long as possible.

169 Patience and being well rested each day.

170 Incredibly competent, caring respite when needed.

20. How likely are you to recommend the care partner resources, education, and events offered by the Davis Phinney Foundation to other care partners?

NPS® Score: 57.7



Promoters		72.6%	122
Passives		12.5%	21
Detractors		14.9%	25

Totals: 168

21. If you chose 8 or below for your recommendation, what could we do so that you would be more likely to recommend the care partner resources, education, and events offered by the Davis Phinney Foundation to other care partners?

ResponseID Response

1 Make the days and times of virtual care partners meetings more varied and flexible.

10 More close attention to the care population. More resources. We may not look big because we aren't as vocal but we work hard and expect little.

11 Really make an effort to incorporate PD SELF. But it needs to improve. (we just finished a cohort in April). It needs to go beyond just Bandera's self-efficacy. Incorporate resources from neuropsychiatrist Rick Hanson (<https://www.rickhanson.net/>), as well as concepts in Jane McGonigal's Super Better. Personally I've gotten more out of Super Better and Rick Hanson's "Resilience" than from the PD SELF program.

16 I chose 8 because it is so much more "distant" than our local and smaller zoom groups where we get to know each other.

17 Have services for the non-religious with practical solutions rather than prayers

23 More personalization and individual contact/discussions verses more lecture-type meeting.

25 See above. I think Davis Phinney is awesome for patients with Parkinson's, but not so great at addressing the real issues and needs of care partners. I applaud the effort though, and feel DP is just scratching the surface. There's so much more that DP could be for care partners.

29 I think you are doing very well. I'm usually just too busy "caring" to participate.

30 sometimes i am not sure people are ready for the available resources so i don't say much

34 Please, give space to care partners voice directly. We have listened to others too much, we would like to be heard, this is a way to provide healing and hope for us. Thanks in advance.

35 I need to try to attend more virtual care partner events.

46 I find the virtual meet ups are well meaning but not realistic. Very focussed on their particular experiences. The other materials are more helpful but not helpful for dementia with other PD symptoms

70 Have more local options- groups, activities, etc.

72 Many things offered are not close enough for me to take advantage of

ResponseID Response

73 my problem, I don't like to attend

78 more education focused meetup

86 Today has been a bad day so not sure

87 Help me find people who partner as Lewy body.

92 I'm a high fact-finder so the educational materials and presentations are helpful. But perhaps some carve out looking at ways an event could provide true focus on care-giver needs as opposed to focus on helping care-giver meet the needs of the person w PD

104 perhaps events should be separated by severity of symptoms of person with PD

109 I just joined and haven't participated in anything yet

124 My own fault, I haven't taken the time to explore all DPF has to offer. The monthly meetups are great!

131 I just signed up for Davis Phinney so I don't know much or have any experience. It's a start

134 Most of the information and the resources are excellent. My rating was lower specifically related to my Davis-Phinney caregiver support group experience.

148 I found the website hard to find any resources specifically for car givers. If they are there it needs to be obvious. I only saw a place where there were some questions asked, no how-to type help

151 Make them relative to everyday life.

161 Not sure

163 I don't find I get actual real support, just written materials.

22. Is there anything else you would like us to know about your experience as a Parkinson's care partner?

ResponseID	Response
1	I never imagined how hard this was going to be.
3	You are terrific, just can't get to many of the meetings as I'm so busy taking care of my partner.
5	That it's OK to ask for help
6	With a passive partner it is very hard to plan or do anything. Impossible to know what is next.
7	I think many of us are dealing with dual diagnoses, not just Parkinson's alone.
8	No
9	have to go
13	I really appreciate the resources and CP support group that DPF offers - they are so practical.
16	I find myself not wanting to do things that involve loading and unloading equipment in order to get out for more than the necessary medical appointments. That's not good for the PWP or the care partner.
17	Celebrate every day
20	DPF has been a wonderful ally as we progress through this situation
21	Thank you for the work you do. Alexandra Maurer
22	Things change all the time — sometimes daily, sometimes hourly. Learning how to cope with patience is an ongoing challenge.
25	By the way, I just have to say this - I dislike the term "caregiver" and am happy DP changed it to "care partner", but "Partners in Parkinson's" would be even better. To me "caregiver" , or even "care partner" implies a very one sided relationship and I don't see it that way with my husband. I will not see myself as a "care partner" or "caregiver" until he is essentially bedbound.
27	It can be scary watching your PD partner move through the stages of the disease.
28	No
29	Thank you for all you do.

ResponseID Response

30 i really got tired of people telling me how brave and tough i was during the final years which frankly were an ordeal. i simply did what had to be done and luckily we had some resources so i could hire people and services to help.

31 Finding others with things in common

32 I have not felt the satisfaction or pride in taking care of my husband. He constantly interrupts everything I do - chores, cooking, etc at home. Some care partners express a closer relationship. Not true with us. He wants me to pull him up, take him to bathroom (which is a long ordeal), has becomes very dependent on me for everything. If I say to wait a few min, he gets mad, may throw something in the floor to get my attention. Never try's to clean up his many spills. He has dementia also.

33 no

34 this is an unexpected career as Julie Ward said, and as Connie says, this is a long term career, so we better take care of ourselves. I am learning to be more aware of my inner adaptive capacity, from time to time I need somebody give me a hug. Muchas gracias.

35 It's hard to balance your "free" time with trying to read or listen to PD information or attend PD events. Sometimes you don't want PD to be in your face 24/7.

38 It is a crushing responsibility to do this alone. It gives me no hope and nothing to look forward to. It is isolating. I have lost the few friends I had. No one wants to be around someone that is in this situation. I feel completely alone and forgotten.

40 It is hard....

41 Still learning. Everyday is different. Ups and downs in how I feel about being able to deal with whatever's around the corner. Guess the uncertainty is what weighs on me.

43 How to accept help from my adult child without him feeling like he is obligated to alter his life goals.

44 I also rely on the great resources available from the AARP Caregivers Resources Center. <https://www.aarp.org/caregiving/>

45 As Jack Nicholson said, "What if this is all there is?"

46 More information in tools such as planning and controlling medications. Recognizing the impact of uncertainty of the future and frankly that your life is also going downhill fast

47 My husband does try to be helpful. And for someone to scratch your back or massage your toes you could not ask for better.

48 Your organization has been amazing. I just now am thinking also of the support that we both get from our local Parkinsons association in the form of counseling - both alone and together. It has been a god send.

ResponseID Response

52 HARD JOB

54 Are there some markers for when a person should quit working or when a person should begin a higher level of treatment?

55 You all do excellent work and I so appreciate it.

56 I know you know this but it is the hardest most challenging task to undertake.

57 I find the care partner meet up helpful.

58 All that you offer I wish there was more but thank you so much for doing what you do. I'm so glad I found your organization.

59 It is tough to do, especially self-care for care partners, just not enough time in the day

60 I wish I had gotten help sooner.

62 I'm always appreciative of your work.

63 I just discovered your site as a care partner and have found it helpful

66 The hospital kit is extremely helpful. I also did lots of reading on Parkinsons. I was always on the lookout for helpful devices and tried many.

69 I appreciate the clear info that DPF offers to us.

73 I don't like to share my problems with others and I hate asking for and receiving help.

76 I think it is very hard t be a resource partner when the disease is so idiopathic.

79 Your care manuals have been a gift. Thank you.

80 I am grateful to Davis Phinney for offering the Care Partner & People with Parkinsons Zoom Calls. My husband watches both & it is helpful for him to understand He is not alone AND what caregivers experiences are. Thank U

81 My spouse is now 16 years into PD, and although he does remarkably well, the disease progress still takes over our lives. in every aspect. Good days are great, but the crappy, bad days happen even more often as the disease progresses. Can't ditch it if we wanted to!

83 Very anxious about what lies ahead. Unusual situation we have I suspect, both having it,

85 not really but thanks so much for asking

86 You already know this but some days it is very hard

ResponseID Response

88	We have good days and bad days. It's a disease, don't take things personally. Stay optimistic. I count my blessings everyday.
89	The DPF Care Partner manual is very helpful. We have an amazing PD community in Boulder County and amazing resources. The DPF educational resources are remarkable! Thank you!
90	How I can relax and be more brave to deal with this anxiety.
91	No
93	Love the Davis Phinney monthly care partner meeting and also my local caregiver's support group meeting. They are invaluable!
95	It's important to keep the romance in your relationship. You are a wife or husband. FIRST.
96	There are special moments and silver linings but I cannot emphasize enough to have everything lined up way before you think you may need it from wills and POAs to learning about available caregiving and what Medicare will and will not pay for and decide on what next 5 years looks like right now as difficult as it is. Reminder that this IS a progressive disease so it WiLL progress we just don't know how and when so know before you need it what the plan is ans then you just have to implement that it when the time comes. Also best investment to make if you can afford it is long term care policy. My biggest mistake not to have this in place.
98	Grateful to have the many resources that we do have and the ongoing quest to help those dealing with the disease
99	It's just heartbreaking to watch the person you love leave you a little more every day. My husband also has the PD dementia.
100	Thank you for all you do/offer.
101	No
103	After 10 years, this new dementia and cognitive decline aspect is breaking my heart.
104	no
105	I think you've already been there. You know it is difficult and that there is very little hope for those currently diagnosed.
107	My experience has made me resentful at times. My care is taken for granted and no gratitude is expressed.
108	I know I can do hard things Not sure for how long given my age and possible health We have kids who make them self's available however right now we are managing We have made our house safer for now It's day by day

ResponseID Response

110	I've done this for 35 years because he was onset. I've learned so much that sometimes it is hard to find new info beyond PD 101 so I am probably missing good info that is mixed in.
112	It is overwhelming at times being a care partner.
113	A new learning experience!
115	I greatly appreciate the programs and meet-ups and resources that Davis Phinney Foundation has made available. I have learned so much. Thank you sincerely. I miss being able to virtually attend the meet-ups since they moved to a later time
116	My fear of the future
117	It is important to retain your interests, both social with friends, walking, talking, connecting, and with hobbies, such as crafts, puzzles, book clubs etc. Caring is consuming, but your own other life must be maintained. Again, this depends heavily on your circumstances. Rural, poor, and technically disadvantaged carers are sadly placed.
118	How to diffuse anger...
119	I struggle with the mental aspects of my person with Parkinson's. It's crazy making. I haven't been able to find a counselor who is knowledgeable about caregiving, and I really need some help.
120	I would like to become a Davis Phinney Ambassador.
121	You are doing well - thank you
122	To me Parkinson's is not a death sentence but a change of life. My husband didn't want this dreadful disease. He is a farmer and it is known farmers never retired1 Nope this is wrong. He didn't want to retire and retiring hurt him but he had no choice. We still have a small farm that is planted and harvested by someone else. I pray and pray and this is what gets me through tough times. And I pray for you all and so very thankful you care for everyone! Take care:)
123	I know I am emotionally dumping. But this is what it is like for me. Loss of Executive Function in my partner. I want to be in a better mind set so that I can protect my Parkinsons person. He needs me to be happy to reduce his worry and stress. That is what is hardest about being a care giver. How to have patience for my loved one when in fact I am overwhelmed.
127	I appreciate all then DPF does for the PD community. Keep up the great work!
128	Just that it is exhausting and you have to be constantly aware of what is going on

ResponseID Response

129 I miss having someone to share things with - a sharing often evolves into a long explanation he may or may not need repeated - I find myself choosing not to share things (something I see or read or something that just occurs to me to comment on)

131 It's awful, hard every single day, and I spend the vast majority of my time inside organizing the my life and that of my partner. I no longer have a partner in many areas. It's all on me

133 Know that I value highly the Davis Phinney Foundation. We've attended programs. I attend the monthly virtual care partners meetup. I have and refer to the EVC Manual. I donate money when I can and always wish I could donate more.

134 I am a retired health care professional (Nurse Practitioner) and my spouse had a focused US procedure at a renowned academic medical center—which was supposed to give 3-5 years of relief from severe tremors. It lasted 5 weeks and the tremors are now worse than ever and resistant to every single medication that is used for tremor control. Now we are exploring DBS. And sought a second opinion, which has resulted in a change in health systems (both of which are Parkinson's Centers of Excellence) and essentially starting over with all the bureaucratic hoops that entails. Meanwhile, our social life has evaporated because he cannot eat without assistance and does not want to draw attention to himself. While I have a network of family, friends, and health professionals, being a caregiver is still extremely lonely.

136 Your virtual events have been very helpful, however trying to "attend" around lunch time is difficult. Mid-afternoon would be better. Dealing with my husband's doctors and my husband has not always been productive, so really enjoy hearing from the experts you have provided.

137 No

138 Thanks for being there

141 it would be helpful to have a video to share with extended family to help them understand what I am dealing with, maybe something shorter to begin with so they actually watch it. again this may exist but sent to a website with a bunch of resources gets overwhelming to find what you want

142 18 months in I still find it shocking and hard to believe. Especially because we have no idea what is coming for us.

144 Thank you for the wonderful resources!

145 Our needs are as varied as the symptomology of our People with Parkinson's. I live in a heightened level of awareness wondering what will happen next.

ResponseID Response

146 I feel alone most days. My spouse stays home when he feels poorly, so other people only see him when he's "on" When I tell my friends how it really is when he is "off" his meds, they don't believe me. Or they find it impossible to imagine. I had to quit my job about 2 years ago (during COVID) so I could care for my spouse. The stress during the pandemic made his Parkinson's almost unbearable. I still haven't returned to work. I feel resentful about this, but there's no one to tell. My spouse was 38 when he was diagnosed, he had the brain stimulator (worked for about 10 years) and now he has the GJ tube and wears Duopa about 16 hours a day. He's only 61. I'm 57 These are supposed to be good years. But it's really hard to find 'good' when I never know what day is going to be a struggle. The unpredictable nature of Parkinson's can be the biggest obstacle to our social life, not that we have much of a social life. In some ways, I am creating my own life, without my spouse, and I feel like I am getting farther and farther away from him and he'll never be able to catch up. We've been married for 38 years. Going down this road, what seems like our final journey, on 2 separate paths is not how I imagined my life would go. This uncertainty and the constant loneliness contribute to an overwhelming sense of loss.

149 I am just beginning to embrace this role in my marriage and am seeking more support as a care partner. Beyond grateful for DPF and what you do. Looking forward to partnering with YOU!

150 DPF is the best, we appreciate everything you do to help everyone living with PD.

151 Maintaining so far

152 It was a real traumatic time for 4 years. He (and I) hated it , but was ready "to go" not he had any choice.

154 No

156 Connie is correct in urging us to build a team for help BEFORE you need it. It's a better plan when you set it up without being in crisis mode. I feel pretty lucky that my PWP has a slow-progression version of PD. Thanks for this survey...it's well designed meaning that you asked the right questions.

157 In the first diagnostic in Parkensons , if there was a workbook of legal preparation, caregivers navigation , resources available for dummies..

159 Glad there is a DPF organization to use as a resource.

161 No

162 I do tell EVERYONE I know about your organization and the support you give to both PWP and caregivers.

164 This disease affects everyone differently. We just try to make the best of each day.

165 It's like a slow death for both of us. No cure for that.

ResponseID Response

166 My doctor told me I was going to die first if I didn't get him to a facility, and he wouldn't go. It came to a crisis before family could see what I dealt with.

167 No

168 Your emotions are on a roller coaster ride. One minute you feel positive and strong and the next you are discouraged, scared, unsure, and hopeless.

169 Keep up the excellent work you do. I couldn't get along with out the monthly meet up.

170 Emotions are all over the place at times. It's hard to articulate the day to day experience because it's so unpredictable.