

Care partner self-assessment



Rate each item below from 1 (never) to 5 (almost always) according to how much of the time each statement applies to you. Add all the numbers you have selected to determine your results.

1 Never **2** Rarely **3** Occasionally **4** Frequently **5** Almost always

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

Total

Assessment results

12-24 You are at extremely high risk for personal health problems. It is important for you to talk to your personal health care provider as soon as possible. Remember, you can only provide good care for someone else if you take good care of yourself.

37-48 You have room for improvement. Assess where you experience challenges and seek help from family, friends, or professionals and make some changes.

25-36 You are at moderate risk for personal health problems. Talk to your health care provider or others who can help you create and stick to a plan to take better care of yourself.

49-60 You are doing very well at taking care of yourself.

Adapted from *Caring and Coping: A Caregiver's Guide to Parkinson's Disease*, published by the Parkinson's Foundation, 2016. Original version adapted from "Checklist for Caregivers: Do you take care of yourself?" Bass, D.S. 1990, *Caring Families: Supports and Interventions*, p. 35, National Association of Social Workers



Care partner burden calculator



Rate each item below from 1 (never) to 5 (almost always) according to how often you feel this way. Add all the numbers you have selected to determine your results.

☐ 1 Never
 ☐ 2 Rarely
 ☐ 3 Occasionally
 ☐ 4 Frequently
 ☐ 5 Almost always

I feel my care recipient...						
1	Asks for more help than they actually need.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
2	Takes up so much of my time, there's none left for me.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
3	Behaves in a way that is embarrassing.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
4	Makes me angry.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
5	Makes the future look bleak.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
6	Depends on me too much.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
7	Causes me additional strain and stress.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
8	Affects my relationship with other family members in a negative way.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
9	Has needs that mean less privacy for me.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
10	Has impacted my social life in a negative way.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
11	Makes me embarrassed to invite others over.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
12	Attempts to control me.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
13	Expects a lot from me, and me alone.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
14	Doesn't understand the financial burden placed on me as a result of providing them care.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5
15	Doesn't know that I am exhausted and cannot take care of them for much longer.	<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3	<input type="radio"/> 4	<input type="radio"/> 5

Total

Assessment results

15-30 Little or no burden

Your experience of the burden is manageable.

31-45 Mild to moderate burden

Your experience of the burden is somewhat stressful.

46-60 Moderate to severe burden

Your experience of the burden is increasingly stressful and may have an impact on your health.

61-75 Severe burden

Your experience of the burden is extremely stressful and puts you at a high risk of stress-related health issues.

Adapted from the FTLDA Caregiver Burden Scale; Zarit, S.H. et al (1980).



Home safety evaluation checklist



Use this checklist to ensure that your home is safe and easily accessible.

Throughout the house

- ☐ Floors are stable, non-skid surfaces without excessive patterns.
- ☐ There is good lighting throughout the home, with no dark or shadowy areas.
- ☐ Walking paths are wide, allowing easy access and/or use of a walker or wheelchair, if needed.
- ☐ Electrical/phone/computer cords do not pose a tripping/fall risk when walking or moving about.
- ☐ Stairs are in good shape, have railings, and can be blocked for safety, if needed.
- ☐ Chairs are stable, have arm rests and adequate seat height to make standing up easier.
- ☐ Dining area can be easily accessed.
- ☐ A communication system is in place to allow you to hear the person with Parkinson's in another area of the house.

To do:

- ☐ Remove any small area/throw/scatter rugs.
- ☐ Remove any clutter to decrease the risk of tripping or falls.
- ☐ Store medication in a safe place.

Bedroom

- ☐ Environment is quiet and relaxing.
- ☐ Bed height allows feet to touch the floor when seated at bedside.
- ☐ Half side-rail or bed pole is in place to assist in rolling and getting up.
- ☐ Nightlight is placed in easily accessible spot and bright enough to fully light the path to the bathroom.
- ☐ A bedside commode/urinal is available for nighttime use, if needed.
- ☐ A communication system or monitor is in place, so you can hear calls for help at night.

To do:

- ☐ Place slippery fabric or drawsheet on the middle third of the bed to make rolling easier.
- ☐ Remove the top sheet and instead use only a lightweight comforter on the bed.
- ☐ Avoid flannel sheets and nightwear, as they impede movement.

Bathroom

- ☐ Grab bars are installed near the toilet, tub, and shower so that towel racks, faucets, or soap dishes are not used or seen as substitutes.
- ☐ Toilet has an elevated seat and arm rests or grab bar within easy reach.
- ☐ Tub/shower has a sturdy bench with back support for bathing/shower safety.
- ☐ Seating is available when performing tasks like brushing teeth, shaving, and combing hair, if needed.
- ☐ A communication system or monitor is in place, if needed, so you can hear calls for help.

Adapted from *Caring and Coping: A Caregiver's Guide to Parkinson's Disease*, published by the Parkinson's Foundation, 2016.

Activities of daily living support schedule (weekly)

Use this form to map out daily living activities and identify who is responsible for each task during the week. Filling it in can highlight where extra support may be needed and help keep routines organized. Review and update regularly as needs change.

Around the home

Activity	SUN	MON	TUE	WED	THU	FRI	SAT
Cooking/preparing							
Doing dishes							
Tidying kitchen							
Floor/carpet							
Cleaning							
Dusting/tidying							
Cleaning bathrooms							
Laundry/ironing							
Yard work							
Gardening							
Snow shoveling							
Taking out garbage/recycling							
Sending/picking up mail							

Personal care

Activity	SUN	MON	TUE	WED	THU	FRI	SAT
Eating							
Oral care							
Bathing							
Dressing							
Toileting							
Other hygiene							

Transportation

Activity	SUN	MON	TUE	WED	THU	FRI	SAT
Health care appointment							
Exercise							
Social event							
Shopping							
Other appointment							

Coordination of other activities

Activity	SUN	MON	TUE	WED	THU	FRI	SAT
Booking appointments							
Filling/picking up prescriptions							
Banking							
Paying bills							
Ongoing income tax preparation							
Car servicing							
Pet care							

Psychosocial

Activity	SUN	MON	TUE	WED	THU	FRI	SAT
Social visits							
Check-in calls							

Daily needs and routine tracker



Copy and complete this worksheet so alternate care providers (paid or unpaid) will have a list describing the specific needs and schedule of the person living with Parkinson's.

Sleep

Waking time	
Napping time	
Sleeping time	
Notes/preferences	

Personal care

Bathing	
Dressing	
Oral hygiene	
Other	
Notes/preferences	

Activities

Mornings	
Afternoons	
Evenings	
Notes/preferences	

Diet and meals

Breakfast	
Snack	
Lunch	
Snack	
Dinner	
Snack	
Notes/preferences and allergies/dietary restrictions	

Medication

Dose 1	
Dose 2	
Dose 3	
Dose 4	
Dose 5	
Notes/preferences	

Other

Assistive device(s)	

What-if plan

Use this template to complete the *What-If* statements with intended actions. Add your own statements in the blank spaces provided.

What if my care recipient has a sudden illness?

Then...	
Then...	
Then...	
Special notes	

What if my care recipient has a sudden admission to the hospital?

Then...	
Then...	
Then...	
Special notes	

What if there is a family emergency?

Then...	
Then...	
Then...	
Special notes	

What if I (or my care recipient) has an emotional crisis?

Then...	
Then...	
Then...	
Special notes	

What if my health is compromised and affects my ability to provide care?

Then...	
Then...	
Then...	
Special notes	

What if _____

Then...	
Then...	
Then...	
Special notes	

What if _____

Then...	
Then...	
Then...	
Special notes	

Adding family, friends, and volunteers to your caregiving



Take advantage of your network and the kindness of others, but be mindful of potential schedule conflicts and time constraints. Consider having several options or a back-up plan in case your regular assistance is unable to help. Be honest, open, and specific regarding what is needed when you ask for and accept help from those who are close to you. Even the healthiest families can be stressed by long-term care. It can help to keep everyone up-to-date on your care recipient's needs and condition.

Different people will have different skills and preferences for how they help out. Help may not always involve direct caregiving. Someone who is willing to cut the grass every week frees up your time or money to use in another way.

Enlisting the help of volunteers will allow you to diversify your support system but will also require flexibility and coordination on your part. The chart below can help you decide who you can ask, what job that person can do, and what the time commitment would be.

Filled out by:	Date:
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Person to ask	Activity	Contact	Time commitment
Example: Brother Tom	Take Jack to lunch	Tom@email.com	Once a week, 90 minutes
Example: Neighbor Jim	Take garbage out	555-1212	Once a week, 10 minutes

Adapted from *Caring and Coping: A Caregiver's Guide to Parkinson's Disease*, published by the Parkinson's Foundation, 2016.

Questions to ask a potential paid individual care provider



Hiring someone to take care of your care recipient is a decision that must be made with careful consideration. There are many questions you can ask to make sure the individual can meet your needs, as well as questions to make sure the person is competent and has the proper training, licensing, and insurance.

Filled out by:

Date:

Potential care partner name:

What is your education and training?

If individual is a skilled provider (RN, PT, OT, SLP, SW):

Do you provide clinical care (e.g., nursing, physiotherapy) as well as personal support (e.g., bathing, meal preparation)?

☐ No ☐ Yes

What hours are you available?

Are you registered or certified with a provincial/territorial regulatory body (if applicable)?

☐ No ☐ Yes

Do you carry liability insurance, or are you covered through an agency or professional association?

☐ No ☐ Yes

Will you perform an in-home assessment prior to starting service?

☐ No ☐ Yes

Will you create a care plan?

☐ No ☐ Yes _____

Is there a process for updating the services provided if our needs change?

☐ No ☐ Yes _____

Can you provide in writing the care services provided and clearly describe all rates and fees?

☐ No ☐ Yes _____

What are your fees?

What is the billing schedule for services?

What happens if you become ill or are otherwise unavailable? What are the alternate arrangements?

How do you document that your services were completed?

How quickly can you initiate service?

Can you provide a list of references?

☐ No ☐ Yes _____

Questions to ask a potential home care agency



Hiring someone to take care of your loved one is a decision that must be made with careful consideration. There are many questions you can ask to make sure the agency can meet your needs, as well as to help ensure that the agency and its employees are competent and have the proper training, licensing, and insurance.

Filled out by:	Date:
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Potential care provider/agency name:

Questions about services provided

Does your agency provide both clinical services (such as nursing, physiotherapy, occupational therapy, speech-language pathology, or social work) and non-medical services (such as bathing, mobility assistance, or meal preparation)?

☐ No ☐ Yes

Are any of your services eligible for coverage through provincial/territorial home care programs or extended health benefits?

☐ No ☐ Yes

Will you perform an in-home assessment prior to starting service?

☐ No ☐ Yes

Will you create a care plan?

☐ No ☐ Yes

Does your agency provide in writing the care services provided and clearly describe all rates and fees?

☐ No ☐ Yes

Is there a process for updating the services provided if our needs change?

☐ No ☐ Yes _____

Can your agency provide 24-hour care?

☐ No ☐ Yes _____

Does your agency provide transportation services for clients?

☐ No ☐ Yes _____

Can your agency provide emergency monitoring systems and other safety technology?

☐ No ☐ Yes _____

Questions about certifications and liability

What are your education and training requirements for care providers?

Is your agency licensed or accredited by any government agency to provide home care?

☐ No ☐ Yes _____

Is your agency accredited or certified by a recognized Canadian body (e.g., Accreditation Canada, provincial health authority)?

☐ No ☐ Yes _____

Do you carry liability insurance?

☐ No ☐ Yes _____

Are your employees bonded and insured for theft and client injury?

☐ No ☐ Yes _____

Do you perform background checks on employees?

☐ No ☐ Yes _____

Can your agency provide documentation explaining the client's rights, your code of ethics, workers' compensation, and client confidentiality compliance?

☐ No ☐ Yes _____

Do you handle all payroll deductions, Canada Pension Plan (CPP) contributions, Employment Insurance (EI), and income tax remittances for your employees so that families are not legally responsible?

☐ No ☐ Yes _____

Can you verify that all employees are legally entitled to work in Canada?

☐ No ☐ Yes _____

If your employee is injured at a client's residence, who is responsible? Are your employees covered under workers' compensation (WSIB/WCB) or another insurance program? (Many homeowner's insurance policies exclude injuries to "domestic employees.")

Questions about working with a paid care provider

Can we meet the person before receiving services?

☐ No ☐ Yes _____

Do you send the same person each time?

☐ No ☐ Yes _____

Do you provide back-up coverage in case your employee cannot make it to work?

☐ No ☐ Yes _____

How do you monitor/supervise employees?

How do you document that your services were indeed completed?

Questions about administration

Is there someone I can call with questions or complaints?

☐ No ☐ Yes _____

Can you provide a list of references?

☐ No ☐ Yes _____

What are the fees for your services (per hour, per day)?

What is the billing schedule for services?

Is there a payment plan option?

☐ No ☐ Yes _____

Do you require a minimum number of hours per shift? If so, what is it?

☐ No ☐ Yes _____

How quickly can you initiate service?

Adapted from Caring and Coping: A Caregiver's Guide to Parkinson's Disease, published by the Parkinson's Foundation, 2016.