The 7 Needs of Caregivers

1. Education about Parkinson’s disease
   • Understand the symptoms and learn about available treatments.
   • Consider the impact of Parkinson’s and your role in caregiving on everyday life.

2. Time management
   • Make daily and weekly lists of things to do, keep it manageable and realistic
   • Prioritize: do the important or difficult things first.
   • Save up errands to do more of them at one time.
   • Try to accomplish a small task when you know you will have to wait.
   • Delegate what can be delegated and determine and avoid unnecessary tasks.
   • Take breaks and protect yourself from doing too much
   • Break large tasks into smaller, more manageable parts
   • Establish and stick to routines.
   • Acknowledge that some time will be spent on things beyond your control.

3. Self-care, health and respite
   • Build in quality time for yourself (1–1½ hours a day, if possible) and protect it.
   • Keep up with your own needs, hobbies, and regular activities.
   • Exercise: it leads to better sleep, decreased tension and depression and increased energy.
   • Eat a balanced, nutritious diet and drink water.
• Recognize stress in yourself, get enough rest, and take time to relax.

• Maintain a sense of humor.

• Get regular check-ups and keep your own medical appointments.

• Think about your future, goals you hope to achieve and how can you achieve them?

• Set limits and stick to them.

• Bring in outside help (family or paid worker) so that you can take a break.

4. A support team
• Share the care. Get assistance and support as needed (physical and emotional).
  
  o Develop your coping skills. Caregivers experience a wide variety of emotions and it is OK to feel sad or frustrated at times. It’s okay to grieve the losses that you and your loved one may experience.

  o Take time to enjoy life and focus on the present, the needs, and rewards of the day. Give yourself credit, not criticism and guilt, and try to forgive any mistakes.

  o Use positive self-talk: for example, tell yourself, “I am doing a good job.”

  o Writing – in a journal or other format – can help you work through your feelings and emotions (What causes sadness for you? Or joy?)

• Develop your emotional and spiritual support networks.

  o Include your health care team (physician, nurse, social worker, etc.), family, friends, neighbors, support group and individual support group members, clergy, volunteers, and online support forums.

  o Seek comfort from your faith, faith community, and spiritual practices.

  o Adjust your expectations: Life and you are not perfect. Accept changes as they occur.

• Be aware of the core symptoms of depression:

  o Sleeplessness

  o Loss of appetite
o Difficulty concentrating

o Feeling slowed down or restless inside

o No interest in once-pleasurable activities

o Thoughts of death or suicide

o Feelings of hopelessness and worthlessness

If you think you may be depressed, talk to a doctor or mental health professional about your symptoms.

o Get help if necessary. Remember, it is strength not a weakness, to ask for help, including emotional help or counseling. Depression is different in each person.

o Acknowledge any symptoms you experience that could signal depression; you should not feel embarrassed or ashamed.

• Find a supportive professional that you trust and with whom you feel comfortable. In most cases, depression is effectively treated with psychotherapy, antidepressant medications, or a combination of both.

• Activities such as regular exercise, spirituality, supportive social interactions, and meditation are also very beneficial.

5. Your relationship with the person with Parkinson’s

• Maintain open communication.

• When conversing, remove or turn off loud and distracting noises.

• Express love and appreciation as well as concerns and feelings of frustration. Don’t let those feelings transform into resentments.

• Share special time together apart from caregiving tasks.

6. Medical, financial and care decisions

• Define and clarify issues, including family participation in caregiving, advance directives, long-term care options or other topics.

• Devise steps for carrying out these plans.

• When making decisions about hands-on care, ask if your decision promotes your loved one’s independence: Do not confuse “caring” with “doing.”

7. Community resources
• Take advantage of physical and practical assistance and products.

• See what resources local associations have to offer.

• Seek education materials from Parkinson’s disease organizations

• Get legal documents (e.g., power of attorney for health care) in order.

• Explore resources for financial assistance, e.g., disability.

• Reach out to a variety of professionals, such as specialist physicians, nurses, therapists, socialworkers and clergy.

Adapted from publication *Caring and Coping* by Parkinson’s Foundation