

SIMPLE WAYS TO FEEL BETTER

Here are some things you can do:

- Ask family or friends to help you.
- Take short breaks every day to do something fun.
- Learn about PD from a doctor.
- Take care of yourself - eat healthy food, sleep enough, and try to exercise.
- Talk to other helpers to share your feelings.
- Try taking deep breaths or sitting quietly to relax.
- Stay in touch with your friends and family.



WHEN TO GET HELP FROM A DOCTOR

Talk to a doctor if:

- You feel very sad or worried all the time.
- You can't sleep for many days.
- You feel too tired to take care of the person with Parkinson's Disease.

IMPORTANT THINGS TO REMEMBER:

- It's okay to feel "Not Ok" and okay to ask for help.
- Take breaks when you need them.
- Learn as much as you can about Parkinson's disease.
- Talk to other caregivers about how you feel.
- Take care of your health too.
- Keep in mind that your role as a caregiver is very important.
- Be kind to yourself.

Remember, it's okay to ask for help. You're doing an important job, and you deserve help too.

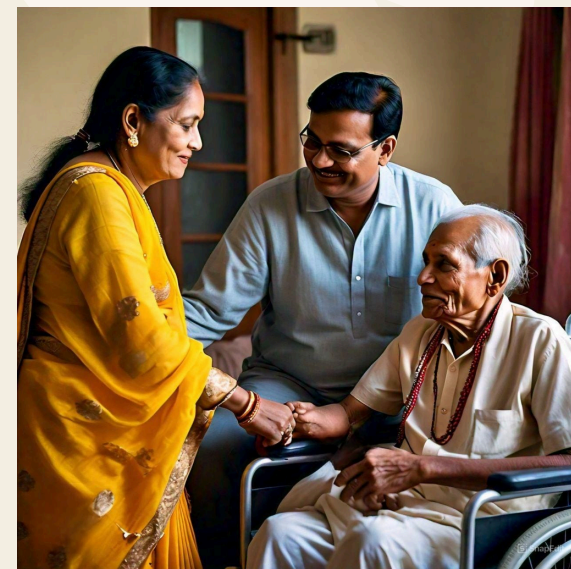
We hope this guide helps you feel stronger and less alone in your important job as a caregiver. What you're doing is making a big difference in someone's life. Take care of yourself, and keep up the great work!



Prepared by
National Parkinson Network,
Movement Disorders Society
Of India



CARING FOR SOMEONE WITH PARKINSON'S DISEASE



If you're reading this leaflet, you're likely caring for someone with Parkinson's disease (PD). We understand that this role can be rewarding and challenging. This guide is designed to support you on your caregiving journey. Whether you're new to caregiving or have been doing it for years, you'll find helpful information about understanding caregiver challenges, recognising signs of stress, and practical strategies for caring for yourself while caring for your loved one.

We hope this guide helps you feel stronger and less alone in your important job as a care partner.

WHO IS A CAREPARTNER?

- A care partner (Helper/Caregiver) cares for a person with Parkinson's disease.
- In many families, care partners are often the spouse [wife or husband], mothers, fathers, children, or other relatives.
- They give medicines, help with daily tasks, and make the person feel better.

WHAT MAKES HELPING OR CAREGIVING HARD?

People use different words to talk about the hard parts of helping:

- Care partner Stress: All the worry and work that comes with helping.
- Care partner Sadness: Feeling upset or worried because of helping.
- Care partner Work: The tough jobs helpers have to do every day.
- Care partner Stigma /Shame: Feeling bad or judged because you're a helper.

These words all have a similar meaning - helping can be hard sometimes!

WHY IS IT IMPORTANT TO KNOW ABOUT CAREPARTNER STRESS?

- When care partners are too stressed, they might get sick.
- Stressed helpers might have trouble taking good care of the person with Parkinson's disease.
- If we know about care partner stress, we can find ways to make them feel better.

SIGNS THAT CAREGIVING IS GETTING TOO HARD

You might be too stressed if you :

- Feel very tired all the time
- Get angry or upset easily
- Feel sad or worried a lot
- Have trouble sleeping
- Don't enjoy things you used to like
- Feel lonely
- Have headaches or body pain often



SPECIAL THINGS ABOUT CAREGIVING IN INDIA

- In India, families often take care of sick people at home.
- There aren't many places that can help take care of people with Parkinson's disease.
- Medicine and doctor visits can cost a lot of money.
- Some people might not know much about Parkinson's disease.
- Some people might feel ashamed about having a brain disease in the family.

It is estimated that one in six to one in four caregivers of Parkinson's Disease in India would feel stressed. Money problems are also a big reason for this stress. Lack of facilities for rehabilitation, physiotherapy, nursing care and occupational support are also contributory factors.