



As Parkinson's disease progression is variable, the level of care required will be variable. A newly diagnosed person with Parkinson's Disease may require emotional support and someone to speak with & be listened to. A person with more advanced symptoms of Parkinson's disease will rely more on a care partner for a variety of aspects of care.

Husband, wife, son or daughter, father or mother. You may not see yourself as a care partner but recognising your role is important. A change of role occurs when you provide care at a different level for your loved one. You may not put a label on yourself as a care partner but that you are simply caring for a loved one in a different way.

The role of a care partner can be a demanding role. You may evolve into the role of a care partner while perhaps working or raising a family, often you don't have time to think about yourself. But it's important to acknowledge your feelings. It may bring changes to your personal relationships, relationships with others and your working life. It may bring challenges to your relationship together. It may cause confusion about the changes in your role in your relationship. Open communication, between the care partner and the person receiving the care, is an important step which should be initiated at the beginning of this journey.

Types of Care:

- **Medical Care:** Providing medical/nursing care. Administering medications. Assisting with activities of daily living (ie washing and dressing)
- **Practical/ Financial Care:** Shopping, cooking, cleaning, care around house
- **Emotional Care:** Providing support & care of the emotional aspect of the person. Managing all aspects of care can be difficult. If instigated at the beginning of this journey, it may make management and dealing with situations easier when they arise.

If you begin your path together as care partner and person with PD, the path will be easier to navigate. As the person with PD can be involved with decision making, knowledgeable about services and supports available which may be necessary in the future and will help empowerment when coping with disease diagnosis and progression.

Care Partners Advise:

- Obtain knowledge of Parkinson's Disease
- Get organised
- Seek support from the start. Be informed of supports available
- Divide up care among family members or close friends.
- Accept help & don't be afraid to accept it. Help from even one extra person will ease burden of your role
- Look after yourself. If you don't care for yourself, you won't be able to care for others. It is important to look after yourself both physically and mentally. Remember to take time out, regular breaks are essential. Engage in social outlets.
- Connect with others- community support, group or online support via organisations.
- Ensure you have a person you can talk to outside of your role, talking to others will help & provide an outlet for you.
- Plan ahead where you can, to help reduce uncertainty.
- Encourage independence – it is important to let the person you care for be as independent as possible, even if tasks take much longer. Resist the temptation to take over and offer support rather than inundating the person you're caring for with advice and practical help.
- Plan things together – try not to let Parkinson's dominate everything. Do things you enjoy doing together, even if this means doing them differently.

Acknowledge that you are doing a great job and providing a level of care to a loved one that is very much appreciated.



Disease progression

As Parkinson's disease progresses, symptoms will lead to greater challenges in the care of the person with PD. These great challenges are not limited to motor related symptoms.

- **Communication** problems (reduced facial expression or quietened speech) can affect relationships, as they can often be mistaken for low mood or depression. A speech and language therapist may be able to help. (See speech & Language info)
- **Depression** can affect people with Parkinson's and their care partners. Don't ignore it –speak to your doctor about treatment, which may include medication or counselling.
- **Anxiety**- Some people with Parkinson's disease can be anxious about going out or being in social setting. Encourage them to remain sociable. Suggest local support groups, involvement in local day centres & community activities. (See [anxiety info page](#))
- **Sleep** may be disrupted due to nocturnal symptoms both motor and non-motor. It is important to get rest when possible. Sleep is important for both person with PD and carer (see Sleep info page)

Please visit below websites for further support information.

www.familycarers.ie

www.citizensinformation.ie

www.carealliance.ie

www.nhi.ie

Acknowledgements

www.parkinsons.org

[The carer's guide WEB.pdf \(parkinsons.org.uk\)](#) www.familycarers.ie

Support/Information

Establish relationships with your Gp, Public Health Nurse, community OT/SALT/Physio/ Dietician (including other multidisciplinary members). These relationships and the input that give will be invaluable and of huge benefit, in preparing for the future.

The below schemes are just an example of some of the other supports available to care partners. All schemes are based on an application process & assessment some more in depth than others. It is good to know some of the supports available, although not all will qualify for these schemes.

HSE supports: Nursing home support scheme, LTI Scheme, Public health nurse/ centre, GP visit card

Social Welfare supports: Carer's allowance/ benefit

Revenue supports: Tax credit/ relief, disabled driver/

passenger scheme,

Senior Alert Scheme: Home/ personal alarm system

Better energy Home Scheme

Treatment Abroad Scheme

