

MANAGING ADVANCED PARKINSON'S DISEASE

Every person living with Parkinson's (PD) has a unique experience of the disease. While there may be similarities between symptoms, progression, and treatment, most people with Parkinson's require their own individualized care plan to meet their needs.

As Parkinson's advances, medications may become less effective, and the person with PD may require more attention. Carepartners must often transition into a more involved caregiving role, as well as taking on more household duties. For both the person with PD and their carepartner, disease management in later stages is more focused on maintaining safety, comfort, and quality of life.

Accepting Change

Parkinson's changes lives. Adjusting to a diagnosis takes time, and involves an important process of adapting to the new roles of *person with Parkinson's*, and *carepartner* or *caregiver*. This process is ongoing as the disease progresses, and no one is ever truly prepared for late-stage PD. As a chronic, degenerative disease, PD can present a unique and complex set of challenges that are difficult to predict. You may face changes in relationships, financial status, identity, self-esteem, future plans, and more – all of which can be major sources of stress. While change may be inevitable, the way you respond to your circumstances is in your control.

Acknowledging and accepting change is difficult. At times, you may find yourself in deep sadness or anger. You must grieve the losses in your life to give way to new, memorable experiences. Being able to sit down and talk with your loved one about these losses can validate your experience, and be a means to adapting, and moving forward together.

Talking about disease progression can be straining, so you may want to consider talking points that will keep your conversation grounded in mutual support and understanding, rather than difficult topics such as pain, cognitive impairment, or disability. You can focus your discussion on a symptom tracking checklist, or a game like Go Wish, which helps individuals give voice to their end of life values, and share them with their loved ones, and other key figures in their care.

Planning Ahead

In advanced stages, people with PD will have difficulty with their activities of daily living, like dressing, bathing, and eating. Planning ahead to know the support services that are available to you can be important to stay safe and in your home for longer. One way of keeping your home safe is to complete an in-home safety check. This will help you declutter your living space, and remove hazards. To get the job done, you can hire a professional organizer to help sort through old boxes, closets, or rooms to remove unwanted household items and belongings. Some people may even set up external support for personal care, such as hiring a care aid for dental care, toileting, skin care, and bathing.

Preparing for late stage PD also includes personal planning, which involves four aspects of your life: health, personal, legal, and financial. This can save you time, and help ease the burden of an already challenging situation. It is especially important to get your financial and legal affairs in order when you and your loved one are still capable of doing so. Appointing a representative, or giving someone enduring power of attorney, can help ensure that end of life wishes are fulfilled.

Please note that everyone is unique in their care preferences and needs. Planning ahead is especially important for people with PD, because disease progression may cause loss of voice, cognitive changes, or other impairments, which may make it difficult to express their end of life wishes.

Approaching End of Life

As Parkinson's progresses, and symptom management becomes more complex, palliative care may be introduced to maintain quality of life for as long as possible. Palliative care uses a team approach, aimed at providing relief from pain and other distressing symptoms, and supporting the family as they cope with change and loss. It affirms life, and regards dying as a normal process, while neither hastening nor postponing death. For those living with Parkinson's, palliative care can be integrated earlier in the course of illness to control pain and maintain the best quality of life. Talk to your doctor about palliative care options available for you or your loved one, while still living at home.

If advancing Parkinson's symptoms cause continued decline and medical complications, hospice care may be added to continue support at home, or within a home-like setting. Hospice care is available to anyone with limited life expectancy (under 6 months), and emphasizes comfort care, rather than aggressive treatment. Quality, rather than quantity, of life is stressed, and options may be offered to reduce carepartner stress and burnout. Professional medical care and emotional support continues throughout the hospice process, and many families find these support services invaluable during this difficult time.

Additional Resources

Go Wish Game | www.gowish.org

Parkinson Society British Columbia Resources

In-Home Safety Checklist Helpsheet | bit.ly/pdhomesafetycheck

A Comprehensive Guide for Parkinson's Caregivers | bit.ly/pdcaregiverguide

Comprehensive Care Plan Checklist | bit.ly/pdsymptomchecklist

Healthcare Decision Making Helpsheet | bit.ly/pdadvancecareplan

How to Stay Safe and in Your Home for Longer

Video | youtu.be/AoLn-YLUJ40

Helpsheet | bit.ly/pdgeriatrics

Palliative Care for Parkinson's Video | bit.ly/pdpalliativecarewebinar

Advance Care Planning Helpsheet | bit.ly/pdadvancecareplan

Wills & Estate Planning | Video | youtu.be/yPLvh7BfvZo

Sources

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Parkinson's UK (2018). *Advanced Parkinson's*. Retrieved from:

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