

# Caregiving Through the Progression: Themes from Parkinson's Care Partners through early, mid-stage, and advanced Parkinson's

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#### Introduction

The Parkinson's Foundation conducted interviews with three Parkinson's Care Partners for the **Care Partner Program** online course "Caregiving Through the Progression." The following highlights the unique experiences of a diverse group of care partners throughout their Parkinson's journey. Self-care is an important theme across all three interviews, but as expected it looks quite different in different contexts. To see their full interviews, register for the free course at <a href="Parkinson.org/CarePartnerProgram.">Parkinson.org/CarePartnerProgram.</a>

#### **Early Parkinson's Caregiving**



Julia highlights the turbulent road to her husband Phil's diagnosis and the frustrations along the way. She also shares her experience of Black cultural norms around not disclosing a medical diagnosis and how this presented unique challenges, as well as the strength of their core family unit that allows for unique support

**Scan the QR code** to hear Julia talk about journaling as a self care tool and share the role that partnership has played in her relationship with Phil, particularly as she initiated her own journey towards a healthier life.



### Mid-Stage Parkinson's Caregiving



Dick shares how he has prioritized his spiritual and emotional wellness as he cares for his wife Chris through regular support sessions through both his church and a men's group. He expresses his fears about the future as the disease progresses and how he and Chris have prioritized having conversations about advanced directives. He shares his experience as a male care partner expressing emotions in a healthy and productive way.

**Scan the QR code** to hear Dick share his struggle with asking for help and how he has worked towards feeling more comfortable in both paying for help when they are able and asking for help from family and friends.



## **Advanced Parkinson's Caregiving**



Edna shares the impact of her husband Mark's PD on their daughters, who grew up with Parkinson's as an everyday part of their childhood, and her perceived mistakes along the way as a mother and wife. She walks us through a realization that based on cultural norms as a Filipino woman in her 30's at the time of his diagnosis, she did not feel that divorce was an option though now, at 60, she recognizes that she would not want her daughters to feel that same obligations.

**Scan the QR code** to hear Edna walk us through losing herself in the caregiving role, the moment she realized she needed help, and her "year of Edna" in her 20th year of caregiving which initiated a rare and revolutionary expression of self-care in advanced Parkinson's caregiving.

