## Organizing Community Resources for Patients with Neurodegenerative Diseases

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# Barriers for a growing disease population

- With the rising population age, neurodegenerative diseases, such as Alzheimer's disease (AD), Parkinson's Disease (PD), and amyotrophic lateral sclerosis (ALS), are expected to become increasingly more prevalent in the next few decades [1, 2].
- Patients and families dealing with these diseases must manage not only their health, but also added factors including transportation to medical appointments, increased care needed at home, and caregiver support/respite, all on top of the financial burden of these additional costs.
- While a variety of programs exist to lessen the onus put on patients and families, access to resources, particularly in rural areas of the United States, remains a crucial barrier.
- Coupling access issues with the significantly higher prevalence of certain neurodegenerative diseases in rural areas [3]. improving and expanding the connections of patients and families with local resources will be a vital step towards improving all-around care and well-being.

# Public Health Costs

- In the US in 2020, the annual cost of AD and related dementias, PD, ALS, and spinal muscular atrophy was $655 billion [4].
- Lifetime care costs for individuals with dementia have been estimated as $350,228 [5].
  - This is $200,811 more compared to individuals without dementia

# Community Voices

Regarding Long-Term Medicaid and Choices for Care: “People think they have to make like $0 to qualify…they don’t realize it can also help them get services in the home. They think they always have to pay out of pocket”

– *Sasha Emerson, Patient Care Coordinator*

Regarding the Dancing with Parkinson’s Class at Dartmouth Hitchcock Medical Center: “I wish we had heard about it earlier”

Discussing the process of switching to an assisted living facility: “Somewhere in the process there wasn’t enough information”

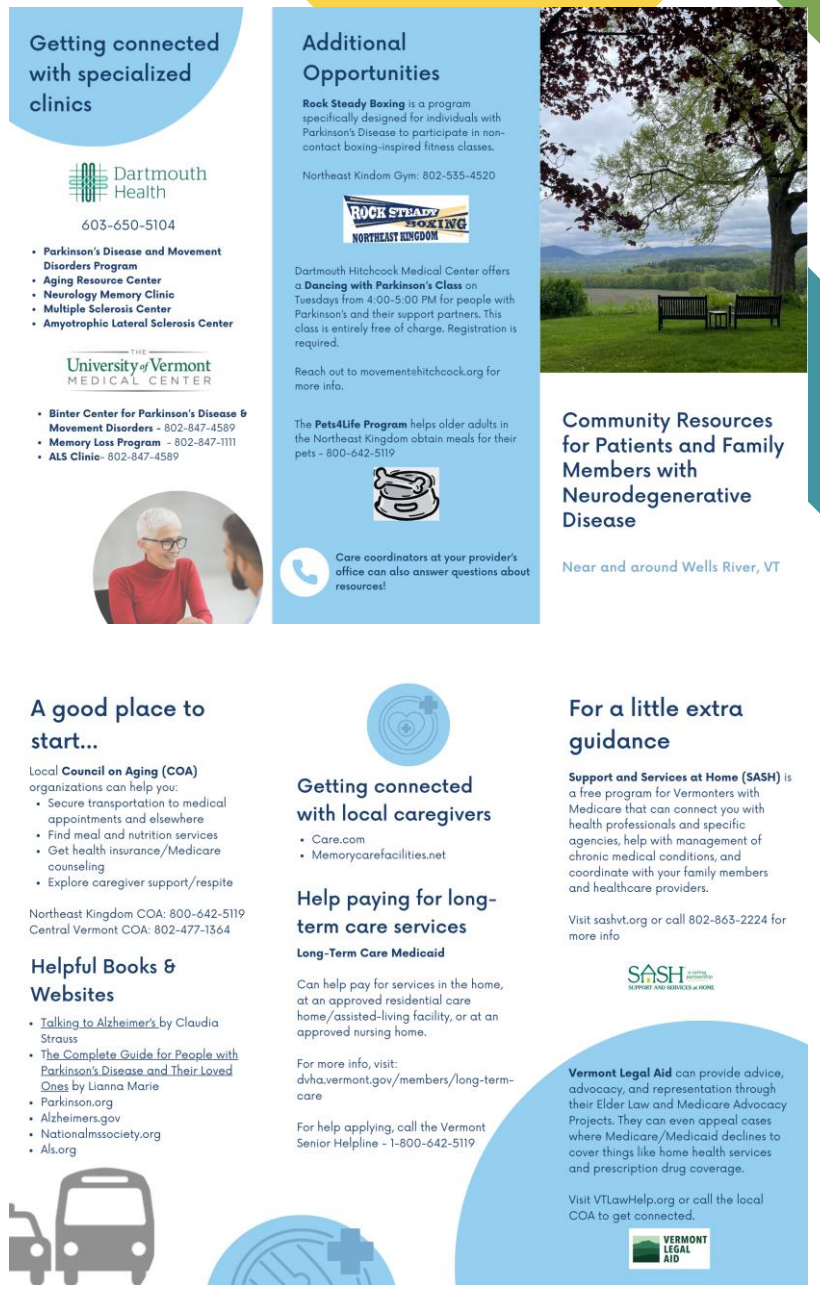
- *Partner of a patient with Parkinson’s Disease*

# Intervention & Methodology

- Information was gathered on available resources through conversations with providers, reviewing relevant websites, and interviews with a patient care coordinator and a patient support person.
- Resources were then synthesized into categories and presented in a hand-out fashion.
- Hand-outs will be available at the supervising clinic in Wells River and will additionally be distributed to the other Little Rivers sites.

# Results/Response Data

- Hand-outs were made available to providers working at the Little Rivers clinic in Wells River.
- Hand-outs were not yet given out to providers at other Little Rivers clinics. There are plans for this to be done in the upcoming weeks.
- Due to the limited timing of the rotation, handouts were not given out to any patients yet.



# Evaluation of effectiveness and Limitations of intervention

- This project served to gather information and create a physical handout for patients
- Direct evaluation of the effectiveness of this intervention could include interviewing providers and patients about utility and benefit to patients and friends/family members
- Limitations include small interview sample size and lack of resources for printing color copies of hand-outs

# Future Directions

- Getting more input from patients to learn about additional resources and determine which resources are most helpful
- Creating a hand-out directed more towards New Hampshire resources (many patients at this clinic reside in NH)
- Adding QR codes to the handout that directly link to helpful websites

# References


1. Dorsey ER, George BP, Leff B, Willis AW. The coming crisis. Neurology. 2013;80(21):1989-1996. doi:10.1212/WNL.0b013e318293e2ce

2. Hou Y, Xiuli D, Babbar M, et al. Ageing as a risk factor for neurodegenerative disease. Nature Reviews Neurology. 2019;15(10):565-581. doi:10.1038/s41582-019-0244-7

3. Wiese LAK, Gibson A, Guest MA, et al. Global rural health disparities in Alzheimer's disease and related dementias: State of the science. Alzheimer's & Dementia. 2023;19(9):4204-4225. doi:10.1002/alz.13104

4. Thorpe KE, Levey AI, Thomas J. U.S. Burden of Neurodegenerative Disease. Literature Review Summary. 2021.05. Emory University.

5. Jutkowitz E, Kane RL, Gaugler JE, MacLehose RF, Dowd B, Kuntz KM. Societal and Family Lifetime Cost of Dementia: Implications for Policy. Journal of the American Geriatrics Society. 2017;65(10):2169-2175. doi:10.1111/jgs.15043