



# Creating and Implementing and Empowerment Program for People with Parkinson's and their Care Partners



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## OVERVIEW OF CAPSTONE SITE

**Primary Site:** Elite Performance and Rehab is an outpatient rehabilitation clinic in Vicksburg, MS. This site treats a variety of neurological and orthopedic diagnoses including Parkinson's disease. The patient population includes people from adolescent age and beyond who are either Vicksburg residents or residents of more rural surrounding towns. Payer sources range from private insurance, Medicare, Medicaid, self-pay, or no insurance.

**Secondary Site:** The Rocksteady Boxing program is a non-contact boxing program that is held twice weekly at the Vicksburg YMCA for people with Parkinson's disease. It is an evidenced-based program that incorporates skills such as balance, strength, rhythm, and hand eye coordination. The class is led by a fitness instructor who is a certified Rocksteady Boxing coach.

## LITERATURE SUMMARY

There is increasing available literature regarding care givers, particularly those caring for people with Parkinson's disease (PD). According to one study, caregivers of people with PD spend an average of 110 hours per week providing caregiving services (Lageman, Mickens, & Cash, 2015). Additionally, in another study on burden of care among people providing caregiving for those with PD, it was found that most caregivers were providing care without any formal training related specifically to Parkinson's disease (Razali et al., 2011). A lack of formal training and education can lead to increased experiences of caregiver burnout and burden of care. One study found that increased caregiver burden and decreased quality of life were linked to the person with Parkinson's having difficulty with performance of activities of daily living, having depression, or having physical limitations (Lee, Kim, Kim, & Kim, 2019). Some of the greatest needs expressed by caregivers in the literature include education on symptom management and lifestyle changes. The greatest barrier to accessing knowledge on these topics was due to services not being offered in the local area (Lageman et al., 2015).

## NEEDS ASSESSMENT

### Phase 1 Needs Assessment

- Method: 12 question semi-structured interview with capstone mentor was designed to elicit a comprehensive understanding of populations served, services offered, and any gaps in services or programming.
- Outcome: A need for further educational resources at the site and within the local community was identified.

### Phase 2 Needs Assessment

- Method: Informal interviews were conducted with capstone mentor as well as observation of the current patient population at the capstone site. Research was also done on available resources in the community.
- Outcome: It was determined that there was a local group of people with Parkinson's that met at the YMCA and this was also a diagnosis commonly treated at the capstone site. Neither site currently possessed any educational materials for patients/members.

## PROJECT GOALS / OBJECTIVES

- Goal 1: The student will develop a comprehensive manual for people with Parkinson's disease and their care partners.
- Goal 2: The student will present contents of manual to a group of relevant stakeholders.
- Goal 3: The student will assess efficacy of educational manual and make adjustments as needed.

## PROJECT DEVELOPMENT and IMPLEMENTATION

The capstone project consisted of 2 elements:

- Creating a comprehensive educational manual for people with Parkinson's and their care partners for use at Elite Performance and Rehab and at the Rocksteady Boxing program
- Presenting contents of the educational manual to a group of people with Parkinson's and their care partners at the Rocksteady Boxing Program

The manual was completed based on themes found within the literature review and various forms of needs assessments. Once completed, the presentation took place in the form of three 45-minute interactive group sessions following the Rocksteady Boxing class at the Vicksburg YMCA. There were approximately 20-25 attendees at each session including people with Parkinson's, care partners, leaders and volunteers associated with the Rocksteady Boxing program, and the capstone mentor. Topics covered in each session were as follows:

### Session 1

- Overview of Parkinson's disease including motor and non-motor symptoms
- Adaptive equipment for bathing, dressing, toileting, feeding, and grooming

### Session 2

- Fall prevention strategies and risk factors
- Symptom management including evidence-based therapies and exercise

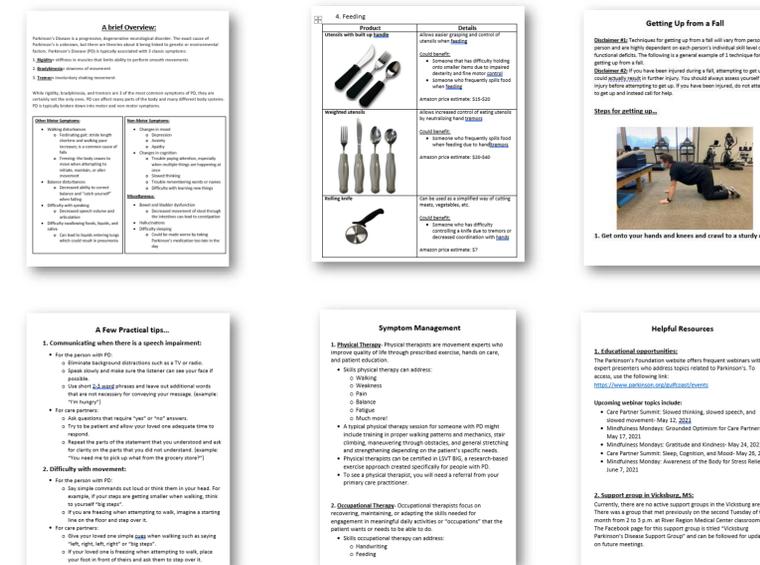
### Session 3

- Techniques for getting up from a fall
- Adaptive strategies for communication and movement dysfunction
- Local, state-level, and global resources

To ensure sustainability of program, three measures were taken:

- Each course attendee was given their own copy of manual in a 3-prong folder to reference in the future.
- A copy of the manual was left at the capstone site for use with future patients.
- A copy of the manual was left with leaders of the Rocksteady Boxing program and a local Parkinson's support group to distribute to future members. Of note, all leaders were present for the 3 informational sessions and would likely be able to lead future sessions covering the capstone manual themselves.

## EXAMPLE RESOURCE DOCUMENTS FROM MANUAL



## PLAN FOR PROJECT EVALUATION

In order for this project to be successful, the educational manual needed to (1) be effective in developing knowledge and skills for the person with Parkinson's and their care partners, as well as (2) demonstrate adequate usability for the therapist and Rocksteady Boxing leaders. This was assessed by:

- Administration of a student-developed survey to attendees at conclusion of the course containing Likert scale and open-ended questions
- Conducting informal interviews with the capstone mentor and leaders of the Rocksteady Boxing program to assess their perceptions of usability of manual

## PROJECT SUMMARY AND FUTURE RECOMMENDATIONS

- Per survey responses, the Empowerment Program for People with Parkinson's and their Care Partners had overall positive outcomes on perceptions of knowledge in people with Parkinson's disease and their care partners.
- An increased emphasis on patient and caregiver education is needed in healthcare and should always be a primary focus of occupational therapists regardless of practice setting.
- Allowing open dialogue throughout the 3 sessions allowed people with Parkinson's and their care partners to share additional resources and strategies that had been successful for them, and this contributed greatly to the overall success of the course.