



# Parkinson's Disease Training Across the Continuum of Care: A Collaborative Model



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## BACKGROUND

- There is no paradigm in the Parkinson's disease arena, as there is in Alzheimer's, for uniform standards of **Parkinson's disease-specific care across the healthcare continuum**. In order to pave the way for better and broader care delivery to people with PD and their families, professionals in community-based and residential care settings need **comprehensive PD training**, similar to the model developed by the Alzheimer's Association.
- CJE SeniorLife invited Northwestern University Parkinson's Disease and Movement Disorders Center to collaborate in the development of a PD comprehensive care system in four existing CJE levels of care.

## PROJECT GOAL

To train multidisciplinary professionals at CJE SeniorLife in order to create an infrastructure for, and standards of, clinical care for people with Parkinson's disease and movement disorders across the spectrum of CJE SeniorLife older adult services: Long-term Care, Assisted Living, Home Care and Adult Day Services.

## PROJECT PARTNERS

### CJE SeniorLife (CJE)

A comprehensive network that facilitates the independence of older adults and enhances their quality of life by advocating on their behalf and by offering programs and services throughout the continuum of care for individuals, families and the community.

### Northwestern University Parkinson's Disease and Movement Disorders Center – National Parkinson Foundation Center of Excellence (NUPDMDC/NPF)

A center that 1) provides innovative, multidisciplinary care for patients and families affected by Parkinson's disease and other movement disorders; 2) promotes health, education, and support for patients, caregivers, family members, healthcare providers, and the community; and 3) conducts pre-clinical and clinical research in order to extend the knowledge and treatment of movement disorders.

### National Parkinson Foundation

An organization that strives to improve the quality of Parkinson's care through research, education and outreach.

### Rehabilitation Institute of Chicago (RIC)

A rehabilitation hospital committed to providing the most comprehensive physical medicine and rehabilitation services to patients in a continuum of care: inpatient, outpatient and day rehabilitation, uniting excellent patient care, research, and education to promote lifelong health and independence for people with disabilities.

## PHASES AND OBJECTIVES OF OVERALL PROJECT

### Phase One: Months 1-18

**July 1, 2008 – December 31, 2009**

- NUPDMDC/NPF and RIC to develop 12 educational modules and web-based adaptations, including pre- and post-tests and References, for CJE staff training purposes
- CJE to conduct initial assessments of PD knowledge of staff, clients/patients, and families, and develop strategies to monitor QA data with regard to PD
- NU, RIC, and CJE to pilot the modules in focus groups at CJE
- NU and CJE to revise modules based on pilots

### Phase Two: Months 18-24

**January 1, 2010 – June 30, 2010**

- NU and RIC to audiotape the lectures
- CJE to design implementation strategy for system-wide web-based training
- NU to apply for CME accreditations for the course
- CJE to implement mandatory PD staff training throughout its continuum of older adult care
- CJE to develop clinical service protocols

### Phase Three: Months 25-36

**July 1, 2010 – June 30, 2011**

- CJE to monitor the effectiveness of training through evaluation of clinical services and by tracking changes in Quality Assurance indicators
- NU and RIC to assist CJE in developing innovative clinical services for movement disorders' clients at each level of CJE care

## PHASE ONE METHODS

- Collaborative meetings among CJE, NU, and RIC
- Module Development
- Piloting the modules receiving feedback on them
- Revising the modules
- Adapting the modules on the web

### **Quarterly Collaborative Meetings Among the Partners**

- To review progress and timeline
- To discuss issues regarding format and language of the modules, taking into consideration criteria that would accommodate on-line use by a mixed audience of adult learners, with the primary intention of practical application
- To determine the audience—by discipline—for each module

## Outline of Modules

- 1a. Parkinson's Disease and Movement Disorders: Introduction and Overview – for professionals
- 1b. Parkinson's Disease and Movement Disorders: Introduction and Overview – for non- professionals
2. A Comprehensive Team Approach to Movement Disorders
3. Medical Management of Motor Symptoms
4. Medical Management of Non-motor Symptoms
5. Physical Therapy and Exercise
6. Falls and Fall Prevention
7. Occupational Therapy and Practical Pointers
8. Nutrition and Parkinson's Disease
9. Speech and Swallowing in Parkinson's Disease
10. Cognitive and Psychiatric Manifestations of PD
11. Social Work Role; Impact of PD on Families; Stress Reduction
12. Parkinson's Disease Resources

## Piloting the Modules

- 12 40-minute live lectures piloted 7/09-10/09
- Target audience – Disciplines appropriate for each module: RN, SW, PT, OT, ST, dietary, creative art therapists, activities staff, and direct care providers (aides)
- Audience from a variety of settings
- Pre/post test with each module
- 15 30-minute audio-taped discussions about the module followed each presentation
- 4-18 attendees at each lecture, average of 8
- Post-lecture discussions focused on topics such as:
  - Is this module appropriate for your discipline?
  - Is the content understandable, too easy, too hard?
  - What do you feel could make this module better?
- Pre/post tests analyzed for question content and number of correct/incorrect responses

## Revising the Modules

- Each 15-30 minute taped discussion was transcribed and summarized
- Meeting of CJE and NU to discuss summaries and potential changes to modules
- Modules changed to incorporate staff feedback
- Most notable changes:
  - Removed introductory rehabilitation therapy module and placed pertinent information for OT and PT into existing modules
  - Added a comprehensive care module with introduction and responsibilities of all disciplines
  - Stressed adding anecdotal information to the commentary, as people wanted more practical information and examples
- Pre/post tests to be rewritten to incorporate comments, question analysis, and changes in module content

## ANALYSIS

- Quantitative evaluation by CJE of records of clients of CJE SeniorLife care facilities (home health, Adult Day Services, long term care, and Assisted living) to establish baseline quality assurance measures
- Qualitative evaluation by CJE, prior to staff education and initiation of care standards, via focus groups and interviews of staff, family members, and person's with PD to understand:
  - client/family expectations for care
  - client/family suggestions for care
  - staff 's current knowledge of PD
  - educational needs of staff

## WHERE ARE WE NOW?

- Project is on time – Set to begin Phase Two in January 2010
- Preliminary qualitative and quantitative data are being analyzed
- Module revisions have been completed
- Pre/post tests will be revised
- Presentation mode (web-based versus CD) to be finalized
- Presenters will audiotape lectures utilizing power point slides formatted for online and/or CD
- NU is procuring video clips to be added to completed modules

## NEXT STEPS: PHASES TWO AND THREE

- Beginning March 2010, all CJE SeniorLife staff will start training on the educational modules appropriate for their discipline
- Beginning March 2010 standards of care protocols will be available to all staff
- Evaluation of records will be compared to the quality assurance measures after initiation of staff training and standards of care
- Qualitative evaluation will be repeated after initiation of staff education and initiation of care standards

## Project Personnel

### **CJE SeniorLife:**

- Herbert Sier, MD – Vice President of Medical Affairs
- Ron Benner, RN – Director of Center for Health and Rehabilitation
- Carrie Robinson, RN MA – Project Coordinator
- Rebecca Berman, PhD – Director of Evaluation
- Madelyn Iris, PhD – Director of Research
- Linda Factor, MPH – Research Assistant

### **Northwestern Parkinson's Disease and Movement Disorders Center:**

- Tanya Simuni, MD – Medical Director of Northwestern PDMDC
- Diane Breslow, MSW, LCSW – Project Coordinator
- Kristin Larsen, MA, SLP – Speech Therapist
- Department of Continuing Medical Education (CME) at Northwestern University

### **Rehabilitation Institute of Chicago:**

- Santiago D. Toledo, MD – Psychiatrist/Medical Director of PDMD Rehabilitation Program
- Miriam Rafferty, PT – Physical Therapist
- Uzma Khan, OT – Occupational Therapist