

NURSE COURSE

Module 1: Overview of Parkinson's Disease (PD): 1hr. 15 mins

Section 1: What is PD and How is it Diagnosed?

Section 2: Treatment Strategies in PD

Module 2: The Unique Role of Nurses: 1hr. 50 mins

Section 1: Unique Role of Nurses

Section 2: Nursing Care Across Settings

Section 3: Interprofessional Care Coordination

Module 3: Motor Symptoms & Care Implications: 1 hr. 15 mins

Section 1: Motor Symptoms and Care Implications

of Impaired Mobility

Section 2: Swallowing Dysfunction and

Weight Loss in Parkinson's Disease

Module 4: Most Non-Motor Symptoms & Care Implications: 1 hr. 35 mins

Section 1: Non-Motor/Psychiatric Features of Parkinson's Disease

Section 2: Autonomic Changes, Fatigue and Pain Challenges

Module 5: Palliative Care and Principles: Advanced Planning: 1 hr. 10 mins

Section 1: Support for Family CareGivers

Section 2: Palliative Care and Late Stages of PD

Module 6: Additional Independent Topics

Hospitalization and Parkinson's Disease: Patient and Family: 50 mins

Deep Brain Stimulation (DBS): 40 mins

Duopa®: 20 mins

Time

30 mins

Introduction: Why is Nursing a Critical Component of Care? Time

5 mins **Ruth Hagestuen, MA, RN**

MODULE 1: OVERVIEW OF PARKINSON'S DISEASE

Section 1: What is PD and How is it Diagnosed?

Presenter: Cathi A. Thomas, MS, RN CNRN Time Program Director and Assistant Clinical Professor 45 mins

Boston University Medical Center

Parkinson Disease and Movement Disorders Center

Section 2: Treatment Strategies in Parkinson's Disease

Presenter: Raymond James, BS, RN

Clinical Research Nurse

Boston University Medical Center

Parkinson Disease and Movement Disorders Center

MODULE 2: THE UNIQUE ROLE OF NURSES

Section 1: Unique Role of Nurses

Presenter: Lisa Mann RN. BSN. MA

Time Education Director, Team Care Coordinator 30 mins

Oregon Health & Sciences University

OHSU Parkinson Center

Parkinson's Foundation Center of Excellence

Section 2: Nursing Care Across Settings

Presenter: Joan Gardner, RN, BSN Time

40 mins Clinical Supervisor Park Nicollet Struthers Parkinson's Center

Parkinson's Foundation Center of Excellence

Section 3: Interprofessional Care Coordination

Presenter: Lisa Mann RN, BSN, MA

Education Director, Team Care Coordinator Time

40 mins Oregon Health & Sciences University

OHSU Parkinson Center

Parkinson's Foundation Center of Excellence

45 mins

25 mins

Time

MODULE 3: MOTOR SYMPTOMS & CARE IMPLICATIONS

Section 1:

Time Motor Symptoms and Care Implications of Impaired Mobility

Presenter: Edie Simpson, RN, CNRN

Parkinson and Movement Disorder Alliance Board Member

Education Advisor

Section 2:

Swallowing Dysfunction and Weight Loss in Parkinson's Disease

Presenter: Gwyn Vernon, MSN, RN, CRNP

Time National Director

Edmond J. Safra Visiting Nurse Faculty Program at Parkinson's Foundation

Nurse Practitioner

University of PA Parkinson's Disease and Movement Disorders Center

Parkinson's Foundation Center of Excellence

MODULE 4: MOST NON-MOTOR SYMPTOMS & CARE IMPLICATIONS

Section 1: Non-Motor/Psychiatric Features of Parkinson's Disease

Time Presenter: **Arita McCoy**, **MSN**, **CRNP**

35 mins Johns Hopkins Parkinson's Disease and Movement Disorder Center

Parkinson's Foundation Center of Excellence

Section 2: Autonomic Changes, Fatigue and Pain Challenges

Presenter: Joan Gardner, RN, BSN

55 mins Clinical Supervisor

Park Nicollet Struthers Parkinson's Center Parkinson's Foundation Center of Excellence

40 mins

MODULE 5: PALLIATIVE CARE AND PRINCIPLES: ADVANCED PLANNING

Section 1: Support for Family CareGivers

Presenter: Julie Carter, RN, MN, ANP

Time Professor of Neurology

30 mins Oregon Health & Sciences University

OHSU Parkinson Center

Parkinson's Foundation Center of Excellence

Section 2: Palliative Care and Late Stages of PD

Presenter: Julie Carter, RN, MN, ANP

Time Professor of Neurology

35 mins Oregon Health & Sciences University

OHSU Parkinson Center

Parkinson's Foundation Center of Excellence

MODULE 6: CAN BE VIEW INDEPENDENT OF FULL COURSE

Hospitalization and Parkinson's Disease: Patient and Family

Time Presenter: Susan Heath, MSN, RN, CNRN

50 mins Movement Disorders Nurse Clinician

San Francisco VA PADRECC

Deep Brain Stimulation (DBS)

Time Presenter: Susan Heath, MSN, RN, CNRN

40 mins Movement Disorders Nurse Clinician

San Francisco VA PADRECC

Duopa®

Time Presenter: Susan Heath, MSN, RN, CNRN

Movement Disorders Nurse Clinician

San Francisco VA PADRECC



The following nurse professionals, each leaders in the industry, form our nurse faculty and planning committee for this course. It is with great appreciation and gratitude that the Parkinson's Foundation thanks all who have contributed to creating this course.

* Planning Committee



JULIE CARTER, RN, MN, ANP*

Ms. Carter is a nurse practitioner and Professor of Neurology at Oregon Health and Science University. She received her BSN and MS from OHSU. She joined the department of neurology in 1979 and was one of the original founders of the Parkinson Center of Oregon (PCO). Ms. Carter has dedicated her career to improving the lives of people with Parkinson's disease and their families. She approaches Parkinson's disease as a family centered disease and brings a family centered emphasis to her practice as a nurse practitioner and to innovative program development at the PCO. She has been instrumental in the creation of the annual patient and family symposium, family caregiver series, young person with PD symposium, newly diagnosed program, the Strive to Thrive (self-management) program for PD, and most recently the PD palliative care program. Throughout her career she has valued the importance of a team-based approach in the care of people with Parkinson's disease and their families. Since 2002 she has been part of the Allied Team Training Program (ATTP®) faculty which provides national training to health care professional teams on best practices. She has also been instrumental in developing a similar program (TEAM-PD), a training program for health care teams in rural Oregon to improve Parkinson care.

Ms. Carter has a special research interest in family caregiving and Parkinson's disease. She has been an investigator in multiple clinical trials and is an original member of the Parkinson Study Group. She has authored numerous articles and is a popular speaker nationally and internationally. In 2016 Ms. Carter received the distinguished contribution to the PD community award given by the World Parkinson Coalition (WPC).



Joan Gardner, RN, BSN *

Joan Gardner is the clinic supervisor at the Struthers Parkinson's Center (SPC) in Minneapolis, nationally recognized for its comprehensive interdisciplinary approach to management of Parkinson's and related movement disorders, and is the coordinator of the Parkinson's Foundation (PF) Center of Excellence at this location. Working with the Parkinson's community for over 25 years, Joan is committed to increasing awareness of Parkinson's, improving care for individuals with Parkinson's, and supporting carepartners. She has co-authored numerous publications and resources including the PF website CareMAP, and the companion Caring and Coping workbook. Identifying the need for improved health professional education regarding the unique care needs for people with Parkinson's, she co-developed the educational and outcomes-based Struthers Parkinson's Care Network, comprised of senior residential communities and home care agencies in multiple states who have made a commitment to improve care and provide support to people living with Parkinson's and their families.

Joan has served as nursing faculty for the signature program of PF, Allied Team Training for Parkinson's (ATTP®) from 2009-2018. She has also worked with the inpatient and Emergency Center teams at Methodist Hospital, affiliated with Struthers, to improve on-time administration of Parkinson's medications. Prior to working with the Parkinson's community, Joan was a home health care nurse for 16 years for agencies in Massachusetts, Wisconsin and Minnesota. Joan received her Bachelors of Science in Nursing at the University of Wisconsin-Madison.



Ruth Hagestuen, MA, RN*

Ruth is currently consulting with the Parkinson Foundation as Co-Director of Allied Team Training for Parkinson (ATTP®) and related initiatives. She is also working with the Struthers Parkinson's Center in development of the Struthers Parkinson's Care Network. Her work with Parkinson's disease began in 1987 when she joined the Methodist Hospital Parkinson's Center as nurse coordinator of their interdisciplinary clinic and regional information and referral center. She eventually assumed the role of program director as the Center evolved and was renamed the Struthers Parkinson's Center.

In 2000, she joined the NPF staff as National Program Director and remained with the Foundation as Vice President and Director of Programs until 2009. In this position she worked with affiliates nationally and internationally developing strategies to better meet needs of the Parkinson's community through research, education, care, and outreach.

She served as Director of the NYU Parkinson's and Movement Disorders Center from 2009-2011, working regionally with their interdisciplinary team and collaborative partners to build informed and accessible care and programs that are accessible throughout the course of the disease.

Ruth's passion continues to be development of comprehensive care and support services designed for people with Parkinson's and their families. In addition to her work with NPF and the Struthers Parkinson's Center, she is active in the International Parkinson's and Movement Disorders Society (MDS) and currently serves on the Pan-American Section Education Committee of the MDS.



Susan Heath, MSN, RN, CNRN

Susan Heath has been an Advanced Practice Nurse and DBS nurse coordinator for the Parkinson's Disease Research Education and Clinical Center (PADRECC) at the San Francisco VA since its inception in 2002.

As a founding member of the PADRECC she collaborates with a multidisciplinary team including Movement Disorders Neurologists and Neurosurgeons. The practice specializes in deep brain stimulator (DBS) implants and care of the patient and their families with advanced Parkinson's disease. Susan is considered an expert in the care of the Parkinson's disease patient and DBS management. She teaches nationally on care for the person with Parkinson's disease, DBS programming and the role of the nurse. She actively manages all hospitalized DBS patients and is familiar with the challenges faced by staff and patients admitted for inpatient care.

Susan earned her undergraduate BSN from California State University, East Bay and her Master of Science in Nursing from the University of California, San Francisco, Department of Physiological Nursing, specializing in Neuroscience Nursing.



Raymond James, BS, RN

Ray is the Senior Research Coordinator and nurse clinician in the Parkinson Disease and Movement Disorder Center at Boston University Medical Campus which provides clinical care to over 1500 individuals with PD.

Ray has participated in over 50 research studies. Study aims have included evaluating the impact of pharmacological and surgical interventions in Parkinson's and Huntington's disease. Ray is the lead coordinator of the 10-year biomarker study PPMI and has developed an expertise in managing a large cohort of individuals with Parkinson's and healthy controls as well as an extensive biomarker registry.

Ray is an active member of the Parkinson Study Group and the Huntington's Study Group. He is an experienced psychiatric nurse and has an expertise in managing the non-motor symptoms experienced by movement disorder patients. He has lectured widely to healthcare professionals on the role of research in a movement disorder program. He currently facilitates the largest Parkinson Disease Support Group North of Boston.



Lisa Mann RN, BSN, MA*

Lisa Mann is the Education Director and Team Care Coordinator for the OHSU Parkinson Center. Lisa earned her nursing degree from Johns Hopkins University School of Nursing in 2003. Prior to this she worked in business administration and also taught history at the college level.

Her position includes coordinating the operations of the movement disorders clinic, providing integrated support to patients and families, facilitating interdisciplinary care in the clinic and implementing community education and outreach programs for patients, families and health care professionals.

Lisa brings many skills to the Parkinson Center of Oregon through her extensive and diverse background in education, business, and nursing.



Arita McCoy, MSN, CRNP

Arita McCoy is a nurse practitioner at the Johns Hopkins Parkinson's Disease and Movement Disorder Center. She has worked at Hopkins for over a decade in multiple roles, including community outreach, clinical research and in the regular nursing care of patients with movement disorders and their families.

Her experience has helped her to gain vast knowledge in many areas of Parkinson's disease, from initial diagnosis to more complex, advanced stages. She has special clinical interest in advanced treatment options for those with PD and other movement disorders.



Edie Simpson, RN, CNRN

Edie graduated from Mary Washington College many years ago with a degree in biology. Edie worked as a Research Assistant in the Neuromuscular physiology lab at the University of Virginia after graduation. After 4 years of rats and rabbits, and exploring other opportunities, Edie decided to attend nursing school. After graduation from the University of Virginia School of Nursing, she worked in surgical ICU, then served as the Head Nurse at UVA's regional Burn Center. Moving to San Francisco in the early '80's put her right in the middle of the AIDS epidemic. Returning to her research roots, Edie worked in a variety of disciplines related to AIDS until a move to Phoenix. Family took over then, and she was fortunate enough to be able to stay home with her 2 sons. When they were in their teens, Edie returned to work in clinical research, again in HIV/AID, then eventually found movement disorders. She was a research nurse for the Muhammad Ali Movement Disorder Center from 2009 through 2017. Over the last few years there, her role has been expanded to include clinical support and education. Recently retired, Edie continues to participate in educational activities in the PD community.



Cathi A. Thomas, MS, RN CNRN*

Cathi is an Assistant Clinical Professor of Neurology, the Program Director of the Parkinson's Disease and Movement Disorder Center at Boston University Medical Campus (BUMC) which provides clinical care to over 1500 individuals with PD. She directs services of the American Parkinson Disease Association Information and Referral Center at BUMC. Ms. Thomas has worked extensively with individuals with Parkinson's disease and their families for over thirty years. As a Clinical Nurse Specialist in neurorehabilitation, she has developed programs to assess the impact of Parkinson's disease on a patient and family and provide education to assist in coping with this condition.

She has participated in over fifty research studies. Study aims have included evaluating the impact of rehabilitation, pharmacological, and surgical interventions in patients affected by PD. She was a co-investigator in a NIH-NIA study "Self-Management in Parkinson's Disease" She is currently a co-investigator in a NIH-NIA study Social Self-Management in Parkinson's Disease. She is a member of the Parkinson Study Group. Ms. Thomas has provided over two hundred presentations to professional and lay groups. She has published educational materials and co-authored Parkinson's Disease A Guide to Patient Care.

Ms. Thomas has been a leader in training health care professionals in the care of the person and family living with Parkinson's serving as co-director the BU PD Healthcare Professional Training Seminar, and the BUMC site director of the Safra Foundation Visiting Nurse Faculty Program at the Parkinson Foundation.



Gwyn Vernon, MSN, RN, CRNP*

Gwyn was co-founder of the Parkinson's Disease and Movement Disorder Center at the University of PA in 1982. Over the past 35 years, Gwyn has devoted her career to working with the PD community in multiple ways. In the 1980s, Gwyn helped patients and families establish over 25 support groups and an exercise group in the Philadelphia area. She established one of the first multidisciplinary comprehensive assessments and education programs (COPE) in the country. She has led centers funded by the American Parkinson's Disease Association and the Parkinson's Foundation. Gwyn has coordinated or been co-investigator of 17 phase II, III and IV research trials spanning medications, pharmacokinetics, imaging, epidemiology and neuroprotection.

She is the author of 60 peer reviewed articles, chapters, and CME Webinars and coauthor of the nursing text "Comprehensive Nursing Care for Parkinson's Disease". Gwyn continues to maintain a clinical practice at the University of PA and serves on the leadership committee for Health Professionals of the Movement Disorder Society. Since 2007, Gwyn has been working to enhance PD nursing education and is the co-founder and National Director of the Edmond J. Safra Visiting Nurse Faculty Program at the Parkinson's Foundation. This program for nursing professors attracts those from the USA and other countries and teaches nurse faculty about PD so in turn they can educate student nurses in curriculums where the information was scant or lacking. Over 20,000 student nurses a year learn about PD care through this program and graduate better prepared to care for patients with PD and their families.

In 2016, Gwyn received the Dr. Rana International Parkinson's Community Service Award.