

# Multiple Sclerosis Nurse Leadership Program



2021

## THE EVOLVING ROLE OF THE MS NURSE: *MULTIPLE SCLEROSIS IN THE 21<sup>ST</sup> CENTURY*

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# Florence Nightingale as Our Example

- “Lady of the Lamp”
- Best known for:
  - Work during the Crimean War
  - Passion for patient rights
  - Research in hospitals
  - Philosophy of nursing



# Florence Nightingale's Contributions to Nursing

- Provided direct care to patients and families
- Advocated on behalf of her patients
  - Improved sanitation
- Improved the nursing profession
  - Introduced nurses into military hospitals
  - Established the Nightingale School for Nurses in London
- Conducted extensive research and developed statistical reporting methods
- Published over 200 books including *Notes on Hospitals* and *Notes on Nursing*



# 2020

## INTERNATIONAL YEAR OF THE NURSE AND THE MIDWIFE

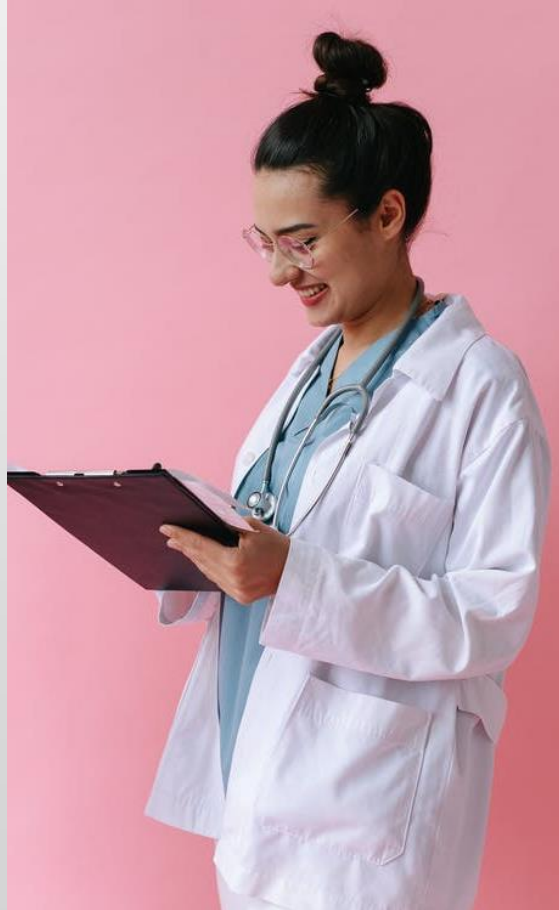
**2020 was the first time in history** the nations of the world united in celebration of the **benefits that nurses and midwifery bring** to the health of the global populations.

- Coincided with the **200th anniversary** of the birth of **Florence Nightingale**, one of the founders of modern nursing
- Nurses and midwives make **up more than half the healthcare workforce** worldwide
- During this global pandemic, **celebrating and honoring** our nurses is even more important
- Time to focus on nursing in the modern context of healthcare
- ***2021: the International Year continues***





# The Evolving Role of the MS Nursing Professional



# What Is an MS Nurse (IOMSN)

An MS nurse is a competent expert who collaborates with those affected by MS and shares knowledge, strength, and hope. MS nurses can enhance adaptive and coping skills, facilitate empowerment and a sense of control, and thereby engender hope and positive attitudes among those affected by MS.

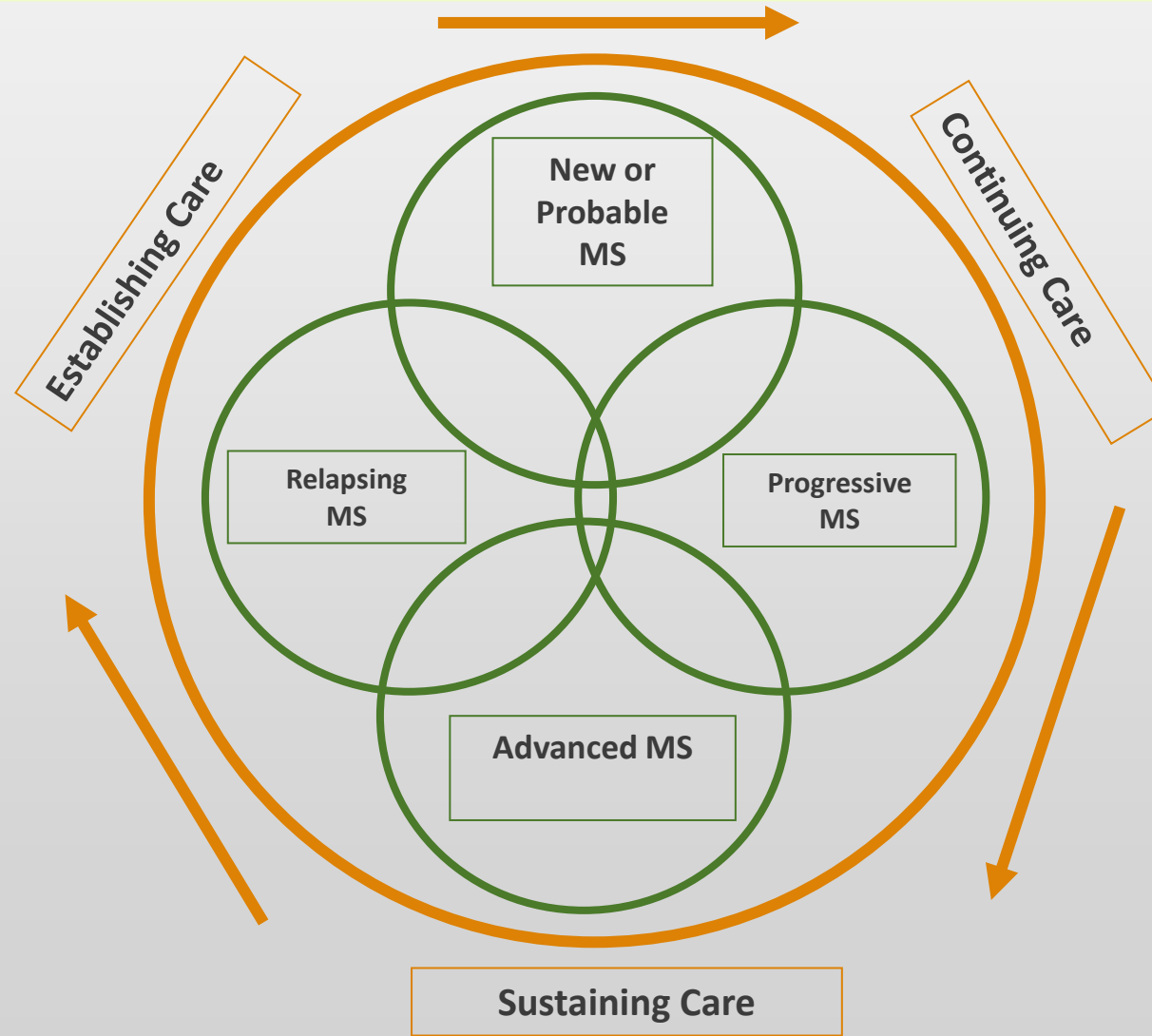
[www.IOMSN.org](http://www.IOMSN.org)

# Philosophy of MS Nursing

- The philosophy of MS nursing is for the MS nurse is to:
  - Shape the course of the disease by facilitating treatment that interrupts acute episodes
  - Delay progression of pathology
  - Facilitate the management of MS symptoms

MS nurses enhance and promote safe, maximal, and where possible, independent function.

# Model of Nursing Care in MS





# Establishing Care

- Relationship building
- Open communication
- Building trust
- Sharing information
- Assessment

# Continuing Care

- Encourage self-care strategies
- Assist with vocational issues
- Preserve independence/interdependence
- Patient and family education
  - DMTs
  - Sustain adherence
  - Symptom management
  - Side effect management

# Sustaining Care

- Maintain patient well-being
- Coordinate referrals
- Identify community resources
- Advocate for and help to ensure comprehensive MS care
- Sustain ongoing relationships and trust
- Inspire HOPE

# Key MS Nursing Domains

- The nurse-patient partnership
- Comprehensive care throughout the health-illness continuum
- Professional persona
- Scholarly inquiry

# Key MS Nursing Activities

- **Identifying** patient care needs along a continuum of health as part of holistic care
- **Recognizing** (not necessarily treating) the patient's symptoms and non-MS-related conditions
- **Referring** to appropriate providers
- **Assessing** outcomes during subsequent visits
- **Educating** patients and healthcare providers about health and wellness within the context of MS

# The Nurse as an Advocate

- To advocate is to speak or act on behalf of another
- Education is an important part of advocacy
- It is important to inform patients and families
- Patients need to know why they are taking special medications or undertaking special treatments, as well as how to take medication
  - They need to know whom to call when they need help



# Creating an Expert MS Patient

**ADHERENCE**

# Adherence Defined

- An active, voluntary, and collaborative participation of the patient in a mutually agreeable course of behavior or treatment that results in a desired preventative or therapeutic outcome
- Adherence means staying on treatment whether it be medications, rehabilitation, symptomatic care, or seeking wellness

# Pillars of Adherence

## Adherence

Empowerment

Knowledge  
Skills  
Resources  
Shared Decision-  
Making

Hope

# Hope



- Hope is a significant factor in coping, especially spiritual hope
- Allport (1951) theorized that a person needs unifying religious belief or a philosophy to effectively cope
- Those with spiritual hope have been found to be better able to set goals and have stronger relationships and supports
- Linda Morgante, one of the IOMSN founders, used the mantra of HOPE with her patients and families

# Hope + Empowerment = Adherence

- Empowerment and hope are related concepts and can lead to adherence to therapy
- Empowerment gives people the recognition of strengths and resources
- Empowerment involves knowledge, skills development, coping, mastery over the environment, and flexibility
- These are the tools we give to our patients and families

# What Is Our Professional Role in MS?

- Become an expert in understanding and treating MS
- Educate patients, families, and the community
- Understand which services and programs are available to patients
- Network with MS nurses and other professionals
- Take care of yourself, learn, listen, grow personally, and professionally
- Seek MSCN certification



# The Evolving Role of the MS Nurse

- Our knowledge of the disease has expanded to include:
  - Basic immunopathology, MRI techniques, diagnostic criteria
  - Mechanism of action of DMTs, as well as symptomatic treatments and rehabilitation strategies
- We must attend to our own education about MS, as we are constantly called upon to provide education and counseling

# The Evolving Role of the MS Nurse (cont)

- As new treatments emerge, the role of the nurse as a clinician, educator, advocate, and counselor will continue to grow more complex. The risks of treatments are likely to be higher, as will the expectations of greater efficacy
- Through these changes, we will sustain our goal of improving the lives of those affected by MS
- MS NURSES CAN DO IT!

Only **nursing organization representing MS nursing** professionals who practice in North America and globally, with **over 1500 members worldwide** across 19 countries.

IOMSN addresses the following domains of MS nursing:



### **Clinical Care**

- Mentorship opportunities
- Case-based learning and annual congress
- Publications: [www.iomsn.org](http://www.iomsn.org)



### **Education**

- Regional programs
- Annual programs
- DVDs
- Webinars



### **Research for nurses and clinical practice**

- Outcomes research
- Protocol development
- Benefits of certification
- Formal and informal nursing surveys



### **Advocacy**

- Networking
- Advocating for new and emerging therapies
- Collaboration with MS Coalition
- Establishing and validating the role of nurses

# IOMSN 2020 and 2021 Nightingale Initiatives

- 2020: 10 US nurses received grants to fund unique programs for nurses, patients, or the community
- 2020: 10 nurses who practice globally also received funding for similar activities
- 2021: IOMSN presented an 8-week program titled the *MS Nurse Immersion Institute*; intensive interaction and learning about MS (March through early May; to be followed in August through September)
- 2021: 10 US nurses will receive Nightingale Awards for their work

# In Summary...

- MS nurses must “leap tall buildings in a single bound” and incorporate the qualities of:
  - Teacher
  - Leader
  - Advocate
  - Caregiver
  - Social worker
  - Florence Nightingale
  - Cheerleader