

The Evolving Role of the MS Nurse: Meeting the Challenges and Advancing the Profession

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Multiple Sclerosis

- Unpredictable disease of the central nervous system with complex immunopathology
- Impacts all aspects of individual and family life
- Many advances in understanding of the disease but many challenges remain

Multiple Sclerosis Nursing

- What is the theoretical underpinning of our profession?
- What is the role of the nurse in MS care?
- How has the evolution of knowledge about MS impacted the evolution of the MS nurse?
- What must we do as individuals and as a profession to meet the many challenges of MS?

Florence Nightingale

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



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”, “Notes on Nursing”

Other Theorists

- Orem Self Care Deficit Model
 - Assumes all individuals want to be independent
 - Nurses role to assess impairment to self-care and provide interventions to restore highest level of independence
 - The Universal self care requisites that all or health are:
 - Air
 - Water
 - Food
 - Elimination
 - Activity and Rest
 - Solitude and Social Interaction
 - Hazard Prevention
 - Promotion of Normality
 - The nurse is encouraged to assign a support modality to each of the self care requisites.

MS Nursing

- Has evolved from committed passionate individuals into
- Individuals becoming organized groups committed to the advancement of the profession and the care of those with multiple sclerosis

Organization of MS Nurses

- 1997 Calgary Alberta Canada
 - Establishment of the International Organization of Multiple Sclerosis Nurses
- 2001 – 2003
 - Establishment of Affiliate MS Nursing Organizations
 - UK MS Trust
 - UK MS Nurses
 - Italian MS Nurses
 - Australian MS Nurses
 - Finnish MS Nurses
 - Swedish MS Nurses
- 2002
 - Certification Exam for MS Nurses

Philosophy of MS Nursing

- The philosophy of MS nursing is for the MS nurse to shape the course of the disease by facilitating treatment that interrupts acute episodes and delays progression of pathology and to facilitate the management of MS symptoms. MS nurses enhance and promote safe, maximal and where possible, independent function.

What is an MS Nurse (IOMSN)

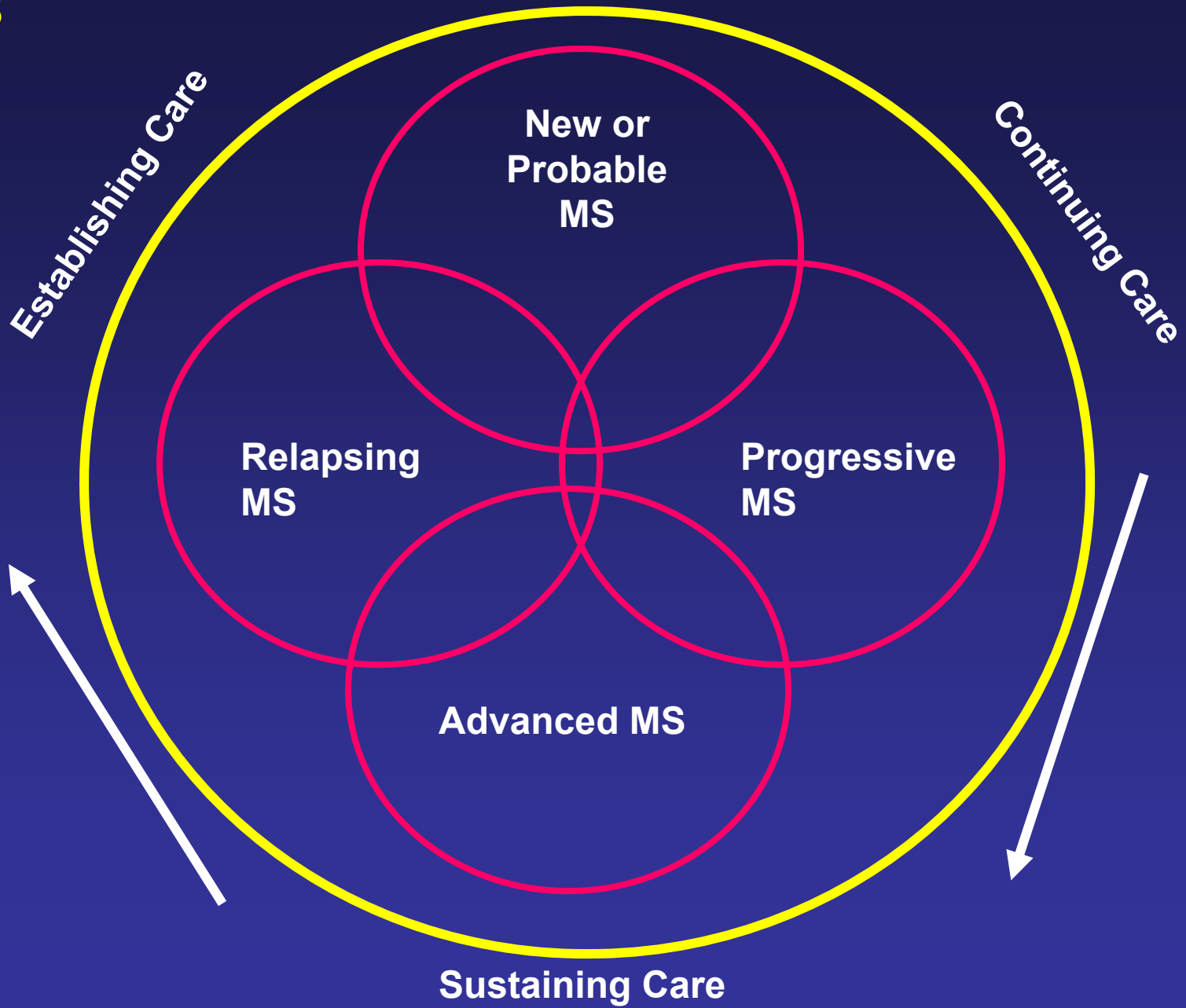
- An MS nurse is a competent expert who collaborates with those affected by MS and shares knowledge, strength, and hope. MS nurses can enhance adaptive and coping skills, facilitate empowerment and a sense of control, and thereby engender hope and positive attitudes among those affected by MS.

www.IOMSN.org

What does the MS Nurse Do? (UK MS Trust)

- "Empower those affected by MS by providing information, support and advice about the condition from time of diagnosis and throughout the disease spectrum. The MS specialist nurse is pivotal in providing a greater understanding of the condition, and by adopting an holistic, collaborative and co-ordinated approach can help those individuals, where possible, reach their goals of self management. The role also involves acting as a consultant and educational resource for staff striving towards greater awareness and knowledge of MS in the health and social arena."

Model of Nursing Care In MS



Establishing Care

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

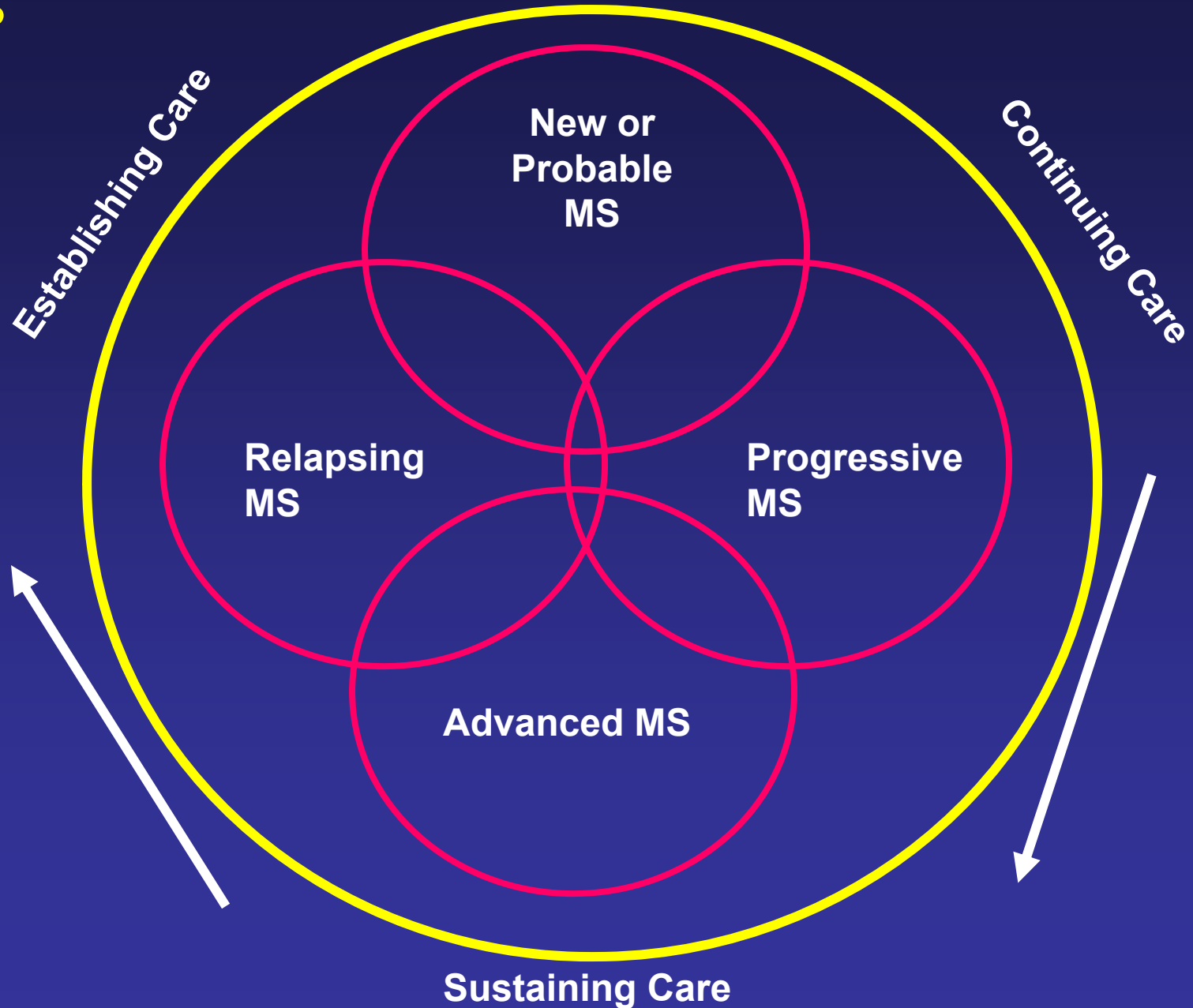
Continuing Care

- Patient and family education
 - DMTs
 - Symptom management
 - Side effect management
- Encourage self care strategies
- Assist with vocational issues

Sustaining Care

- Maintaining patient well being
- Coordinate referrals
- Identify community resources
- Advocate for and help insure comprehensive MS care

Model of Nursing Care In MS



Domains of MS Nursing Practice

- I. Clinical Practice
- II. Advocacy
- III. Education
- IV. Research



How has the knowledge and skills of each Domain evolved as our knowledge of MS has evolved?

I. Clinical Practice

- Pathophysiology of the disease
 - Immune dysfunction
 - Nerve conduction
 - Definition, course and classification
 - Epidemiology and distribution
 - Symptomatology

Pathophysiology

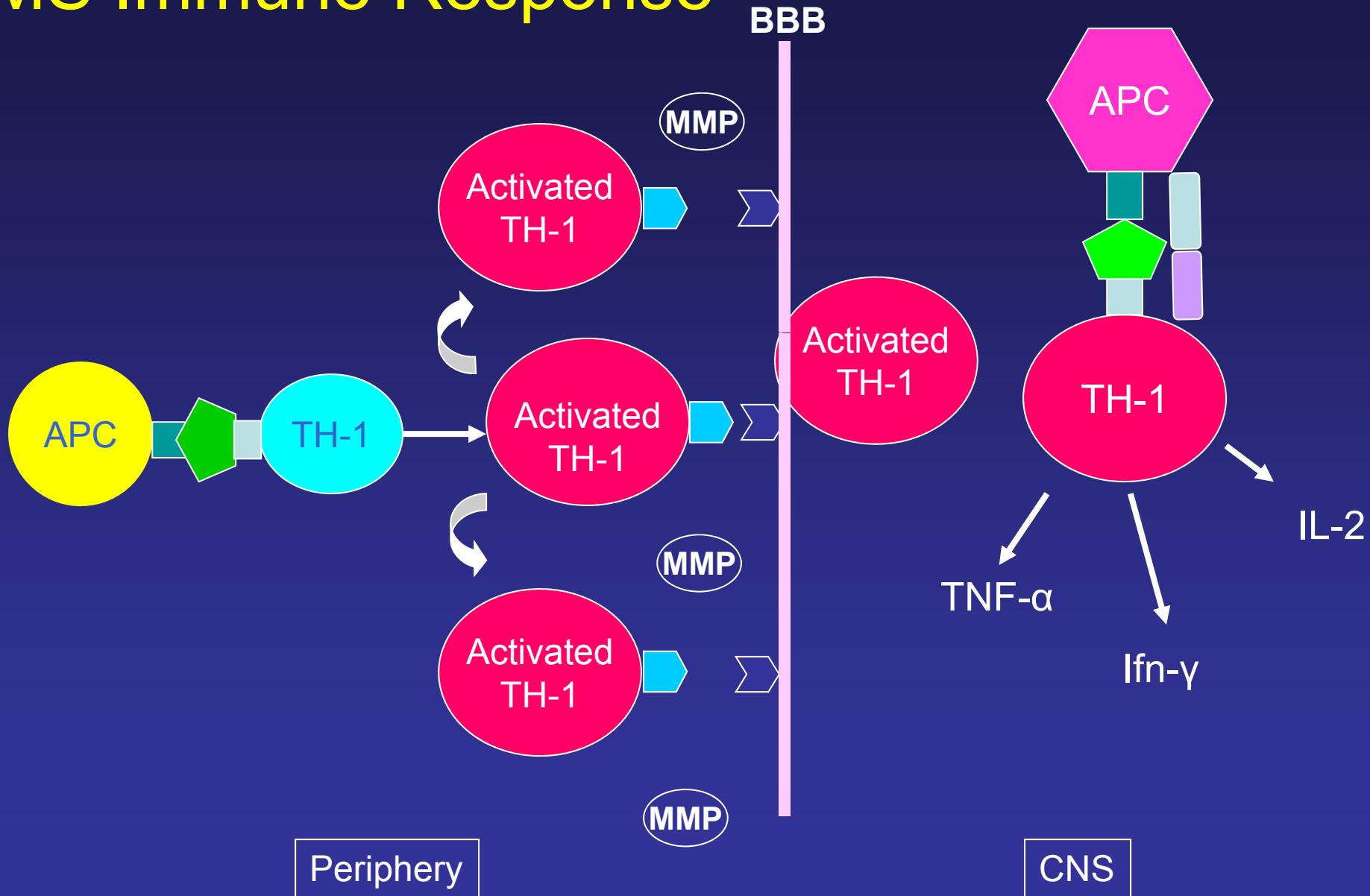
Early Knowledge and Skills

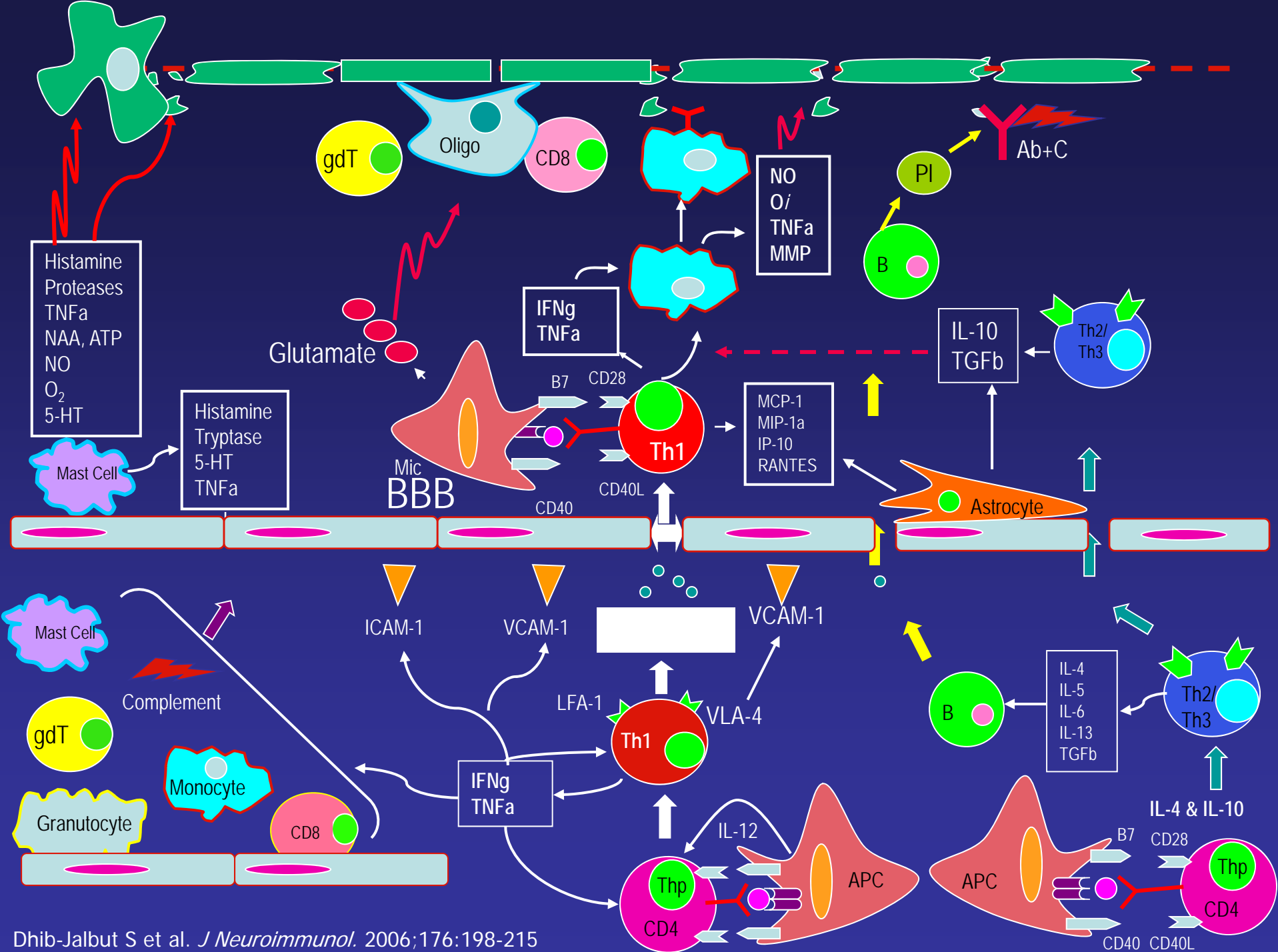
- Disease knowledge
 - Demyelinating disease of CNS with relative sparing of axons
- Diagnosis
 - 2 attacks separated in space and time
 - Often taking years

Current Knowledge and Skills

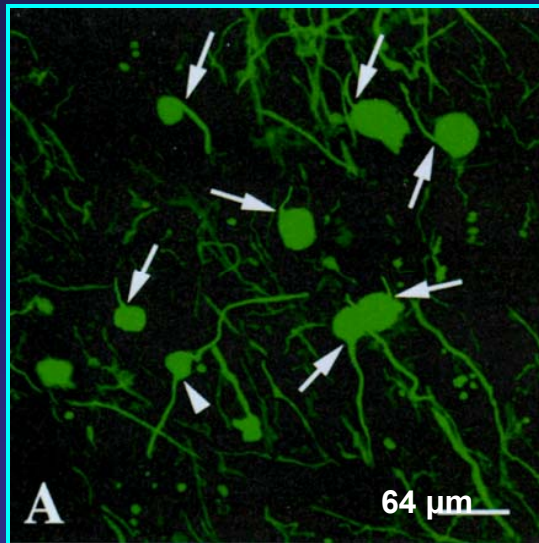
- Disease Knowledge
 - Complex disease of immune dysregulation marked by inflammatory and degenerative changes that affect the myelin and axons in the white AND gray matter usually associated with significant atrophy over time.
- Diagnosis - McDonald Criteria
 - Criteria utilize MRI, CSF or evoked potential testing when only one lesion found and/or only one attack or when onset is insidious neurological progression

MS Immune Response

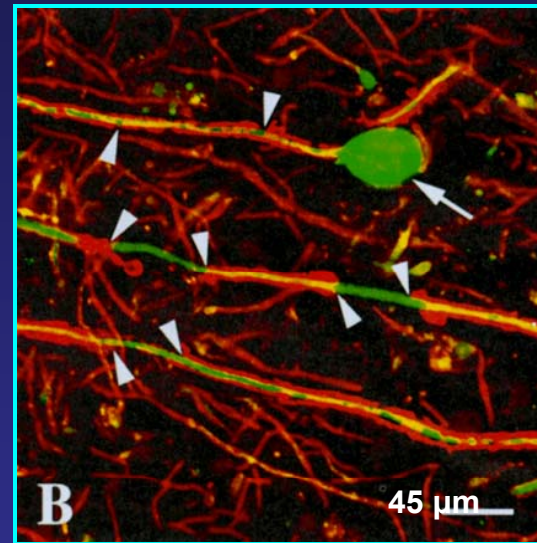




Axonal Damage in MS



Transection of axons (arrows)



Demyelination (arrowheads)

Trapp, et al. *N Engl J Med.* 1998;338:278-285.

- 50-80% axonal loss in chronic lesions (Lovas et al 2000)
- Immune-mediated inflammation is continuous, even during periods of apparent remission

Therapeutic Interventions

- Relapse management
- Disease modifying agents
- Symptoms and symptom management
- Psychosocial issues

Treatments: Relapses/DMT's/Symptoms

Early Knowledge and Skills

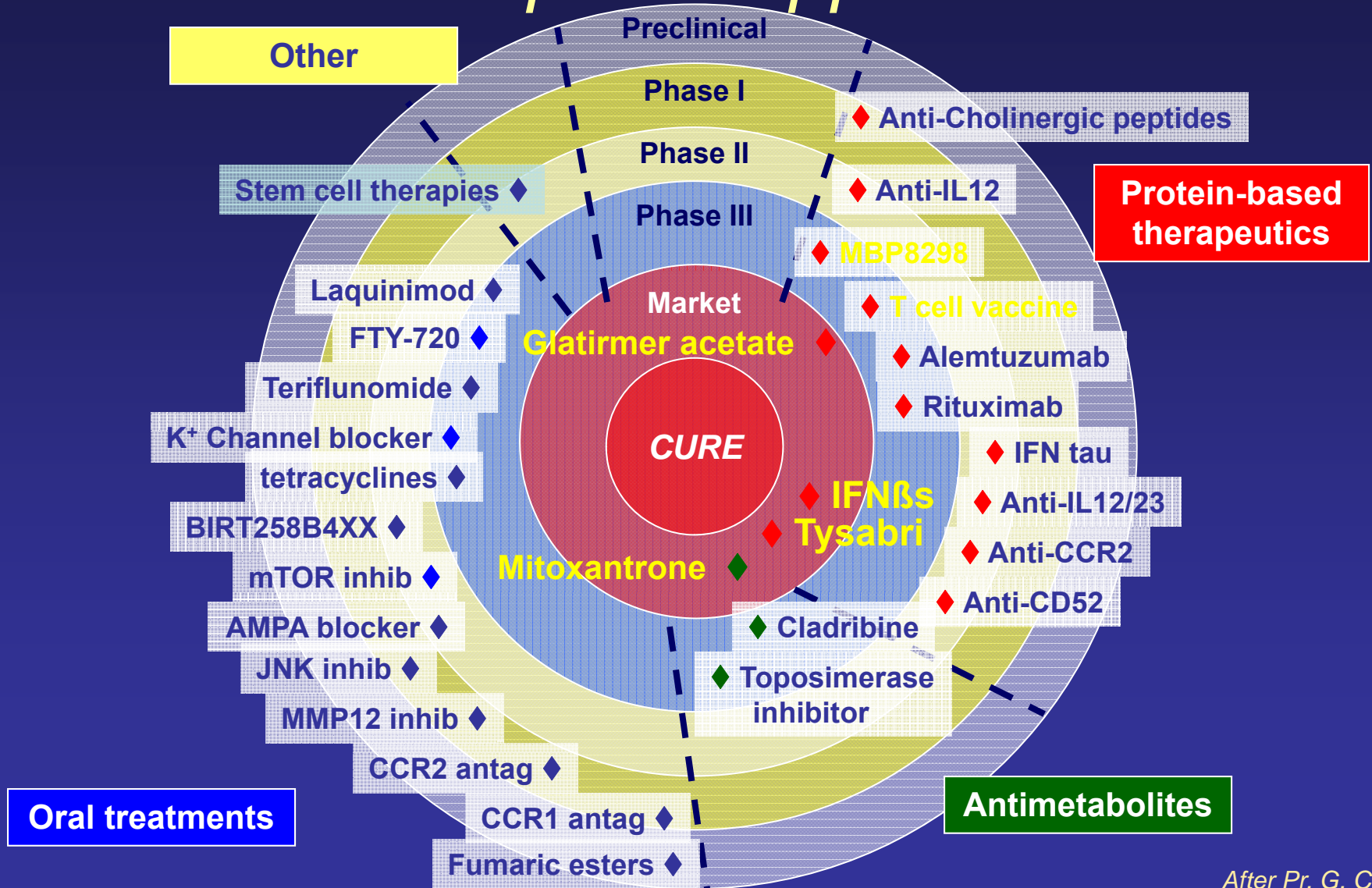
- Relapse Management
 - Rest
 - ACTH
 - Rehab
- Disease Modification
 - ?
 - Immunosuppression
- Symptom Management
 - Rehabilitation
 - Off-label use of medications

Current Knowledge and Skills

- Relapse Management
 - Early recognition
 - Rehabilitation
 - High dose IV OR Oral glucocorticoids
- Disease Modification
 - Interferons
 - Glatiramer acetate
 - Natalizumab
 - Mioxantrone
- Different therapeutic Goals
 - Relapse management
 - Delay of progression
 - Neuroprotection
- Side effect management
- *Research pipeline*

MS Pipeline

Different therapeutic approaches



Psychosocial Issues

Early Knowledge and Skills

- Psychosocial Issues
 - Avoid stress
 - Rest

Current Knowledge and Skills

- Psychosocial Issues
 - High prevalence of depression in MS
 - High prevalence of cognitive decline
- Early assessment and intervention
 - Nursing assessment critical
 - Multiple pharmaceutical options
 - Psychotherapy options
 - Cognitive retraining

II. Advocacy

- Has always been part of the nursing and MS nursing role.
- As interventions change and healthcare costs rise our role as advocate increases
- Nurses work on behalf of patients for better
 - Access to care
 - Access to disease modifying treatments
 - Accessible housing and transportation
 - Protection of patient rights

III. Patient and Family Education

- Knowledge of MS
- Process and theory of education
- Principles of teaching/learning

Education

Early Knowledge and Skills

- Patient and family education
 - Avoid stress
 - Avoid heat
 - Rest when possible
 - Hospitalize when having an exacerbation
- Steroids
 - ACTH
 - Oral prednisone
 - IVSM

Current Knowledge and Skills

- Underlying disease pathology
- MoA of disease modifying therapies
- Research Pipeline
- Symptomatic strategies
 - Medications
 - Rehabilitation strategies
- Employ multiple modalities for educating patients and families

IV. Research and Professional development

- MS Nurses, particularly those who have attained Certification as an MS nurse
 - Role model
 - Mentor
 - Preceptor
 - Public speaker
 - Support group leader
 - Researcher
 - Member in Professional organizations

The Evolving Role of the MS Nurse

- Our knowledge of the disease has expanded to include:
 - basic immunopathology, techniques of MRI, diagnostic criteria,
 - mechanism of action of disease modifying therapies 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
- As new treatments emerge, the role of the nurse as an care provider, 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 though, we will still keep to our goal of improving the lives of those affected by multiple sclerosis.



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