# International Organization of MS Nurses

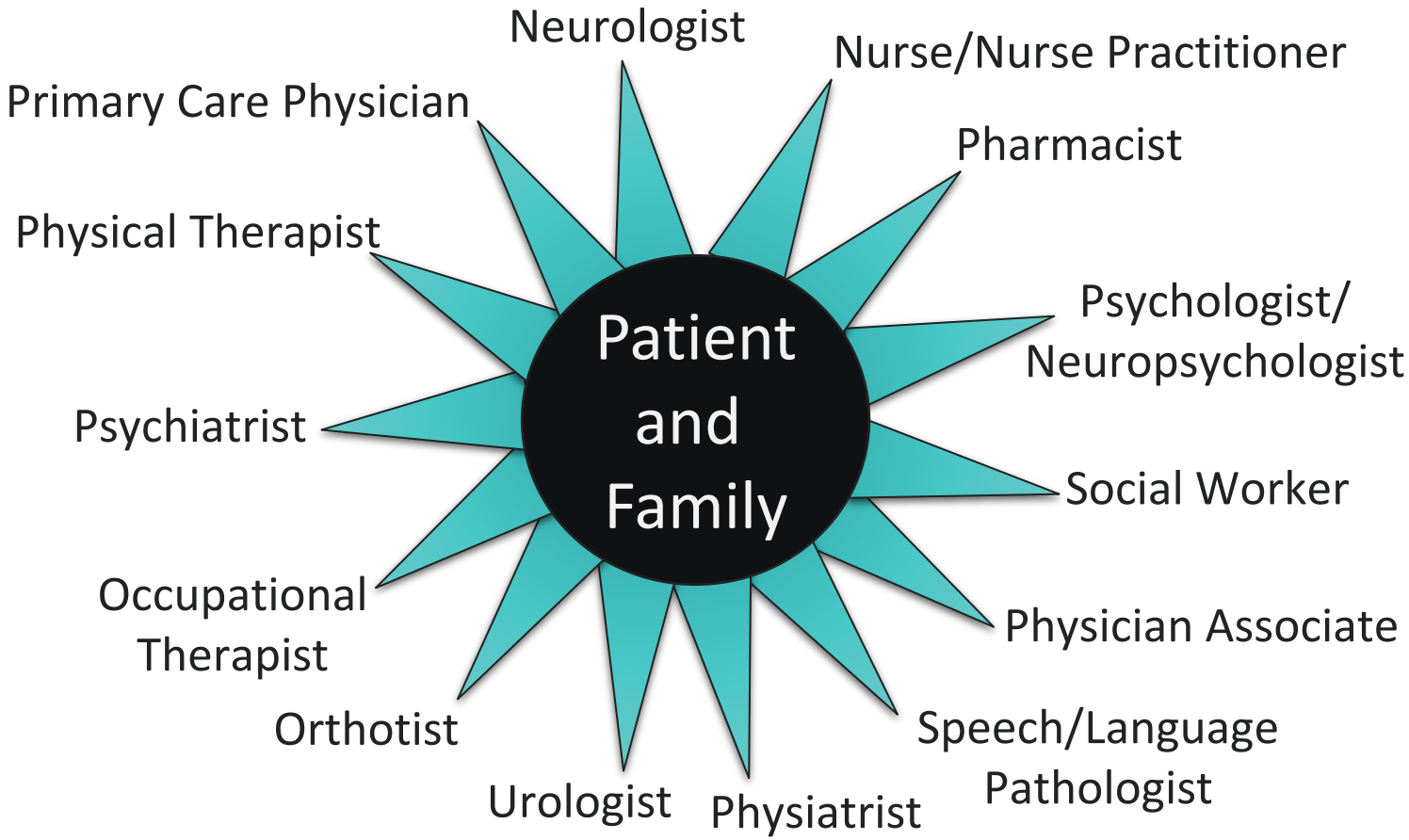
# Symptom Management in MS

Supported by Novartis Pharmaceuticals Corporation

# Goals of Symptom Management

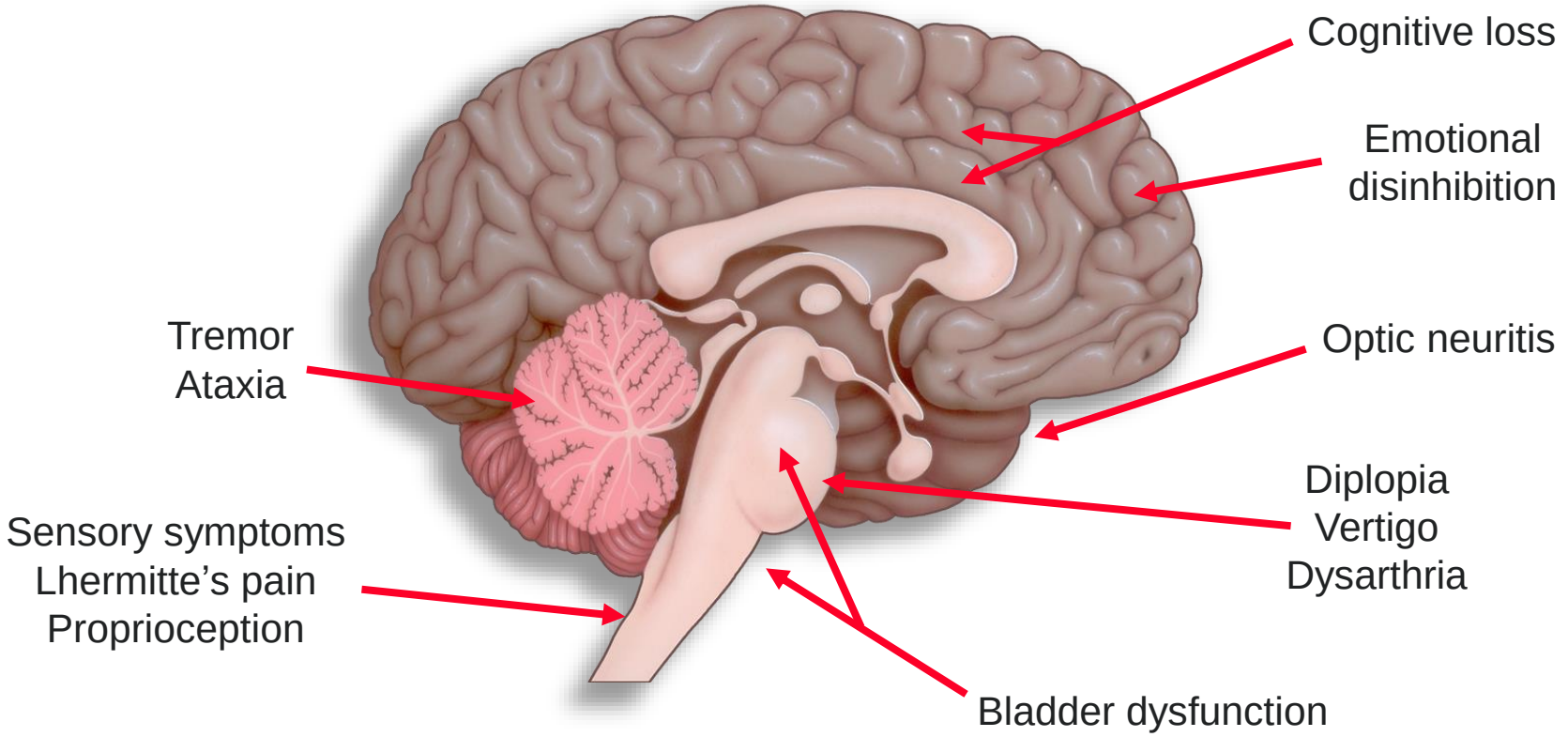
- Eliminate or reduce symptoms that impair functional abilities
- Improve quality of life
- Avoid secondary complications
- Use targeted and individualized treatment of symptoms (essential in management of MS)

# Multi-Disciplinary Team Approach



# Neurologic Origins

## Symptom presentation depends on lesion location




Miller AE. In: *Handbook of Multiple Sclerosis.* 2001:213-232. Medical illustration © MCFlynn.

# Primary Symptoms of MS

- Vision disturbance
- ***Altered mobility, weakness**
- ***Spasticity**
- ***Tremor**
- Altered sensation
- ***Bladder and bowel dysfunction**
- ***Sexual dysfunction**
- Cognitive problems
- Fatigue

***Will be discussed in this presentation**

Halper J, Harris C. *Nursing Practice in Multiple Sclerosis: A Core Curriculum.* 4th ed. 2017;
Ben-Zacharia AB. *Mt Sinai J Med NY.* 2011;78:176-191.

# Secondary Symptoms of MS

- Infections
- Falls
- Skin breakdown
- Pain

Halper J, Harris C. *Nursing Practice in Multiple Sclerosis: A Core Curriculum.* 4th ed. 2017;
Ben-Zacharia AB. *Mt Sinai J Med NY.* 2011;78:176-191.

# Tertiary Symptoms

- ***Psychosocial issues**
- Job loss
- Loss of intimacy
- Role changes/family disruption
- Social isolation
- Sleep disturbance

***Will be discussed briefly in this presentation**

Halper J, Harris C. *Nursing Practice in Multiple Sclerosis: A Core Curriculum.* 4th ed. 2017;
Ben-Zacharia AB. *Mt Sinai J Med NY.* 2011;78:176-191.

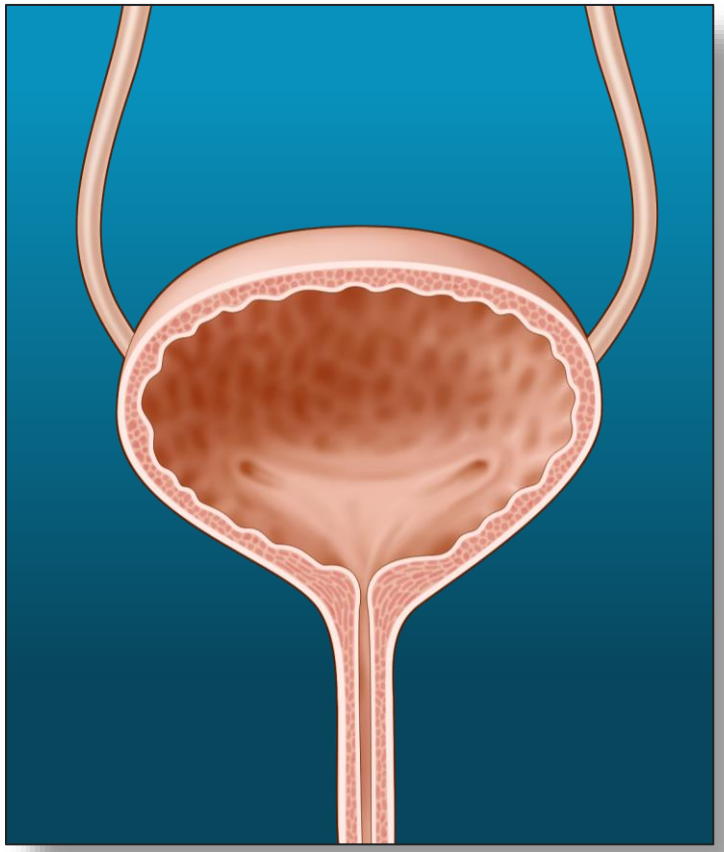
# Bladder Dysfunction

- 70%–80% of persons with MS may experience problems with bladder function

- Symptoms of neurogenic bladder include urgency, frequency, incontinence, hesitancy, incomplete emptying, nocturia
  - Inability to store
  - Inability to empty
  - Combined dysfunction, detrusor sphincter dyssynergia

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Bladder Physiology



- Initial urge 200–300 cc
- Capacity 500+ cc
- Flow rate 15 cc/second
- Voiding Pressure
  - 30–60 cm/women
  - 80 cm/men
- Post-void residual (PVR) negligible

https://www.ncbi.nlm.nih.gov/pubmed/15269341.

# Common Bladder Symptoms

- Urgency
- Frequency
- Hesitancy
- Double voiding
- Involuntary urination
- Nocturia
- Urinary tract infections (UTIs)
- Dysuria

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Bladder Dysfunction

| Inability to Store | Inability to Empty | Combination/DSD |
|---|---|---|
| **Symptoms**<br>• Urgency/frequency<br>• Incontinence<br>• PVR <100 mL | **Symptoms**<br>• Urgency, hesitancy<br>• Double voiding<br>• Frequency<br>• Incomplete emptying<br>• Nocturia<br>• PVR >100 mL<br>• History of UTI | **Symptoms**<br>• Urgency, hesitancy<br>• Double voiding<br>• Incomplete emptying<br>• Dribbling incontinence<br>• Diagnosed by urodynamic studies |

DSD=detrusor sphincter dyssynergia; PVR = post-voiding residual; UTI=urinary tract infection.

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Assessment of Bladder Function

- Thorough history: patient's main concern
  - Voiding patterns (voiding diary)
  - Fluid intake
- Spontaneous void
- Measurement of PVR
  - Determines the amount retained in the bladder after voluntary emptying
  - Evaluated by bladder ultrasound or catheterization
- Other causes of bladder dysfunction:
  - Urinary tract infections
  - Pelvic floor relaxation in women
  - Benign prostatic hyperplasia in men

PVR=post-void residual.

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Treatments: Inability to Store

- Limit fluid intake
- Frequent bathroom breaks
- Quick access to bathroom
- Pads or protective undergarments
- Decrease use of bladder irritants (caffeine, aspartame, alcohol)
- Anticholinergic/antimuscarinic agents:
  - Darifenacin (Enablex®)
  - Solifenacin succinate (VESIcare®)
  - Tolterodine (Detrol®/LA),
  - Fesoterodine fumarate (Toviaz®)
  - Oxybutynin (Ditropan/XL®), oxybutynin transdermal*
- Beta-3 adrenergic receptor agonists
  - Mirabegron (Myrbetriq®)
  - Vibegron (Gemtesa®)
- Onabotulinumtoxin A (Botox®)

*First-generation anti-cholinergics with more side effects than other agents.

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010;
Sanford M. *Drugs.* 2014;74:1659-1672.

# Treatments: Inability to Empty

- Adequate fluid intake
- Structured, timed voidings
- Intermittent catheterization, indwelling catheter, suprapubic catheter
- Alpha blockers
  - Tamsulosin (Flomax®)
  - Doxazosin (Cardura®)
- Anti-spasticity agents/nerve blocks

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.

# What Patients Need to Know

- Drink fluids all at once; if you sip, sip, sip you will feel the urge to go often
- Try to void about 1.5–2 hours after you drink
- Stop drinking fluids about 2 hours before bedtime
- Void right before bedtime
- It is not normal to leak urine regardless of one's age, wake up more than once at night to void, or have frequent UTIs
- Symptoms of UTIs
- Effect of UTIs on MS symptoms
- Importance of early treatment of UTIs

Wright K et al. *Enough of the Fear. An Insider's Guide to Understanding, Managing, and Living Well with Multiple Sclerosis.* 2019.

# Bowel Dysfunction

- Approximately 68% of persons with MS may experience problems with bowel function
- Common symptoms include constipation, diarrhea, incontinence
- Symptoms may be intermittent or constant
- Symptoms can occur at any time in the disease

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010; Cleveland Clinic, 2019; Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Bowel Symptoms in MS

- Constipation
  - Slow bowel
  - Medications
  - Impaired motility
  - Induced dehydration due to bladder issues
- Bowel incontinence
  - Diminished sphincter control
  - Hyperreflexic bowel

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Summary: Bowel Dysfunction Management

**Bowel training/dietary modification recommended for all bowel dysfunction, plus…**

| Constipation | Bowel Incontinence |
| --- | --- |
| • Fluids 1.5–2 quarts/day<br>• Daily fiber 20–30 grams/day<br>• Bulk-forming agents<br>• Stool softeners/stimulants<br>• Laxatives/enemas<br>• Suppositories<br>• Exercise | • Identify dietary triggers<br>• Medications/suppositories<br>• Bulk-forming agents<br>• Timed evacuations |

Wright K et al. *Enough of the Fear. An Insider's Guide to Understanding, Managing, and Living Well with Multiple Sclerosis.* 2019; Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.

# Sexual Dysfunction in MS

- Approximately 40%–85% of women with MS
- Approximately 50%–90% of men with MS
- Has significant impact on quality of life
- Common yet often overlooked symptom of MS

Foley FW et al. *Assessment and Treatment of Sexual Dysfunction in Multiple Sclerosis.* NMSS;
Halper J et al. *Comprehensive Care in Multiple Sclerosis: A Core Curriculum.* 3rd ed. 2022.

# Primary Sexual Dysfunction in MS

Men and women can experience difficulties with:

- ↓ Libido
- ↓ Erectile dysfunction/ejaculation
- ↓ Altered genital sensation
- ↓ Frequency/intensity of orgasms
- ↓ Vaginal lubrication/clitoral engorgement
- ↑ Bladder spasticity
- ↑ Depression

Foley FW et al. *Assessment and Treatment of Sexual Dysfunction in Multiple Sclerosis.* NMSS, 3rd ed. 2010.
Haney M, et al. *Comprehensive Care in Multiple Sclerosis: A Curriculum.* 3rd ed. 2022.

# Sexual Dysfunction Management

- Exclude metabolic causes (eg, diabetes)
- Management strategies include:
  - Pharmacologic management
  - Treat underlying symptoms/secondary dysfunction
    - Spasticity, fatigue, paresthesias, bladder/bowel issues
  - Adjust medications
  - Positioning, lubrication, assistive devices
  - Lifestyle changes
- Key to successful management is open communication
- Counseling and culturally sensitive support

Namey MA. In: Halper J, Holland NJ, eds. *Comprehensive Nursing Care in Multiple Sclerosis.* 3rd ed. 2010.
Choi JM, Kim JH. In: Giesser BG. *Primer on Multiple Sclerosis.* 2016.

# Altered Mobility in MS

## Common Symptom

- Possible causes:
  - Spasticity
  - Weakness
  - Imbalance
  - Sensory loss
  - Vision changes
  - Peripheral neurological changes
- Risks:
  - Decreased safety (eg, increased risk of falls)
  - Impaired biomechanics
  - Pain
  - Immobility
  - Isolation
  - Reduced quality of life

Bethoux F et al. In: Rae-Grant AD et al (eds). *Multiple Sclerosis and Related Disorders: Clinical Guide to Diagnosis, Medical Management, and Rehabilitation.* 2nd ed. 2018;
Bennett SE et al. *Int J MS Care*. 2014;16, Suppl 1:1-40; Bennett SE et al. *Int J MS Care*. 2014;16(Suppl 1):1-11.

# Management of Mobility Issues

- Rehabilitation therapy (physical and occupational therapy)
- Assistive devices, orthoses, adaptive equipment
- Exercise—deliberate, regular movement
- Medications (ie, trial of dalfampridine “walking pill”)
- Surgery (orthopedic surgery or neurosurgical interventions for spasticity)

Bethoux F et al. In: Rae-Grant AD et al (eds). *Multiple Sclerosis and Related Disorders: Clinical Guide to Diagnosis, Medical Management, and Rehabilitation.* 2nd ed. 2018;
Bennett SE et al. *Int J MS Care*. 2014;16, Suppl 1:1-40; Bennett SE et al. *Int J MS Care*. 2014;16(Suppl 1):1-11.

# Spasticity in MS

- Hypertonicity of muscles “tightness, pulling, tugging, aching”
- Results from demyelination in descending CNS pathways
- Different muscle groups involved depending on lesion location
- Spasticity may increase over time without new CNS lesions
- Results in:
  - Increased resistance to stretch
  - Accentuation of deep tendon reflexes and clonus
  - Uncontrolled flexor responses and extensor spasms
  - Limited mobility
  - Excessive energy expenditure
  - Pain and discomfort

CNS=central nervous system.

Bethoux F et al. In: Rae-Grant AD et al (eds). *Multiple Sclerosis and Related Disorders: Clinical Guide to Diagnosis, Medical Management, and Rehabilitation.* 2nd ed. 2018

# Modified Ashworth Scale

| Score | Criteria |
|---|---|
| 0 | No increased tone |
| 1 | Slight increased tone (catch and release at end of ROM) |
| 1+ | Slight increase in tone manifested by a catch followed by min. resistance throughout the remainder of the ROM (less than half the ROM) |
| 2 | Marked increase in tone through most of ROM but affected part(s) move easily |
| 3 | Considerable increased tone, passive movement difficult |
| 4 | Affected part(s) rigid in flexion or extension |

ROM=range of movement.

Meseguer-Henarejos AB et al. *Eur J Phys Rehabil Med.* 2018;54:576-590.

# Spasticity Management

**Non-pharmacologic**

- Stretching
- Positioning/Posture
- Seating
- Range of motion
- Orthotics
- Physical therapy

**Pharmacologic**

- Baclofen
- Tizanidine
- Clonazepam, diazepam
- Gabapentin
- Onabotulinum toxin A
- Cannabis?

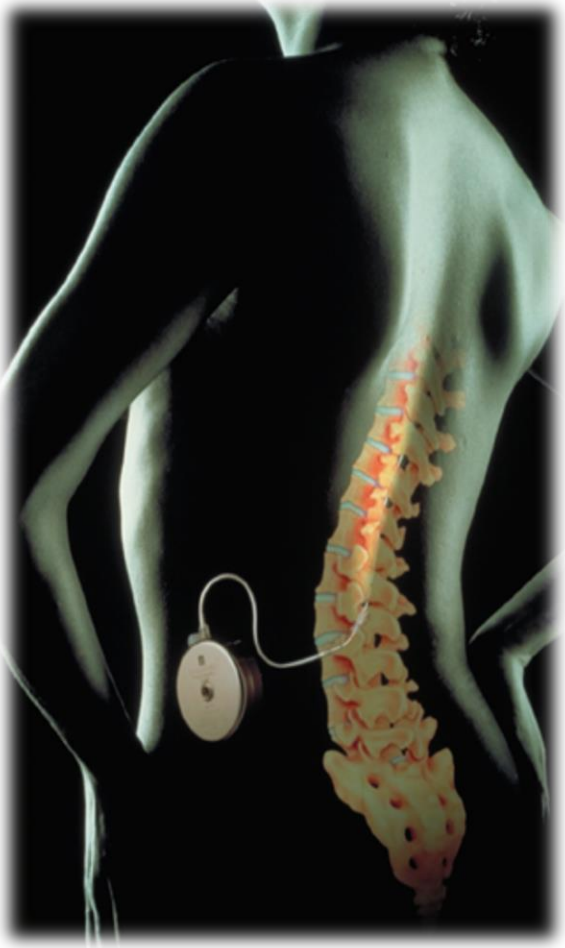
**Surgical**

- Baclofen pump

Bethoux F et al. In: Rae-Grant AD et al (eds). *Multiple Sclerosis and Related Disorders: Clinical Guide to Diagnosis, Medical Management, and Rehabilitation.* 2nd ed. 2018;
Halper J et al. *Comprehensive Care in Multiple Sclerosis: A Core Curriculum.* 3rd ed. 2022.

# Intrathecal Baclofen (ITB™) Therapy

- Pump infuses drug at programmed rate
- Catheter delivers drug to the intrathecal (subarachnoid) space of the spinal cord
- Programmer allows for precise, easily adjustable dosing

Bethoux F et al. In: Rae-Grant AD et al (eds). *Multiple Sclerosis and Related Disorders: Clinical Guide to Diagnosis, Medical Management, and Rehabilitation.* 2nd ed. 2018.

# Tremor in MS

- Less common symptom
- Caused by MS lesions in cerebellum and its pathways
- Can affect head, limbs, trunk, eye movements, and speech (dysarthria)
- Titubation-tremor in the head, neck, or trunk
- Difficult to treat and can be embarrassing

Halper J et al. *Comprehensive Care in Multiple Sclerosis: A Core Curriculum*. 3rd ed. 2022.

# Tremor Management

## Non-pharmacologic

- Proximal stability
- Self-care strategies
- Weight-bearing activities
- Weighting (utensils, assistive devices)
- Coordination exercises
- Occupational therapy

## Pharmacologic

- Clonazepam
- Gabapentin
- Primidone
- Propranolol
- Levetiracetam
- Topiramate

## Surgical

- Deep brain stimulation

Halper J et al. *Comprehensive Care in Multiple Sclerosis: A Core Curriculum*. 3rd ed. 2022.

# Psychosocial Issues

- Depression
  - About 50% of patients with MS experience depression at some time
  - Rate is much higher than general population
- Suicide
  - Rates are much higher than general population
- Screen for depression and other mental health problems frequently
- Refer as appropriate for counseling
- Medications: variety of antidepressants are available

Patten SB et al. *Int Rev Psychiatry.* 2017;29:463-472; Scalfari A et al. *Neurology.* 2013;81:184-192; Nathoo N, Mackie A. *Mult Scler Relat Disord.* 2017;18:177-180; National MS Society.

# Lifestyle Recommendations for Managing All Symptoms

- Education about disease and its symptoms
- Stress management
- Healthy diet
- Regular activity/exercise
- Socialization
- Complementary and alternative therapies (CAM)
- Psychosocial support

Halper J et al. *Comprehensive Care in Multiple Sclerosis: A Core Curriculum*. 3rd ed. 2022.

# Summary: Symptom Management

- Clinical approach to symptom management is what healthcare providers do best and most often
- MS symptoms affect quality of life of individuals with multiple sclerosis
- Left untreated, symptoms may worsen or precipitate other symptoms, producing a cycle of inter-related symptoms
- Nurses listen, respond with care and concern, treat, and make referrals

# Nursing Implications

- Symptom management follows the same general rules as disease management
- Diagnose the problem and intervene early
- Identification of symptoms is key
  - Need to confirm the nature of the symptoms and link to MS (MS or not MS)
  - Secondary causes (comorbidities may contribute to symptoms)
- Use multimodal, multidisciplinary management
- Identify interventions (non-pharmacologic and pharmacologic)
- Monitor and adjust treatment plan as needed over time

# Nursing Implications (continued)

- Acknowledge that many MS symptoms overlap
- Educate patients regarding role of contributing factors (ie, medications, infections, heat, deconditioning, etc)
- When a symptom is new or suddenly worsens, re-evaluate for contributing factors both internal (disease activity) or external (environmental issues)