



# 4<sup>th</sup> MENACTRIMS CONGRESS

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Hosted by

**MENACTRIMS**  
Middle East North Africa Committee for  
Treatment and Research in Multiple Sclerosis

In collaboration with

**ECTRIMS**  
EUROPEAN COMMITTEE FOR TREATMENT  
AND RESEARCH IN MULTIPLE SCLEROSIS



European Charcot Foundation



THE CONSORTIUM OF  
MULTIPLE SCLEROSIS CENTERS



## Managing Multiple Sclerosis: A Team Approach

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# Core Multiple Sclerosis Team

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- Neurologist
- Other medical consultants (urologist, physiatrist, orthopedist)
- Nursing Professional
- Rehab therapists (PT, OT, SLP)
- Case manager, social worker
- Counselor (psychological, vocational)
- Clergy

# Nurses Role in Rehab Team

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- Education
- Coordination and Continuity of Care
- Medication Management
- Skill practice
- Bowel, bladder, sexual function, skin, respiratory
- Nutrition
- Family/caregiver training
- Reassurance and emotional support

# Shared Roles of the MS Multidisciplinary Care Team

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- Assessment
- Education
- Patient Safety
- Rehabilitation
- Patient advocacy
- Emotional support
- Case coordination and continuity of care
- Emotional Support
- Discharge/home care planning
- Medication management and skills training (eg. self injection)
- Symptom management (eg. bowel, bladder, sexual function)
- Nutrition/wellness
- Family/caregiver support, education
- Community resources

**SPEECH THERAPY**

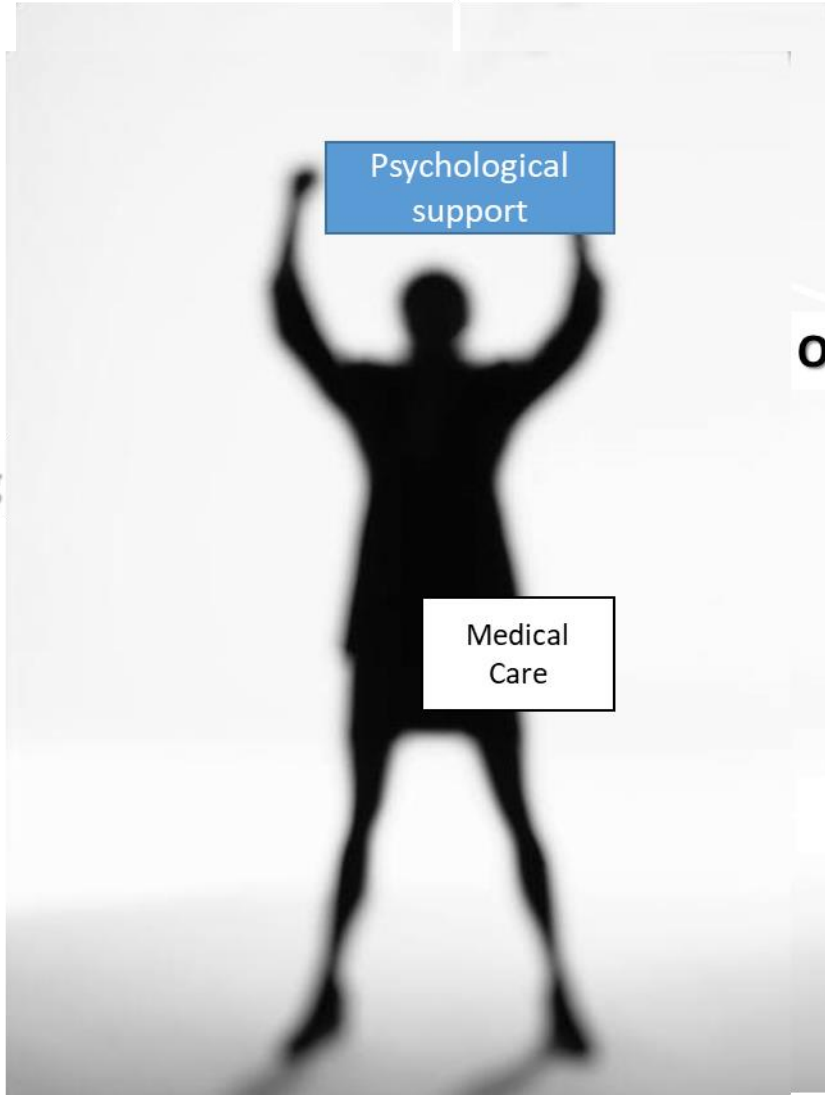
Psychological  
support

**OCCUPATIONAL THERAPY**

**Nursing**

Medical  
Care

**PHYSICAL THERAPY**



- Unidisciplinary Model (one professional)



- Multidisciplinary Model (A Team)



- Interdisciplinary Model (Communication/Collaboration)



# Rationale for MS Team

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- MS is complex and dynamic
- MS care must be patient-centered
- Collaboration reduces the burden on one person
- Has proven to be the best practice throughout the world
- Outcomes of team care have proven to be effective
- Prevents burnout
- Addresses MS-related problems with the appropriate professional

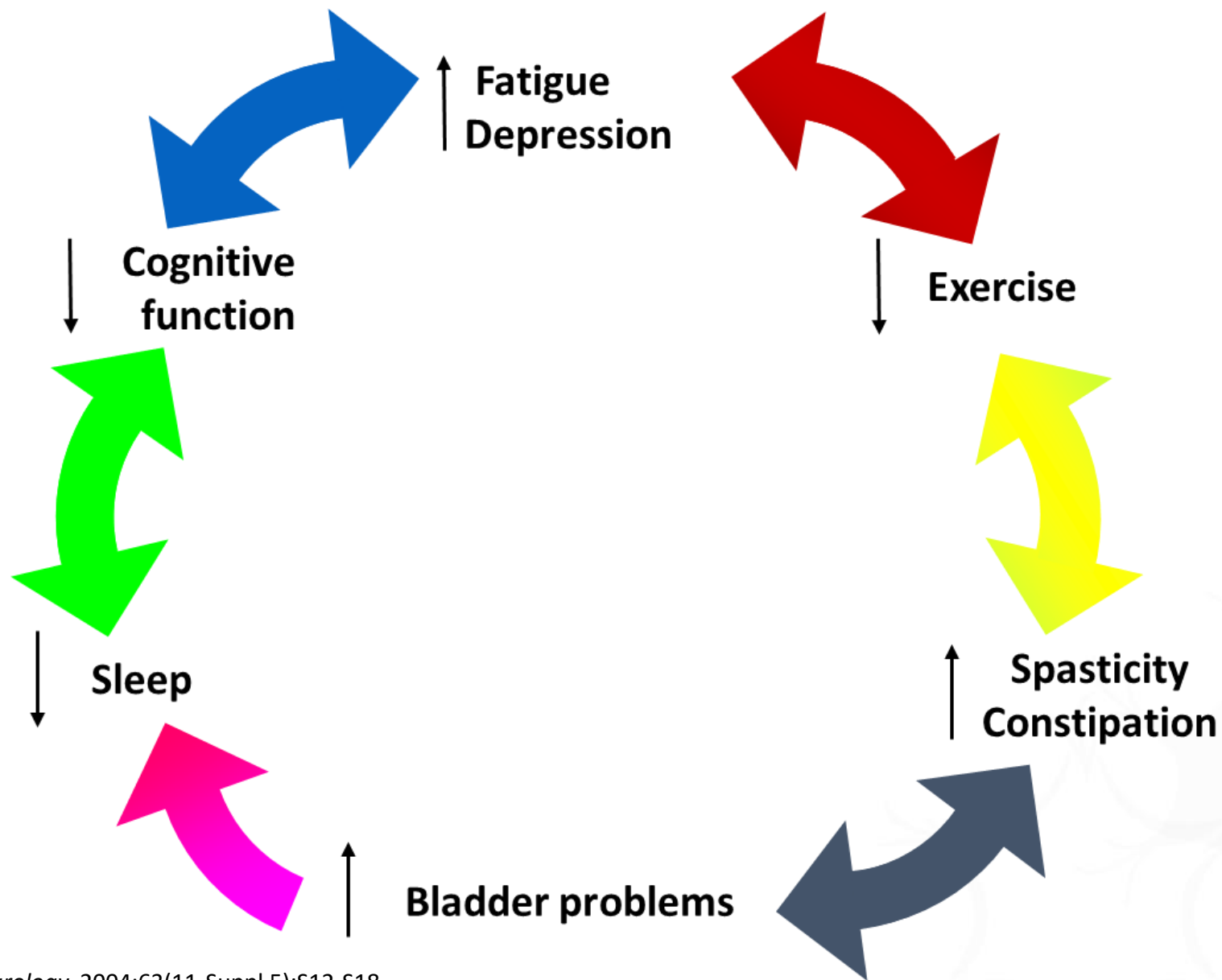
- Free flowing communication
- Transfer of knowledge and skills across disciplines
- Commitment to collaborate
- Ability to ask for help without feeling diminished professionally (mutual respect)



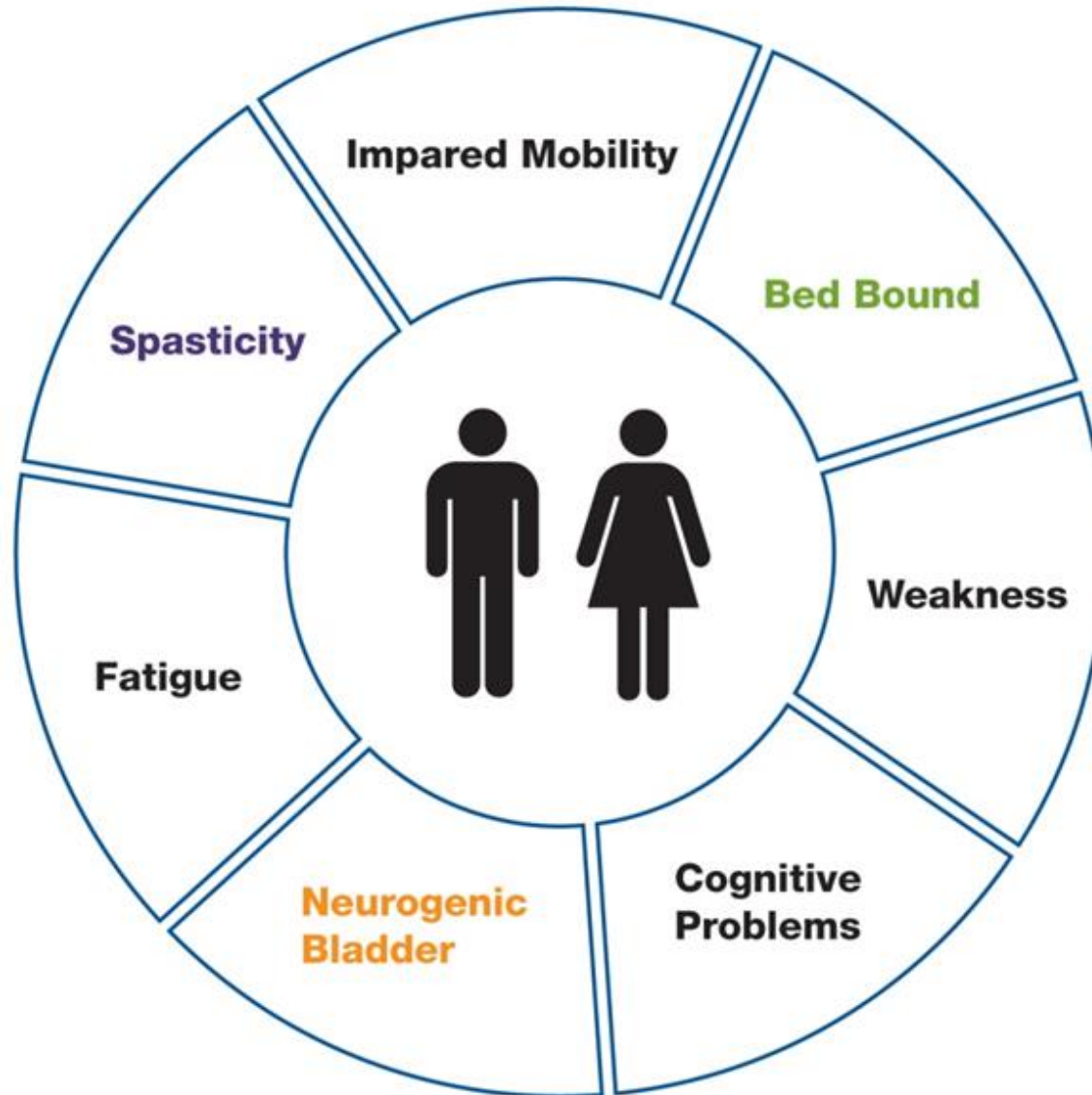
# OPTIMAL MS TEAM CARE....



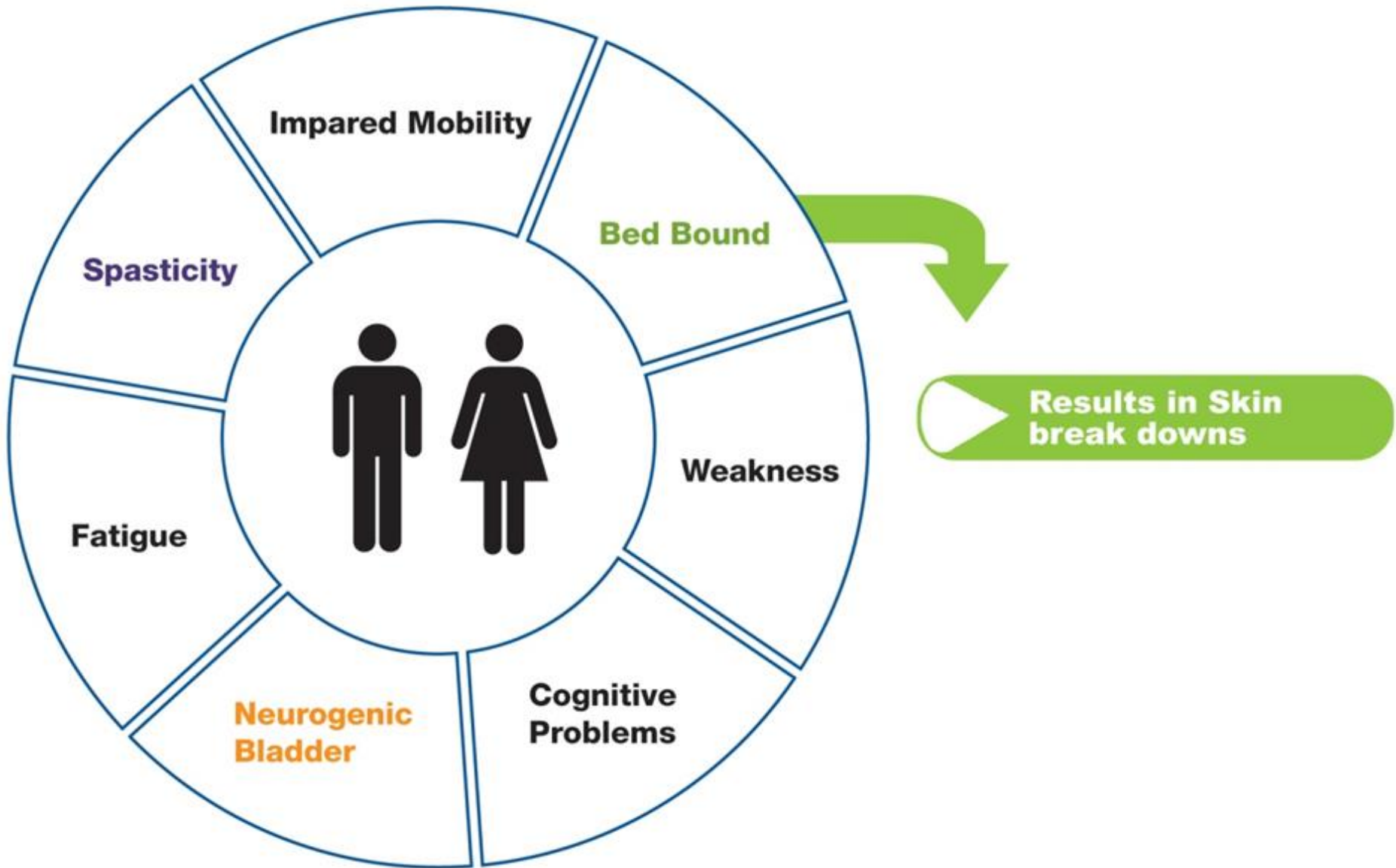
# Cycle of Symptoms Addressed by Team Care



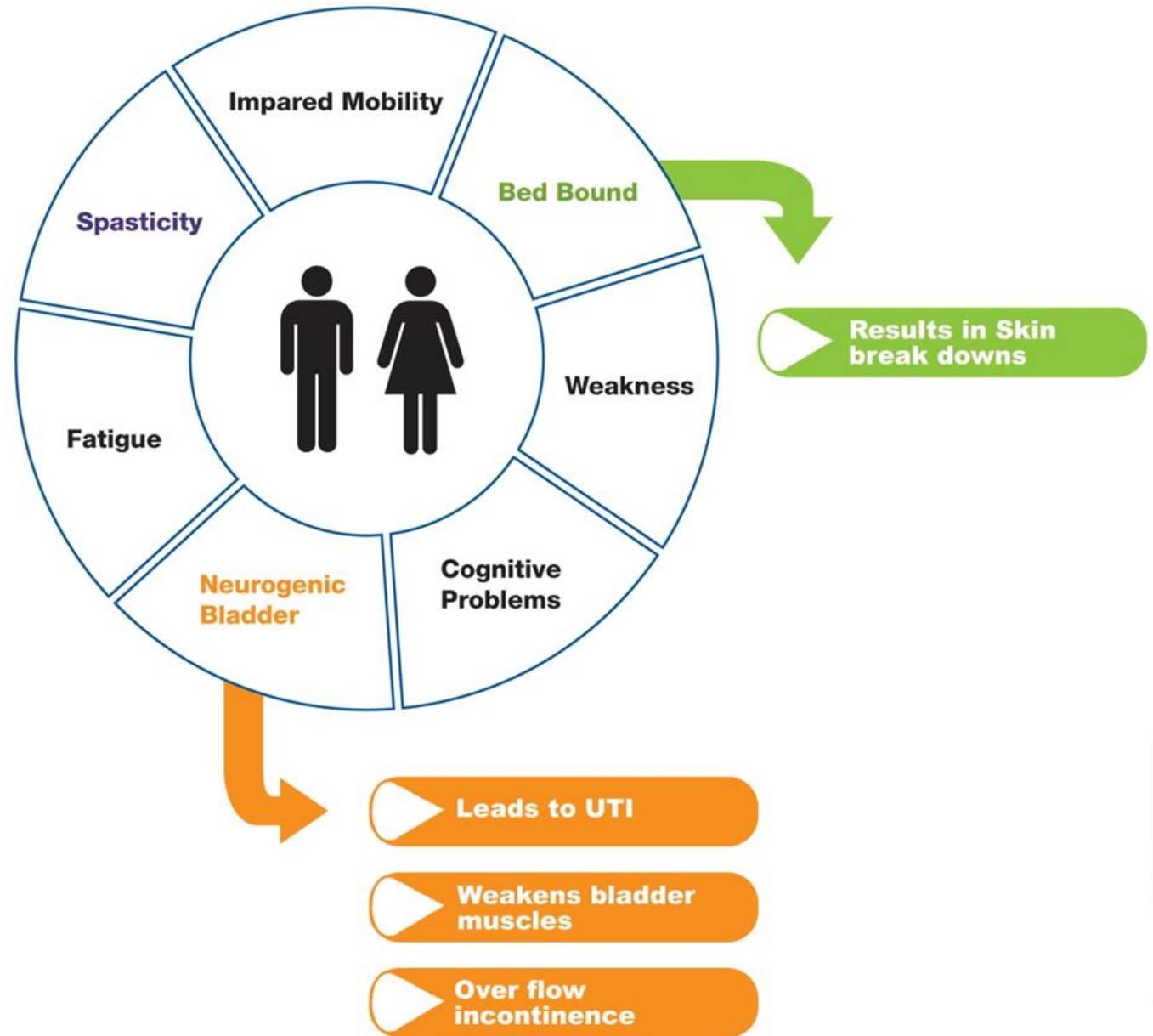
# Major Mobility and Functional Problems



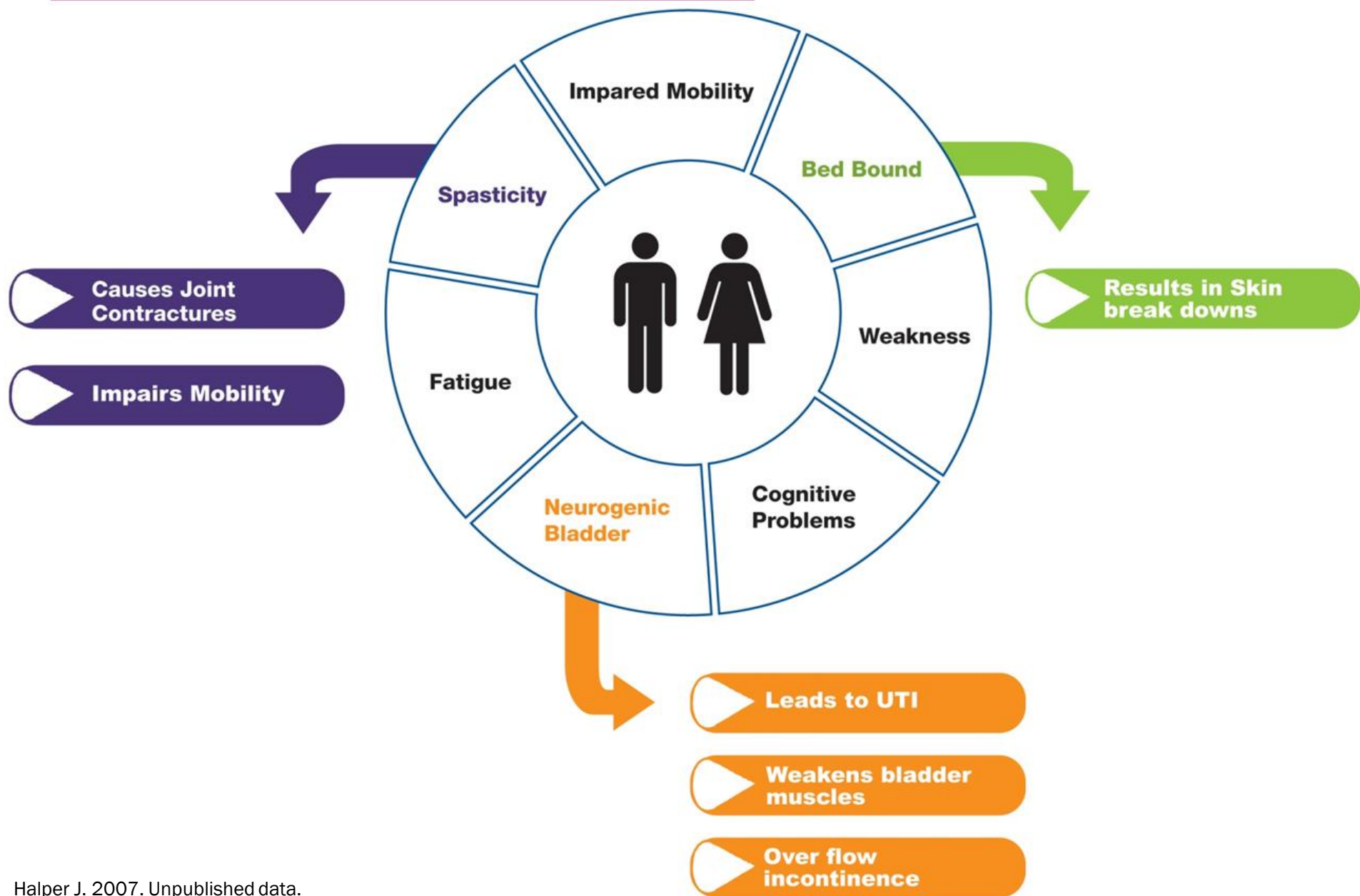
# Major Mobility and Functional Problems



# Major Mobility and Functional Problems



# Major Mobility and Functional Problems



- Rehab in MS is a process that helps a person achieve and maintain maximal physical, psychological, social and vocational potential, and quality of life consistent with physiologic impairment, environment, and life goals. Achievement and maintenance of optimal function are essential in a progressive disease such as MS. (Expert Opinion Paper, Medical Advisory Board of the NMSS 2004)

- Rehab interventions can only be as good as the assessments on which they are based
- Multidisciplinary evaluation is best
- Important to obtain baseline information to track changes over time
- Periodic reassessments to revise treatment plan and promote adherence
- Driven by patient identified priorities
- Use standardized assessment tools as often as possible



- Infection
- Noxious Stimuli (i.e. pressure sores, constipation)
- Pseudo-exacerbation (i.e. from overheating)
- Exacerbation/progression
- “Current state of the neurological system”

- Minimize the impact of existing impairments on day to day functioning
  - Improve mobility
  - Improve ADL's/IADL's
  - Improve QOL
  - Prevent complications
  - Reduce health care utilization
  - Improve safety/promote independence

- Chronicity
- Variable course
- “Invisible” symptoms
- Anxiety/psychosocial issues
- Multiple problems requiring prioritization
- Changing circumstances of the disease and the person

- Focus on prevention of secondary effects of the disease
- Education to empower the individual and manage symptoms
- Support and motivate the individual to follow treatment plan
- Looks to have a positive change in behaviors

- Restorative after an exacerbation or a decline to regain previous functional abilities
- Preventative to maintain maximum function in the face of a disease that may be progressive
- Treatment goals should be developed to meet individual needs and be consistent with their priorities
- Goals must be attainable, realistic and functionally based

- Encourage “well” visits
- Promote smoking cessation
- Good nutrition/maintain healthy weight
- Adequate rest/sleep patterns
- Emotional well-being/stress management
- Spiritual
- Balance

- Become expert in understanding MS
- Educate the public
- Knowledge of services and programs available to patients
- Network with other MS professionals
- Seek MSCN certification
- Self-advocacy and self-care

# The Nurse's Roles in Research





# Why are nurses necessary in clinical trials?

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- Because tasks involve:
  - Caring for patients and families
  - Educating and monitoring patients
  - Moving systematically through a complicated process that comprises experimental procedures
  - Communicating with the multidisciplinary team of MS health professionals
  - Being highly organized
  - Knowing how to set priorities

# What do nurses do in clinical trials?

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- Contribute to patient selection
- Participate in diagnostic and therapeutic program planning
- Utilize clinical, interpersonal, administrative, and creative skills to help patients emerge successfully from the rigors of a clinical trial
- Assist with documents such as informed consent, adverse event reporting, patient recruitment and retention, as well as inspiring realistic hope

- Acts as a link between the sponsor and study site
- Interfaces with all members of the research team
  - Principal investigator
  - Co-investigators
  - Patient and the family
  - Research associate representing the sponsor

- Ensures all information conveyed is accurate and complete
- Helps patients navigate through the maze of tests and procedures
- Coordinates appointments and follow up
- Ensures communication between the patient and researcher(s)

- Education and re-education are required throughout studies
  - Clarification of protocol expectations and procedures
  - Review of medication and side-effects
  - Discussion of required documents and testing
  - Reinforce the importance of open lines of communication between patient and the MS professional team

- Ensures that documents are complete
- Files protocols and patient consent forms
- Keeps up-to-date regulatory files
- Reports adverse events to appropriate oversight boards

- Helps select candidates for clinical trials
- Ensures that the patients are able to participate both physically and emotionally
- Reaches out to other professional colleagues to recruit patients for studies

- Encourages patients to enter studies and to continue in studies through completion
- Supports the patient who may wish to withdraw
- Protects the patient's rights throughout the clinical trials



## In summary.....

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- Nursing activities in clinical trials include:
  - Protecting human rights
  - Ensuring patient safety
  - Nurturing patient retention
  - Providing accurate documentation
  - Promoting adherence to the protocol
  - Clarifying false expectations
  - Inspiring hope

# Recommendations for Research Nurse Coordinators

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- Remember that a study has a beginning, middle, and end; there will be closure
- Study work will satisfy your compulsive edge if you have one
- Keep in touch with other nurse coordinators for support; sharing experiences is important for everyone's success

# Recommendations for Research Nurse Coordinators

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- Take care of yourself; study work is tiring and stressful; try to relax and re-energize
- Enjoy the investigator's meeting; they usually are very well done
- Think of research questions you might to incorporate into the future studies. Sponsors are often willing to listen to an idea and offer support

# The Morgante Hope Model of MS Nursing

