

## **Consortium of Multiple Sclerosis Centers Recommendations for Care of Those Affected by Multiple Sclerosis**

Multiple sclerosis is a lifelong neurological disease with far-reaching and variable implications for patients, their families, and their social and vocational sphere of influence. The disease course remains uncertain for each patient, symptoms tend to wax and wane due to a variety of causes, and treatment concerns range from physical to social to emotional and back again. This dynamic pattern of need and the necessity for appropriate care calls for a philosophy of care that, to date has not been well-articulated or published. The standards for symptom management and disease altering therapies have been promulgated during the past decade based on both research and expert consensus. Therefore, the Consortium of Multiple Sclerosis Centers has determined that basic recommendations for care are required in multiple sclerosis.

### Background and Vision of CMSC

The Consortium of Multiple Sclerosis Centers (CMSC) is the largest organization of multiple sclerosis health professionals in North America. It was organized in 1986 under the auspices of seven neurologists. Since that time, it has grown to over 180 member centers in the United States, Canada, South America, and Europe.

The CMSC includes numerous individual members who are neurologists, nurses, psychologists, and rehabilitation professionals. It has members who are academic centers, community programs, VA medical centers, individual healthcare providers, students, corporate sponsors, and non-profit partners such as LACTRIMS (the Latin American counterpart of the CMSC) and RIMS (the European counterpart) providing comprehensive care in multiple sclerosis. Today, it continues to experience tremendous growth.

The vision of the CMSC is to be the pre-eminent organization of MS professionals. Through collaborative and interdisciplinary approaches, this group will lead the development and dissemination of scientifically based knowledge regarding MS clinical care. The ultimate goal is to improve the lives of those affected by multiple sclerosis.<sup>1</sup>

To that end, the CMSC engages in activities that consist of professional education, clinical research, advocacy, and communication of activities to the healthcare community. CMSC is particularly interested in the future of chronic care and the role of alternative care in the 21st century. The CMSC/NARCOMS patient registry seeks to identify treatment trends and demographic characteristics of patients throughout the world.

The print and virtual journal of the CMSC is entitled The International Journal of MS Care. This is the official publication of the CMSC, as well as that of RIMS. All CMSC members receive subscriptions as part of their membership. It is a peer reviewed journal with opportunities for special issues, supplements, advertising, and both scientific and clinical articles.

### Review of literature

The CMSC identified a need to provide a document that describes comprehensive care guidelines for those affected by MS. An extensive review of the literature was conducted and revealed that very little had been written in North America about the care for those affected by MS from a diagnostic continuum perspective. Most of the literature in North America is directed toward current disease modifying agents.<sup>2,3</sup>

In a joint publication by the Multiple Sclerosis Society of Great Britain and Northern Ireland and the MS Professional Network<sup>4</sup>, an absence of continued care after the initial diagnosis of MS was identified. The document described the various phases of MS and associated recommendations for care and the importance of proper care and support through the various stages of the illness.<sup>5</sup>

Another UK document written by the Neurological Alliance outlined standards of care for people living with a neurological condition. The focus of this writing is not solely on MS. However it is identified that there is a need for coordinated, patient centered services which ensure continuity of comprehensive care.<sup>6</sup>

One final article written by the European Federation of Neurological Societies and published in the European Journal of Neurology cited the inconsistency and non-existence of care standards for those affected by MS across Europe. The document illustrated the minimum standards of care for MS. The authors conclude a significant improvement in care and support through the application of standards.<sup>7</sup>

The current trend in the North America literature related to standards of care is directed toward the concept of evidence-based practice. The impetus for evidence-based practice comes from payor and healthcare facility pressures for cost containment, greater availability of information, and greater consumer savvy about treatment and care options.<sup>8</sup>

Simply stated, evidence-based practice (EBP) means “integrating the best available research evidence with information about patient preferences, clinician skill level, and available resources to make decisions about patient care.”<sup>9</sup> A comprehensive definition of the EBP approach “incorporates hierarchical ratings of multiple forms of clinical evidence (e.g. Randomized controlled trials, systematic reviews, and meta-analyses) that represent a body of data subjected to rigorous systematic analysis of study design and methodology (see Appendix A) to minimize bias and validate reported findings”.<sup>10</sup> From this body of evidence, clinical practice guidelines are generated to suggest clinical decisions and the prescription of interventions for specific clinical situations.<sup>11</sup>

The literature provides research that correlates the use of evidence-based practice to improved clinical outcomes. This research centers on the clinical management of the patient with guidelines or standards of care. Two of the thousands of citations related to improved clinical outcomes can be found in the cardiac population<sup>12</sup> and pediatric pain management.<sup>13</sup>

The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has revised the proposed standards for disease-specific care certification in the ambulatory environment. A delineation of the JCAHO expectations for patient care management is the following:

Disease management is an interdisciplinary, continuum-based approach to healthcare delivery that prevents or delays exacerbations or complications of an illness or condition. One of the ways that this is accomplished is by using a standardized method of delivering clinical care based on clinical guidelines or evidence-based practice.<sup>14</sup>

Finally, the literature is abundant on issues that have a direct impact on patient safety outcomes. This has been brought to the forefront by reports done by the Leapfrog group<sup>15</sup> and the Institute of Medicine’s publication “To Err is Human.”<sup>16</sup> The literature supports evidence-based practice and its relationship to a positive impact on patient safety outcomes. Leape, Berwick, and Bates (2002) state “there will never be complete evidence for everything that must be done in medicine. The prudent alternative is to make reasonable judgements based on the best available evidence combined with successful experiences in health care.”<sup>17</sup>

Based on several decades of clinical care, the leadership of the Consortium of Multiple Sclerosis Centers has addressed the needs of those affected by multiple sclerosis. This has been accomplished by the Clinical Care Committee through the promulgation and dissemination of the basic recommendations for MS care throughout the spectrum and lifetime of the disease.

### Purpose

An extensive review of the literature along with knowledge that is derived from education and experience, defined a critical need to recommend care for those affected by MS in the North America. The emphasis of this care is on the concept of a diagnostic continuum. The model for this care is flexible and changes

based on the needs of the patient. MS care is not focused on episodic management but on care across the trajectory of the illness that spans a lifetime.

The continuum begins when a patient presents to the health care system, and it is maintained throughout the patient's life. Multiple Sclerosis is not the definitive diagnosis in every case. The core of the model is the patient, family, and relationship sphere. The participation and involvement of the patient in this continuum of care is highlighted to promote adherence, empowerment, and self-actualization.

On behalf of the CMSC, the members of the Clinical Care Committee of the CMSC determined that the purpose of this document as the following:

1. To provide a conceptual and practical framework for health care practitioners involved in the care of those affected by MS.
2. To emphasize the model of a diagnostic continuum of care in MS.
3. To present a format for this document that is "living", meaning that it will evolve and change over time as more research findings become available.
4. To motivate and direct research related to MS using the evidence-based practice framework.
5. To furnish supportive documents which broaden the scope of knowledge and understanding for the care providers of those affected by MS. (see Appendices A, B, C, D)
6. To promote adherence with JCAHO standards for disease management.

#### Overview of MS

Multiple sclerosis (MS) is a disease of the central nervous system. It has a far-reaching and variable impact on young adults, and is one of the most common neurological diseases of the younger generation. It strikes people in the prime of their lives between the ages of 15 – 60. The highest incidence occurring between the ages of 30 – 50.

The hallmarks of MS are unpredictability, uncertainty, and loss of control. The variety of physical impairments can result in drastic changes in the patient's life style, roles, income, productivity, family life, and emotional stability. Each person's prognosis is uncertain and the course of the disease is unpredictable from one individual to another. MS has many symptoms and many related physical and emotional consequences that may affect function and quality of life. Lublin and Reingold have described the clinical course of MS according to four types based on clinical characteristics (see Appendix B).

MS can have profound physical, social, and psychological consequences for patients and their families. It is a disease which has evolved from the mysterious "crippler of young adults" to one that has generated a great deal of public interest due to highly publicized treatments, both conventional and unconventional.

The impairments in MS are the result of demyelination in the brain or spinal cord or both. These may be manifested in mild sensory symptoms, weakness, fatigue, bowel or bladder dysfunction, tremor, poor coordination, depression, and cognitive changes. These impairments can lead to limitations in a person's functional abilities (previously defined as disability and now as activity level in the WHO terminology), and to restrictions in social, emotional, vocational, and sexual participation levels (previously referred to as handicaps). Please refer to Appendix D. These disruptions can result from the disease itself or from inadequate healthcare and related services.

Healthcare in multiple sclerosis has grown and evolved during the past twenty years as knowledge and interest in this disorder has increased due to advances in technology and the emergence of disease modifying therapies. Before the mid-1970s care was fragmented and provided in many locations. Patients received the diagnosis and medical treatment by a neurologist, treatment of bladder problems by a urologist, physical therapy and other rehabilitation care in another facility, and less frequently, mental health services, neuropsychological and vocational care somewhere else. The character of care at that time was "diagnose and adios." With the advent of MRI, that theme changed from "MRI and goodbye."

In the United States and Canada until the early 1980s, there were few specialty MS programs or clinics. There was little or no communication between healthcare providers and minimal continuity of services. Patients whose mobility or lack of transportation precluded access to care received no ongoing care except for emergencies. MS care was fragmented, episodic, and related to crisis intervention instead of maintaining health. Treatment focused on symptomatic management and disease modification was merely a dream. With the advent of MRI which facilitated the diagnosis of MS in the mid 1980s and the approval of disease modifying therapies during the past decade, care patterns have changed not only in North America but also throughout the world.

Comprehensive care in MS is an organized system of healthcare that is designed to address the medical, social, vocational, emotional, and educational needs of patients and their families. This care is provided by a team of professionals in one facility and tries to ensure that the direction and goals of treatment are consistent, logical, and progressive. The team approach facilitates coordination of services and continuity of care, and avoids duplication and fragmentation for the patient and the family.

Comprehensive care embraces a philosophy of empowerment in which the person with MS takes an active role in planning and implementing healthcare and self-care activities and acts as consultant to the team. This active rather than passive role is fitting in light of the fact that MS, like all chronic illnesses, is expected to last a lifetime. Persons with MS must learn to adapt and change in response to alterations in their physical functioning.

The comprehensive care team in MS consists of a well-informed person with MS, the family, relationship sphere, and care partners. The team may consist of a neurologist and other physicians such as primary care physician, internists, urologists, gynecologists, orthopedists, ophthalmologists, physiatrists, as well as other professionals such as nurses, social workers, physical therapists, occupational therapists, speech language pathologists, recreation therapists, psychologists, neuropsychologists, and clergy. This interdisciplinary team evaluates each patient individually, and develops a plan of care that reflects individual function with the individual's input. This plan of care reaches beyond center or clinic walls into homes, workplaces, and places of recreation to enable full and independent functioning and a full quality of life. This vigorous plan of care reflects the ever changing health care, social, and emotional needs expressed by the person with MS.

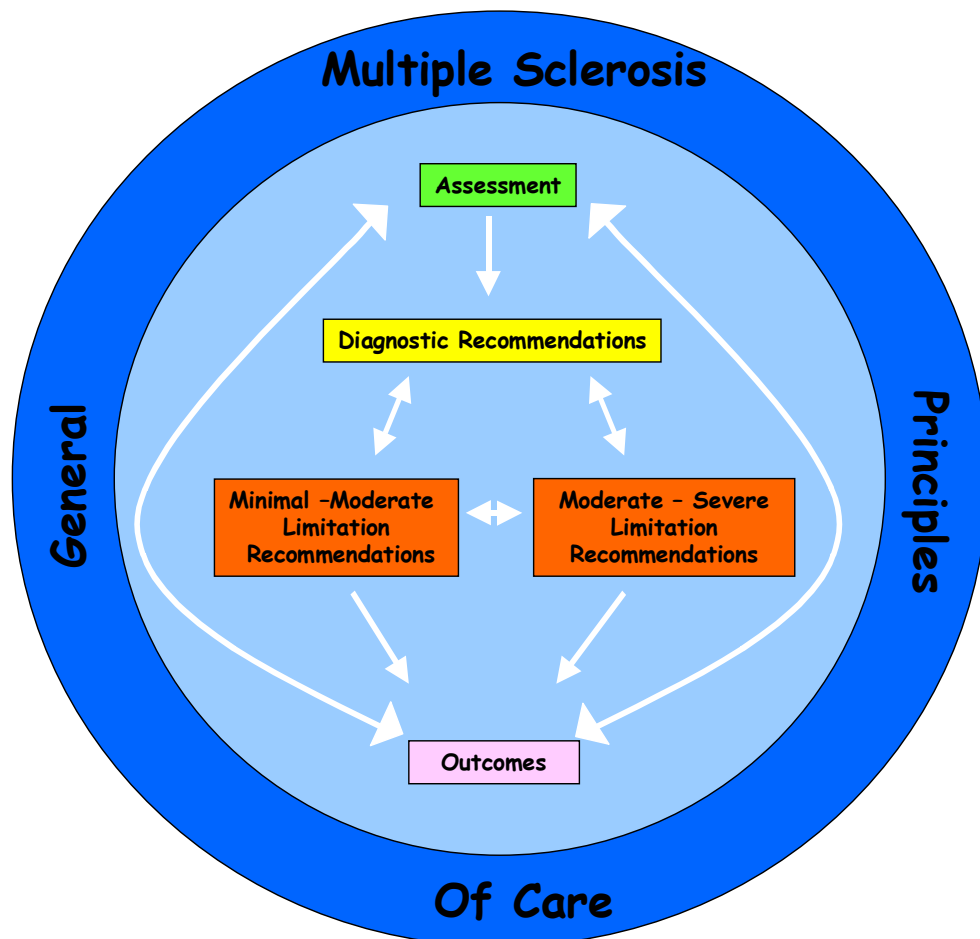
### CMSC Recommendations for Care

In the next two sections, a visual framework for care principles and principles of empowerment is presented. This is followed by the CMSC recommendations for care of those affected by MS for each phase of the disease that include:

- Clinical Evaluation and Diagnostic Continuum
- Mild to moderate limitation in function
- Severe limitation in function

### Visual Framework of Care Principles

This graphic is provided to expand the visual framework for the reader. The model exemplifies the fluid dynamics involved in the continuum of care required for those affected by MS. General principles of MS Care provide the framework for care, no matter the impairment or disability. Additional recommendations for care are based upon the clinical status of the individual at any point in time. As MS is unpredictable and impairment and disability can change due to the relapsing-remitting or progressive courses of disease, the multiple two sided arrows are intended to illustrate the dynamic quality of the disease and it's management.



### General Empowerment Principles

The recommendations for care continue with information about the concept of general empowerment principles. These principles are critical to the care continuum. They should be used to guide assessment and treatment during any part of the disease process.

The word empowerment has been used frequently during the past decade to depict a wide variety of social movements, particularly those addressing the concerns of disenfranchised groups such as minority populations, the disabled, and women. The term “empower” is defined as to give official authority or legal power and to promote the self-actualization or influence.<sup>18</sup> In this case, self-actualization means to maximize the potential of those affected by MS.

Multiple sclerosis is a chronic disease that changes an individual’s life and self-perception.<sup>19</sup> A person with multiple sclerosis, with the assistance of significant others and healthcare professionals, must manage symptoms, implement and adhere to or remain on prescribed treatments, and make modifications in life style and behaviors to adapt to his or her illness.

It has been theorized that empowerment may be likened to the concept of self-efficacy, the belief that one can achieve desired outcomes through behaviors. In multiple sclerosis, the uncertainty of the disease course and the negative perception about the illness itself, causes many people to feel hopeless and out of control. Patients’ personal beliefs about their capacity to manage environmental demands will affect the course of action that they choose to pursue. Personal beliefs will also impact how much effort they will expend, their length of perseverance, and how much anxiety or depression they will feel. A number of studies have documented that individuals with high self-efficacy are more likely to initiate and sustain a valuable activity.<sup>20</sup>

Patient and family empowerment is of profound importance to people with multiple sclerosis and is an important activity for the health professional in this field. Therapeutic actions to empower patients include the following:<sup>22</sup>

- Facilitate goal setting that will allow for mastery experiences. These goals should be realistic and both short-term and long-term and should take all relevant factors into consideration. The establishment of multiple incremental goals has been found to be a motivational technique to encourage a person to strive toward a long-term goal.<sup>23</sup>
- Provide experiences with other disabled people. Support groups provide opportunities for social modeling and for empathy by others who share similar feelings and experiences.<sup>24</sup>
- Provide ongoing affirmation. “Cheerleading” is an important function for the professional working with a patient who is facing a wide variety of challenges and may consist of verbal “applause” or acknowledgement of small and large accomplishments.<sup>25</sup>
- Maximize physical and psychological functioning. Optimal physical and psychological functioning are essential components to the enhancement of self-worth.<sup>26</sup> A fatigued and depressed person will be more susceptible to a sense of diminished self-worth and would be less apt to act on his or her own behalf.
- Provide motivation and encouragement that life has meaning. The MS professional’s ability to provide a patient with encouragement and a positive outlook is an essential art of caring. “While presence and availability are crucial elements to encouragement, offering statements of faith can also be very beneficial.”<sup>27</sup>
- Provide personal belief in the ability to cope. Genuine concern about one’s patient is an important feature of MS care. A non-threatening opening statement will invite your patient to share feelings and concerns. The MS professional can then elicit the patient’s previous coping strategies and evaluate how effective they may be in the face of a chronic disease, activity limitation and/or participation restriction.<sup>28</sup>

Empowerment is essential for patients, families and for the healthcare provider in dealing with multiple sclerosis and its widespread implications. Self-efficacy, self-confidence, skill development, and effective communication are vital components and key features to promote successful coping with this perplexing and vexing chronic neurological disease. The trick to empowerment is to learn and to teach others to focus on not “what was” but “what can be.”

In support of the concept of empowerment, these principles should guide the care of those affected by MS. They are consistent and timeless. These should encompass the family and relationship sphere.

Those affected by MS should have:

1. Full and timely access to healthcare
2. Timely and accurate diagnosis of MS, MS related symptoms, and non-MS-related conditions
3. Accurate information and skilled advice provided by experts in MS care
4. Treatment that is timely, appropriate, and cost-effective
5. Continuity of care
6. Collaborative and interdisciplinary approach to care
7. Care that is sensitive to culture
8. Support for health related quality of life issues (HRQoL).

Note: There is no consensus concerning the definition of quality of life, however there is agreement that it is a multidimensional concept. Health-related quality of life (HRQoL) takes into account three important life domains: physical, psychological, and social functioning and considers a person’s subjective perception of their well being in these areas.<sup>18</sup> Quality of life is normally measured by means of self assessment questionnaires, some of which have been specifically developed for people with MS.

#### Assessment

It is critical for assessment to occur at each part of the continuum. Assessment should include the following key components:

1. Determine:
  - a) current health status and HRQoL
  - b) care providers and home supports
  - c) patient’s and family’s physical, cognitive, emotional, and educational needs
  - d) financial, psychosocial, healthcare, and spiritual resources
2. Evaluate potential causes of symptoms (see Appendix C)
  - a) MS related
  - b) Non-MS-related
3. Review care plan:
  - a) adherence to current treatment regime
  - b) barriers to adherence and empowerment
  - c) evaluate for rehabilitation needs based on the full range of functions and disturbance of those functions (see Appendix D)
4. relationships with other care providers

### **CLINICAL EVALUATION AND DIAGNOSTIC CONTINUUM**

*Definition:* The continuum that includes pre-diagnostic, diagnostic, and post-diagnostic period. This waxes and wanes throughout the life cycle of MS and includes other diagnoses.

### Recommendations

#### **For patients that exhibit symptoms suggestive of MS:**

1. Refer to a neurologist, MS Center, or MS Clinic to establish and/or confirm diagnosis of MS, according to diagnostic criteria (see Appendix C)
2. The results of the diagnostic evaluation should be communicated in an appropriate setting in a timely manner

#### **Once the diagnosis of MS is confirmed:**

1. Post-diagnostic contact should be maintained with the interdisciplinary team
2. Information and support should be provided at an individualized pace
  - a) Offer supportive counseling options and informed advice
  - b) Discuss options for pharmacological/non-pharmacological management
  - c) Provide anticipatory guidance (genetics, family & career planning, etc.)
3. Utilize an interdisciplinary approach to establish a plan of care
4. Promote wellness focused activities
5. Refer to local MS Society or local voluntary organizations

#### **MILD TO MODERATE LIMITATION IN FUNCTION**

*Definition:* mild to moderate limitation in the ability to perform normal activities. This may be transient (acute exacerbation), or permanent (incomplete recovery from relapse or progressive disease).

### Recommendations

1. Post-diagnostic contact should be maintained with the interdisciplinary team
2. Information and support should be provided at an individualized pace
  - a) Offer supportive counseling options and informed advice
  - b) Discuss options for pharmacological/non-pharmacological management
  - c) Provide anticipatory guidance (genetics, family & career planning, etc.)
3. Modify plan of care
  - a) patients with acute relapses should have immediate access to appropriate therapy
  - b) access to appropriate disease-modifying therapies
  - c) access to current symptom treatments
  - d) ensure links with community resources (ie. home care, social services, MS society)
  - e) ensure access to aids, equipment, transportation, and adaptations for home, work, and leisure
4. Promote wellness focused activities

#### **SEVERE LIMITATION IN FUNCTION**

*Definition:* severe limitations in the ability to perform normal activities. This may be transient (acute exacerbation), or permanent (incomplete recovery from relapse or progressive disease).

### Recommendations

1. Post-diagnostic contact should be maintained with the interdisciplinary team
2. Information and support should be provided at an individualized pace
  - a) offer supportive counseling options and informed advice



- b) discuss options for pharmacological/non-pharmacological management
- c) provide anticipatory guidance (genetics, family & career planning, etc.)
- 3. Modify plan of care
  - a) patients with acute relapses should have immediate access to appropriate therapy
  - b) access to appropriate disease-modifying therapies
  - c) access to current symptom treatments
  - d) prevent, and, where necessary, alleviate complications [i.e. identify those at risk for skin breakdown, aspiration, nutritional compromise, sepsis (urosepsis), cardiopulmonary complications (DVT's, pulmonary emboli)]
  - e) minimize social isolation
  - f) ensure links with community resources (i.e. home care, social services, MS society)
    - a. access to aids, equipment, transportation, and adaptations for home, work, and leisure
    - b. access to personal home supports to maintain autonomy
    - c. access to respite if required
    - d. access to age-appropriate long-term care facilities if required
- 4. Promote wellness-focused activities

### Outcomes

The focus of the previous section has been on the recommendations for care of those affected by MS. Through the utilization of this approach to care and the management of care on a continuum, the following positive patient outcomes will be promoted and maintained.

#### **Those affected by MS will have**

1. A timely and accurate diagnosis
2. Knowledge necessary for disease management
3. Effective disease management skills and strategies
4. Adherence to integrated care plan that promotes empowerment
5. Functional abilities and safety measures maximized
6. Relationship with interdisciplinary team established and sustained
7. Optimal symptom management
8. Optimal HRQoL

Care management that stimulate research possibilities related to evidence-based practice

### Conclusion

The ultimate goal for these recommendations is to improve the care, clinical outcomes, and the quality of life for those affected by MS. This can be appreciated through timely access to care, accurate diagnosis, successful symptom and disease management, an interdisciplinary approach to the plan of care, maximized functional abilities, and attention to practices which promote safety. Regional differences and cultural diversity in the care of those affected by MS can not be ignored. Additional benefits from these recommendations include increased education of health care providers and payors. It is anticipated that the deployment of this model will promote standardization and efficiency that will influence a reduction of health care costs.

This publication is presented as a living document. It will continue to develop and grow as more knowledge and experience is gained in the care of those affected by MS. Consequently, the opportunities to engage in research will be plentiful as the management of care improves. The cumulative effect of improved clinical management and research will drive evidence-based practice and the sustained improvement in patient outcomes.

## Appendices

### **APPENDIX A:** Rating systems for evidence-based practice

- Table 1 - Strength of evidence and grade of recommendation
- Table 2 - Rating System for Levels of Evidence

### **APPENDIX B:** Clinical Course of MS

- Table 3

### **APPENDIX C:** Criteria for the Clinical Diagnosis of MS

- Table 4 – Schumacher Criteria for the Clinical Diagnosis of MS
- Table 5 – Poser Committee Criteria for the Diagnosis of MS
- Table 6 – McDonald, et al Diagnostic Criteria

### **APPENDIX D:** World Health Organization definition of terms

- Table 7 - Definition

## Appendix A      Rating System for Evidence Based Practice

<b><i>Table 1 Grading of Studies</i></b>
<p><b><i>Class I - Prospective, randomized, controlled clinical trial (RCT) with masked outcome assessment, in a representative population</i></b>            Required Traits</p> <ul style="list-style-type: none"> <li>• primary outcomes clearly defined</li> <li>• exclusion criteria</li> <li>• adequate accounting for drop outs and cross overs</li> <li>• baseline characteristics similar between groups or adjusted for</li> </ul> <p><b><i>Class II - Prospective matched group cohort study with masked outcomes that meets all of the traits or an RCT that lacks one of the traits</i></b>            Required Traits</p> <ul style="list-style-type: none"> <li>• primary outcomes clearly defined</li> <li>• exclusion criteria</li> <li>• adequate accounting for drop outs and cross-overs</li> <li>• baseline characteristics similar between groups or adjusted for</li> </ul> <p><b><i>Class III - all other controlled trials in representative population where outcome assessment is independent of treatment</i></b>  <b><i>Class IV- evidence from uncontrolled studies</i></b></p>

<b><i>Table 2 Rating of Recommendations</i></b>
<p><b>A</b> - Established as effective, ineffective, or harmful for MS population  <b>B</b> - Probably effective or ineffective  <b>C</b> - Possibly effective  <b>U</b> - Data inadequate or conflicting. Given current knowledge the treatment is unproven</p>

Goodin, D. S., Frohman, E.M., Garmany, G.P., Halper, J., Likosky, W.H., Lublin, F.D. , Silberberg, D.H., Stuart, W.H. & van den Noort, S. (2002). Disease modifying therapies in multiple sclerosis. Report of the therapeutics and technology assessment subcommittee of the American Academy of Neurology and the MS council for clinical practice guidelines

## Appendix B

## Clinical Course of Multiple Sclerosis

<p><b>Table 3 Relapsing Remitting MS</b> – 85% of people begin with this course.</p> <ul style="list-style-type: none"> <li>– Relapse defined as a appearance of new symptoms or a worsening of old symptoms, lasting at least 48 hours in the absence of fever, not associated with a withdrawal from steroids and preceded by stability for at least a month</li> <li>– In RR MS relapses occur with full or partial recovery and disease stability between attacks</li> </ul> <p><b>Secondary Progressive MS</b> – 50% of people with relapsing remitting MS will convert to secondary progressive MS over time.</p> <ul style="list-style-type: none"> <li>– Begins with relapsing MS but after time there is no period of stability</li> <li>– May have relapses but symptoms will progress or get worse between relapses</li> </ul> <p><b>Primary Progressive MS.</b> Occurs in 15% of people with the disease:</p> <ul style="list-style-type: none"> <li>– Symptoms of MS begin gradually and slowly worse over time.</li> <li>– There may be some stable periods</li> <li>– Often difficult to diagnose</li> <li>– Limited treatment options</li> </ul> <p><b>Progressive Relapsing MS.</b> Occurs in 5%. Primary Progressive onset followed by one or more relapses later in disease</p>
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Lublin, F. D., Reingold, S. C. (1996). (1996). Defining the clinical course of multiple sclerosis: Results of an international survey. *Neurology*. 46(2), 907 911

## Appendix C MS Diagnostic Criteria

**Table 4 Schumaker 1965**

<ul style="list-style-type: none"> <li>– Clinically definite, probable, possible MS           <ul style="list-style-type: none"> <li>• Based on age (10-50)</li> <li>• Objective neurological signs on exam</li> <li>• Neurological symptoms and signs that are of CNS white matter origin</li> <li>• Dissemination in time- 2 or more attacks lasting at least 24 hrs and separated by at least 1 month or progression of Signs and Symptoms over 6 months</li> <li>• Dissemination in space</li> <li>• No other explanation for symptoms</li> </ul> </li> <li>– Clinically definite if 5/6 criteria met—always including the last criteria</li> </ul>
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Schumaker, G. A., Beebe, G., Kibler, R.F. Problems of experimental trials of therapy in multiple sclerosis. *Annals of the New York Academy of Science*, 122, 552-568

**Table 5 Poser 1983**

<ul style="list-style-type: none"> <li>– Another committee convened as new technological advances allowed the identification of lesions that were not clinically evident</li> <li>– Allowed for “paraclinical” lesions-those identified by evoked response testing or neuro-imaging</li> <li>– Defined a laboratory-supported MS           <ul style="list-style-type: none"> <li>• Based on positive CSF findings               <ul style="list-style-type: none"> <li>– Elevated IgG levels, increased IgG index, presence of oligoclonal bands</li> </ul> </li> </ul> </li> </ul>
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Poser, S., Paty, D.W., Scheinburg, L. (1983). New diagnostic criteria for multiple sclerosis: Guidelines for research protocols. *Annals of Neurology*, 13, 227-231.

### **McDonald 2001**

- Large international committee funded by the NMSS and IFMSS convened to revise diagnostic criteria to include new technology
- Preserves traditional diagnostic criteria of two attacks of disease separated in space and time
- Must be no better explanation
- Adds specific MRI criteria, CSF findings and analysis of evoked potentials as means of identifying the second “attack”
- The group concluded that the outcome of the diagnostic work-up should yield one of three outcomes:
  - MS
  - Possible MS (if not completely clear)
  - Not MS

**Table 6 McDonald MRI Criteria 2001**

- Abnormal MRI consistent with MS defined as:
  - Must have at least 3 of the following:
    - 1 Gd-enhancing lesion or 9 hyperintense lesions if no Gd-enhancing lesion
    - 1 or more infratentorial lesions
    - 1 or more juxtacortical lesions
    - 3 or more periventricular lesions
      - 1 cord lesion = 1 brain lesion

**MRI Evidence of Dissemination in Time**

- A Gd-enhancing lesion demonstrated in a scan done at least 3 months following onset of clinical attack at a site different from attack
- In absence of Gd-enhancing lesions at 3 mo scan, follow-up scan after an additional 3 months showing Gd-lesion or new T-2 lesion

**Other Paraclinical Evidence**

- Abnormal CSF:
  - Oligoclonal IgG bands in CSF and not in serum
  - Or elevated IgG index
- Abnormal evoked potentials
  - Delayed but well preserved wave-form

**Monosymptomatic Presentation**

- One attack
- One objective clinical lesion

**Primary Progressive Criteria**

- Positive CSF, **AND**
- Dissemination in space:
  - MRI evidence of 9 or more T2 brain lesions
  - **Or** 2 or more spinal cord lesions
  - **Or** 4-8 brain and 1 spinal cord lesion
  - **Or** positive VEP with 4-8 MRI lesions
  - **Or** positive VEP with <4 brain lesions + 1 cord lesion, **AND**
- Dissemination in time:
  - MRI
  - **Or** continued progression for 1 year.

McDonald, W. T., Compston, A., Edan, G. (2001). Recommended diagnostic criteria for multiple sclerosis: Guidelines from the international panel on the diagnosis of multiple sclerosis. *Annals of Neurology*, 50(1), 121-127

**MacDonald Criteria Summary**

- 2 or more attacks
- 2 or more objective clinical lesions
- No other explanation
  
- New criteria utilizes MRI, CSF or evoked potential testing when only one lesion found and/or only one attack or when onset is insidious neurological progression

## APPENDIX D World Health Organization Definition of Terms

Table 7 ICIDH Terminology (Old)		ICIDH-2 Terminology (New)*	
Term	Definition	Term	Definition
Impairment	Any loss or abnormality of psychological, physiological or anatomical structure or function. (ie, blindness)	Impairment	A loss or abnormality of body structure or of a physiological or psychological function
Disability	Any restriction or lack (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being. (ie, disability in bathing, feeding, etc.)	Activity	The nature and extent of functioning at the level of the person. Activities may be limited in nature, duration, and quality.
Handicap	A disadvantage for a given individual resulting from an impairment or disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.	Participation	The extent of a person's involvement in life situations in relation to impairments, activities, health condition, and contextual factors. Participation may be restricted in nature, duration, and quality.
		Context	Includes the features, aspects, attributes of, or objects, structures, human-made organization, service provision, and agencies in the physical, social and attitudinal environment in which people live and conduct their lives.

\*From: World Health Organization. Geneva, 1999, Beta-2 draft, Short version (114 pages)

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