Future Perspectives

Exercise and lifestyle physical activity recommendations for people with multiple sclerosis throughout the disease course

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Abstract

Objectives: To provide clinicians who treat multiple sclerosis (MS) patients with evidence-based or expert opinion—based recommendations for promoting exercise and lifestyle physical activity across disability levels.

Methods: The National MS Society ("Society") convened clinical and research experts in the fields of MS, exercise, rehabilitation, and physical activity to (1) reach consensus on optimal exercise and lifestyle physical activity recommendations for individuals with MS at disability levels 0–9.0 on the Expanded Disability Status Scale (EDSS) and (2) identify and address barriers/facilitators for participation.

Recommendations: Based on current evidence and expert opinion, the Society makes the following recommendations, endorsed by the Consortium of Multiple Sclerosis Centers:

- Healthcare providers should endorse and promote the benefits/safety of exercise and lifestyle physical activity for every person with MS.
- Early evaluation by a physical or occupational therapist or exercise or sport scientist, experienced in MS (hereafter referred to as "specialists"), is recommended to establish an individualized exercise and/or lifestyle physical activity plan.
- Taking into account comorbidities and symptom fluctuations, healthcare providers should encourage ≥150 min/week of exercise and/or ≥150 min/week of lifestyle physical activity.
- Progress toward these targets should be gradual, based on the person's abilities, preferences, and safety.
- If disability increases and exercise/physical activity becomes more challenging, referrals to specialists are essential to ensure safe and appropriate prescriptions.
- When physical mobility is very limited, exercise should be facilitated by a trained assistant.

Keywords: Multiple sclerosis, exercise, physical activity, lifestyle physical activity, recommendations, wellness, disability

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Introduction

Wellness is a priority for people with multiple sclerosis (MS)¹ and can be achieved through health behaviors including physical activity and exercise.^{2–4}

Physical activity, including *lifestyle physical activity* and *exercise*, comprises any bodily movement produced by skeletal muscle contraction that results in a substantial increase in energy expenditure over resting levels.⁵

- Lifestyle physical activity is the daily accumulation of at least 30 minutes of activities, including all planned or unplanned leisure, occupational, or household activities that are at least moderate to vigorous in their intensity.⁶
- Exercise is a form of leisure-time physical activity that is usually performed repeatedly over an extended period of time (exercise training) with a specific external objective (e.g. improvement of fitness, physical performance, or health).⁵

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UAB/Lakeshore Research Collaborative, The University of Alabama at Birmingham, Birmingham, AL, USA These activities are distinct from *rehabilitation*, which is defined as intermittent or ongoing use of interdisciplinary strategies to regain or maintain optimal physical function, promote functional independence, prevent complications, and improve overall quality of life.⁷

Meta-analyses and systematic reviews of randomized controlled trials have demonstrated that people with MS who engage in exercise and lifestyle physical activity experience benefits from immune cell through quality-of-life outcomes. ^{8,9} Furthermore, exercise and lifestyle physical activity are safe for people with MS. ¹⁰ While initial studies established exercise as an effective symptomatic treatment (tertiary prevention), more recent studies have evaluated the disease-modifying effects (secondary prevention) as well as the impact on the risk of developing MS (primary prevention)—explaining why exercise and physical activity have been suggested as "medicine in MS." ¹¹

Unfortunately, MS patients are much less active than healthy controls. ^{12,13} One recent review by an international panel of experts highlighted the opportunity for neurologists, advanced practice clinicians, and primary care providers to promote exercise and physical activity in their patients, ⁹ and a recent study demonstrated that adherence to a physical activity program is higher when referral is made by a physician. ¹⁴ Yet, qualitative research indicates that many providers lack the expertise to do so. ¹⁵

This paper offers clinicians specific exercise and lifestyle physical activity recommendations—evidencebased when possible, and expert opinion where published data are lacking—for their patients at all levels of disability. The recommendations are tailored by disability level using the Kurtzke Expanded Disability Status Scale (EDSS)—a method of measuring neurologic disability in MS (see Figure 1 in Supplemental Appendix 1). Levels 0–9.0 (ranging from no disability to confined to bed) are considered in this paper.

Recommendations for the intensity of exercise/physical activity are based in part on an individual's perceived exertion level (subjective evaluation of intensity, effort, strain, discomfort, and/or fatigue during exercise). See Table 1a in Supplemental Appendix 1 for use of Borg's Rating of Perceived Exertion (RPE).^{17,18}

Methodology

The National MS Society convened international experts in the fields of MS, exercise, rehabilitation,

and physical activity (physicians, nurses, physical therapists, occupational therapists, exercise scientists, community health professionals) to (1) review the literature and reach consensus on optimal exercise and lifestyle physical activity recommendations for individuals with MS across major categories of disability on the EDSS and (2) identify and address barriers and facilitators of participation. The group used published exercise and physical activity guidelines^{19,20} as the starting point, supplemented by additional high-quality studies and expert opinion, particularly at the higher disability levels where evidence has been lacking. Sub-teams were created for three EDSS ranges corresponding to MS with mild impairments (0-4.5), MS characterized by greater mobility impairment (5.0–6.5), and MS characterized by diminished ability to carry out activities of daily living (7.0–9.0)—which are consistent with ranges used in the literature²¹ (see Figure 1 in Supplemental Appendix 1). Following a review of the recent literature, evidence-based and expert recommendations were created.

Exercise and lifestyle physical activity recommendations throughout the disease course

To assist clinicians who are unfamiliar with the EDSS, Table 1 provides clinical descriptors for each disability range. Tables 2 and 3 provide exercise and lifestyle physical activity recommendations, respectively, as well as key messages for individuals in those disability ranges. The recommendations reflect the minimum exercise and lifestyle physical activity targets for people with MS; however, each individual's starting point and rate of progress toward a target will differ. As disability increases and mobility becomes more challenging, so does the importance of personalized recommendations and guidance by a trained rehabilitation or exercise professional. For that reason, the EDSS level 7.0-9.0 has been sub-divided to allow for more specific recommendations for individuals with the highest levels of disability.

Barriers and facilitators to exercise and lifestyle physical activity

Table 4 presents the types of barriers that may reduce a person's ability to engage in exercise and lifestyle physical activity, as well as the facilitators that can increase a person's ability to do so.¹⁵

Discussion

Despite ample evidence demonstrating the benefits of exercise and lifestyle physical activity for people with

Table 1. Clinical descriptors for EDSS ranges 0–4.5, 5.0–6.5, and 7.0–9.0.

EDSS 0-4.5

- Symptoms: Ranging from no symptoms to mild-to-moderate fatigue, unsteadiness/imbalance, sensory changes, mild walking impairment, and reduced visual acuity; bowel and/or bladder symptoms; altered mood state; and cognitive impairment
- Neurologic impairments: Ranging from normal neurologic exam to mild-to-moderate impairments in proprioception, cerebellar function, vision, muscle strength/tone/endurance, bladder function, and cognition
- Functional limitations: Ranging from no limitations to limited endurance, unsteadiness, and impaired information processing and memory

EDSS 5.0-6.5

- Symptoms: Progression of any or all symptoms mentioned above
- Neurologic impairments: May include an increase in the impairments mentioned above, worsening gait (unilateral to bilateral spastic paresis, foot drop with compensatory hip hike, and circumduction with progression from unilateral to bilateral assistance and/or use of manual wheelchair), and upper extremity coordination
- Functional limitations: Limited walking distance (20–200 m); falls; inability to safely complete dual motor/cognitive tasks; work/home activities require adaptations, compensatory strategies, and mobility aids (ranging from cane to wheeled walker for daily use to a manual wheelchair for distances); transfers on/off the floor and into/out of chairs increasingly challenging; and requires assistance from support partner for more complex daily activities

EDSS 7.0-9.0

- Symptoms: Continued worsening of all symptoms mentioned above
- Neurologic impairments: Significant impairments in many or all systems, as mentioned above
- Functional limitations: *Gait*—from 10 ft with a walker to restricted to bed and wheelchair; *Transfers*—from minimal assist to total assist; *Bed mobility*—from minimal assist to total assist; *Seated balance*—from independent to total assist; *Standing balance*—from independent with bilateral support to unable to stand unaided

EDSS: Expanded Disability Status Scale.

MS, MS patients continue to be substantially less active than their counterparts in the general population. Many people with MS doubt their ability to be physically active. Fatigue, mobility impairment, depression, fears about safety, reluctance to engage in activities they cannot do as easily or well as they did them before, and lack of access to appropriate venues are just a few possible reasons for their inactivity. Neurologists, advance practice clinicians, and other healthcare providers can be powerful advocates for exercise and physical activity, emphasizing the benefits for disease and symptom management, overall health, and quality of life, and assuring their patients that it will not worsen their MS. Healthcare providers are encouraged to⁶³

- Ask routinely about a patient's exercise and physical activity habits
- Offer timely information about how and why to be physically active (benefits and expected outcomes) as well as guidance about exercise equipment, accessible exercise facilities, and transportation
- Suggest strategies to increase self-efficacy, accountability, planning and goal-setting, and self-monitoring, to help the person sustain her or his exercise and lifestyle physical activities.

Experts in the field are urged to collaborate with the National MS Society and other advocacy organizations to create, evaluate, and disseminate the materials needed by healthcare professionals to fulfill this role.

Every patient can benefit from guidance that is tailored to her or his needs, abilities, and preferences. To that end, recommendations for exercise and physical activity should include a range of options that take into account individual differences at every level of disability. While individuals with mild disability may continue to be as physically active as they always have, they may benefit from training by specialists in fatigue and energy management, and in ways to adapt their favorite activities to meet their needs. As the disease progresses and engaging in exercise and physical activity becomes more challenging, referrals to specialists are essential for ensuring that patients' exercise and physical activity strategies are individualized to best meet their needs. For these professionals to offer optimal interventions, the existing gaps in our knowledge must be filled by additional research—particularly at higher levels of disability. In the meantime, the expert recommendations in this paper complement the

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- Exercise is beneficial even if a person must do it differently than in the past
 - Referrals to exercise specialists/programs for individuals with chronic conditions can facilitate participatior
- Exercise recommendations should be tailored to address a person's needs/ capacity, as well as personal preferences
- Supervised training generally provides better results than non-supervised training
 - Exercise may temporarily worsen symptoms in patients who are heatsensitive

Recommended exercise strategies (existing guidelines)

- Aerobic: 2-3x/week; 10-30minutes at a moderate exercise intensity (40%-60% of maximum HR² or aerobic capacity), 11-13 RPE (on a 20-point RPE); 19:20.22 modalities might include arm, leg, or combined cycle ergometry; treadmill or overground walking, rowning, or jogging;²³ aquatic activities or upright stepping
- Advanced aerobic strategies:
- 5x/week, up to 40 minutes, 70% of peak aerobic capacity or 80% of maximum HR^a, RPE approaching 15 out of RPE 20 (or 5 out of RPE 10);19 modalities may include running, road cycling, and pole walking
- HIIT: 1x/week, five 30-90-second intervals at 90%-100% maximum HR, with equivalent rest, to replace a continuous bout of exercise; modalities similar to aerobic^{24–26}
 - Resistance: 2-3x/week, 1-3 sets for each exercise, 8-15 repetitions/set, 5-10 exercises;19 modalities might include weight machines, free weights, resistance bands, or body weight exercises
 - Flexibility: daily, 2–3 sets of each stretch, hold 30–60 sec/stretch; modalities might include yoga and stretching exercises 27
- Neuromotor: 3-6x/week, 20-60 minutes, interventions individualized for intensity and duration, targeting fall prevention, 28 postural stability, coordination, and agility at various levels of challenge (seated, standing, walking, upper limb); modalities might include Pilates,20 dance30,31 yoga, 32 Tai chi, 33 hippotherapy, 34 virtual reality, 35 and balance and motor control training 36

EDSS 5.0-6.5 (increasing mobility impairments)

Key messages

Recommended exercise strategies (existing guidelines)

Same as above

Same as above, plus

- Exercise is possible for people with increasing disability
- When balance is affected, adaptations to the exercise or the environment can reduce the risk of falls
- Referrals to specialists are more essential as disability increases, to assure safety, proper form, and appropriate intensity

Expert Opinion (in the absence of published data):

- Adaptive exercise may be desirable for some (e.g. recumbent hand-cycle or three-wheel bike for cycling, pole-walking)
- With the Borg 10-point scale, intensity would typically be between 2 and 6
 - Aerobic: heat sensitivity in some patients may require cooling interventions
- Resistance: functional/multi-joint movements (sit-to-stand, stair climbing, reaching); neuromuscular electrical stimulation
- Neuromotor: good clinical practice incorporates training in posture, coordination, and agility to prevent secondary impairments (i.e. rotator cuff impingement, Trendelenburg gait, low back pain, falls)

EDSS 7.0-7.5 (diminished ability to perform ADLs—non-ambulatory)

Key messages

 At this level of disability, all recommendations are expert opinion except where noted, due to lack of published evidence

Up to 20 min/day, 3-7 days/week (with each person working to her or his own maximum in order to make gains)—can be accumulated across

Recommended exercise strategies, EDSS 7.0-7.5

several shorter sessions, with rest breaks between repetitions and gradual progression in small increments toward the goal:

Every second day, 3 sets, 10 repetitions/set; resistive breathing apparatus (e.g. spirometer)³⁸

Flexibility Breathing

- Exercise is beneficial and achievable regardless of a person's level of disability
- Exercise at this level of disability needs to be guided by a specialist, but may Exercise can be independent (e.g. breathing exercises, arm movements) or facilitated by trained assistants (e.g. stretching, range of motion, transfers)

be carried out by trained family or caregivers

• Six 3-minute intervals at 70% target HR, active range of motion with resistance as able (e.g. arm cycling)³⁹ Upper extremities

• 3x/week, 3 sets, 10 repetitions/set or 10 sets, 3 repetitions/set, as able, with rests as needed; weights or resistance bands

■ 1x/day, ≥30–60seconds, hold/stretch all affected upper and 1ower extremity joints—combining stretches when possible

(Continued)

Table 2. (Continued)

n ADLs—non-ambulatory)	 Lower extremities Overground walking with walker as able (approximately 10ft) • 3 sets, 10 repetition/set of sit-to-stand, reducing assistance and support when possible • 3-5x/week, 30 minutes, power assist cycling⁴⁰⁻⁴² • 3x/week, 30-60 minutes, standing⁴³ • 2-5x/week, 30-60 minutes, standing⁴³ • 2-5x/week, 30-formittes, body weight supported treadmill training⁴⁴ Core • 2x/day, 4-5 repetitions of seated isominal muscle strengthening, holding each repetition 10-15 seconds • 3-5 minday of moving or stationary seated balance, unsupported or supported • Beery 1-2 hours, posture exercises (pull shoulder blades back/head up/straighten back), hold for 10-15 seconds • Consider the impact of immobility as well as disease progression on mobility status • Schedule rest breaks to allow for more exercises • Equipment needs are a major focus 	ing ADLs—confined to wheelchair)	Recommended exercise strategies, EDSS 8.0–8.5 Up to 10–15 min/day, 3–7 days/week with rests between repetitions Breathing • Same as 7.0–7.5 ³⁸ • Same as 7.0–7.5 ³⁸ • Same as 7.0–7.5 ³⁸ • Lixday, 3–30–60 seconds, hold/stretch all affected upper and lower extremity joints, with assistance as needed Upper extremities • Lixday, 3–30–60 seconds, hold/stretch all affected upper and lower extremity joints, with assistance as needed Upper extremities • Six 3-minute intervals at a target HR (or 70% effort), active range of motion with resistance as able (e.g. arm cycling) ³⁹ • 3x/week, 3 sets of 10 repetitions/set or 10 sets of 3 repetitions/set; weights or resistance bands appropriate to ability level Lower extremities • 2–3x/day, 1–2 minutes of standing frame ⁴³ Core • 2x/day, 3–5 repetitions of seated isometric abdominal muscle strengthening, holding each repetition 5–6 seconds • 1-2 min/day of moving or stationary seated balance, unsupported • Every 1–2 hours, posture exercises (pull shoulder blades backhead un/straighten back), hold for 10–15 seconds		-confined to bed or chair)	Recommended exercise strategies, EDSS 9.0 • Up to 10 min/day, 3–7 days/week as tolerated with rest as needed Breathing • Same as 7.0–7.5 ³⁸ Flexibility • Daily passive ROM of all joints with evidence of restriction • Active ROM as able FFS
EDSS 7.0-7.5 (diminished ability to perform ADLs—non-ambulatory)	Expert Opinion: • At EDSS 7.0–7.5, consider rehabilitation and exercise st • Caregiver training, especially at higher EDSS scores, is of Consider the impact of immobility as well as disease pro • Schedule rest breaks to allow for more exercises • Equipment needs are a major focus	EDSS 8.0-8.5 (increasing difficulty performing ADLs—confined to wheelchair)	Key messages Same as for EDSS 7.0–7.5 plus the following: • At EDSS 8.0–8.5, consider strategies that promote quality of life/fitness and reduce morbidity/mortality risks: endurance activities (e.g. arm cycling, lower extremity FES cycling) therapeutic standing, respiratory muscle training	Expert Opinion: • Same as for EDSS 7.0–7.5	EDSS 9.0 (inability to perform most ADLs—confined to bed or chair)	Key messages Same as for EDSS 7.0–7.5 and 8.0–8.5

EDSS: Expanded Disability Status Scale; HR: heart rate; RPE: Rating of Perceived Exertion; HIIT: high intensity interval training; ADLs: activities of daily living; ROM: range of motion; FES: functional electrical stimulation.

Table 3. Lifestyle physical activity recommendations and key messages for EDSS 0-9.0.

EDSS 0-4.5 (mild impairments)

Key messages

- Lifestyle physical activity can be accumulated as part of work, household, and leisure, activities
- Cooling strategies may be useful for those with heat intolerance

Recommended lifestyle physical activity strategies

- Options are: selected rather than prescribed, planned or unplanned/spontaneous, and accumulated in one long bout or multiple, short bouts throughout the day^{6,45}
 - Physical activity is facilitated through behavior change strategies/techniques (e.g. self-monitoring) and environmental stimuli/prompts (e.g. alarms or calendar notes)46
- Physical activity levels can be tracked through self-report (journal) or devices (accelerometry)^{47,48}
- Options include: 150 minutes per week or 30 minutes 5 days per week; 6.45.49 7,500 steps per day (0.5 standard deviation above the expected for the MS population and a clinically meaningful change);30 increasing daily steps by 800 per day (smallest MCID);⁵¹ or increasing daily steps by 15% per day (smallest MCID); Godin Leisure-Time Exercise Questionnaire health contribution scores of either 24+ or 14-23 units based on starting point of 14-23 or <14 units, respectively⁵²
 - Participation options
- o In-person behavioral education/coaching in groups or individually^{53,54}
- Remote physical activity behavioral education/coaching in groups or individually^{50,55,56}
- Lifestyle physical activity is sustained after support interventions are no longer present⁵⁰
- \circ Active gaming⁵⁷
- Environmental stimuli/prompts (alarms/alerts)⁴⁶

Expert Opinion:

- Evidence that most individuals with MS and in the general population do not meet recommended levels of physical activity has prompted a shift from exercise training for fitness toward lifestyle physical activity for health and wellness^{6,45}
- Options include walking, gardening, road cycling, hiking with poles, individual and team sports, and dancing
- Approaches for changing lifestyle physical activity can be delivered in person or through indirect channels (Internet, phone calls, or newsletters)⁵⁸
 - Motion sensors can help monitor activity and serve as motivation⁵⁹

EDSS 5.0-6.5 (increasing mobility impairments)

Key messages

Recommended lifestyle physical activity strategies

Participation options

Same as above Same as above

 Using the appropriate mobility aid can promote physical Same as above, plus

activity and safety

Adapted leisure activities can increase physical activity levels

Specialists can facilitate greater physical activity levels

Expert Opinion/Clinical Considerations:

Same as above, plus

• Inconsistencies may exist when recording step count for people using mobility aids

- Decline in the amount of physical activity often parallels the person's reluctance to use a more progressive mobility device
 - Adherence improves with enjoyable activities and ability to demonstrate progress toward goals

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- Functional movement of any kind, including ADLs, counts as Daily physical activity is essential physical activity
- Wheelchair sports/adapted physical activity programs may be appropriate and beneficial
 - Rehabilitation professionals can help persons integrate more physical activity into the day

Recommended lifestyle physical activity strategies 0 minutes weekly, as tolerated

- Walking, as able
- Manual wheelchair propulsion^{60,61}
- Power-assist cycling
 - Swimming
- Water therapy with skilled provider
 - Adaptive sports of all kinds
- Seated dancing, yoga, boxing Active weight shifting⁶²
- Pressure relief (front/lateral press-ups)

EDSS 8.0-8.5 (increasing difficulty performing ADLs—confined to wheelchair)

	messages Recommended lifestyle physical activity strategies	e as above 150 minutes weekly, as tolerated	• Active participation in ADLs as able, with assistan	
	Key messages	Same as above		
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• Pressure relief (front/lateral press-ups)

• Water activity with skilled provider

with assistance when necessary

• Bed mobility with assistance when necessary

EDSS 9.0 (inability to perform most ADLs—confined to bed or chair)

Same as above Key messages

Recommended lifestyle physical activity strategies As much physical activity as possible

- Bed mobility with assistance
- ADLs with assistance (e.g. dental hygiene)
- Standing in a pool or in a standing frame may be possible with skilled support
 - Passive pressure relief

EDSS: Expanded Disability Status Scale; MS: multiple sclerosis; MCID: minimal clinically important difference; ADLs: activities of daily living.

Table 4. Barriers and facilitators to exercise and lifestyle physical activity.

Barriers

- Physical environment—rural versus urban environments, home environment, community facilities, parking/access, transportation, and temperature/climate
- Social environment—limited support from providers/ family, exclusion, dependence, social stress, attitudes of others, cultural factors, and socioeconomic factors
- Health condition—fatigue, fitness level, symptom fluctuation, co-morbid health conditions, and medications
- Cognitive/behavioral—fear/apprehension, poor selfmanagement, frustration, low confidence, depression, impaired memory, planning and prioritizing, and focus
- Cost—gym membership, clinician fees, transportation costs, equipment costs, and childcare fees
- Time—perceived lack of time

Facilitators

- Physical environment—accessible, disability friendly venue, appropriate temperature, and visual instructions
- Social environment—role models/peer support, coachers/leaders, healthcare input, family support, assistance from others, and affordability
- Health condition—appropriate goal for disability, rest for fatigue, management of co-morbid health conditions, and fatigue management awareness/ approaches
- Cognitive/behavioral—accomplishment, selfmanagement, choice, self-monitoring, coping, perceived safety, diary, and commitment
- Cost—programs, grants, and equipment from MS advocacy organizations
- Time—improved time management and prioritization

MS: multiple sclerosis.

published guidelines to enable clinicians to promote and guide exercise and physical activity in their more disabled patients.

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Supplemental Material

Supplemental material for this article is available online.

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