Strong Medicine—Prescribing Exercise for People Living with Multiple Sclerosis

a report by

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Quality care of people living with chronic diseases such as multiple sclerosis (MS) means treating the patient holistically with all beneficial interventions, whether medical, surgical, behavioral, or spiritual. Everyone involved in healthcare is responsible for encouraging patients to adhere to therapies that may improve or sustain their health and quality of life. For this reason, I supported the Exercise is Medicine™ campaign of the American College of Sports Medicine (ACSM). The initiative was designed to encourage physicians to record physical activity as a vital sign and to advise patients to exercise for at least 30 minutes and stretch for 10 minutes on five days of each week. On the website for this program (www.may-kithappen.org) it is recommended that nearly two-thirds of patients would be more interested in exercising to stay healthy if advised by their doctor. Exercise may be the best weapon we have to fight disability progression in MS.

The drugs that we have to treat MS can help control the progression of the disease or help alleviate symptoms, but do not improve function. For this, rehabilitation is the best treatment yet.[1] Rehabilitation does not end with the interaction between therapist and patient. That is just the first step. The therapy must generate an individualized exercise program for the patient to use at home. Rehabilitation is akin to writing a prescription, but exercise is the medicine. Part of our job as physicians is to make sure that patients adhere to an exercise program. In this article I will review the principles of exercise prescription for people with MS.

Fitness Deficit in Multiple Sclerosis

Too many people with MS are not getting enough physical activity. The Centers for Disease Control and Prevention (CDC) recommends that Americans take 30 minutes of moderate intensity aerobic exercise on most days, or 20 minutes of vigorous exercise three times per week.[2] In a survey of people with MS living in Washington State, only 13% were meeting the CDC guidelines and 29% reported no physical activity at all for the past month.[3] Since Washington State has one of the highest rates of physical exercise in the country, this may underestimate the problem on a national scale. The exercise gap is also reflected in the relatively poor fitness demonstrated in MS studies conducted in the US and Europe. Findings include 35% lower daily ambulatory activity than in sedentary controls, 30% lower isometric and isokinetic leg strength, about 30% lower maximum aerobic capacity, and 28% lower aerobic endurance.[4,5,6] Since all of these fitness parameters are about 30% less than controls, we may think of this as the ‘30% off’ rule. This means that exercise instructors should anticipate about 30% lower exercise capacity at baseline for their MS clients than for healthy clients, and set appropriately conservative and established initial expectations that are conservative.

Some, but not all, studies have found that poorer exercise capacity correlates with greater disability in MS.[7] This is partly because impairments such as muscle weakness, spasticity, and ataxia increase the energy requirements for a given amount of activity.[8] On the other hand, exercise habits may make a difference in determining how disabled a person will become. A five-year longitudinal study of MS found that a greater baseline level of exercise predicted a slower rate of change in disability rating over the course of study.[9] Continued exercise throughout the five-year period was even stronger as a predictor of slower progression of disability.

Barriers to Exercise

Although many studies and reviews have supported the use of exercise in MS, and doctors and patients accept that exercise is important, exercise is underutilized. Why is this? My own surveys have identified two main factors: not enough time and not enough energy. People with MS have a lot to do. Trying to stay employed, meet responsibilities to friends and family, and dealing with the physical, medical, and emotional issues that arise from living with MS can be extremely time-consuming. This can make it hard to carve out time for exercising. Fatigue is probably the most common symptom complaint in MS, which creates another big barrier to exercise. A person may say, “I am too fatigued already, how can I take on an exercise program?”

Overcoming these barriers requires strong motivation. This means that health providers must consistently emphasize the importance of exercise to their MS patients. At each visit, providers should ask their patients about their exercise program (exercise as a ‘vital sign’), praise them when they are doing well with exercise, and intervene when they are not

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following the program. It is important to ask how they would like to exercise and ask what barriers stand in their way. Many communities have classes in aerobics, water aerobics, and yoga, among others, that can accommodate people with MS. Group exercises allow people with MS to encourage each other. However, for most people exercise needs to be more convenient, so it may be better to have simple exercises that can be done at home instead of programs that require expensive equipment at the gym or an exercise coach. A person should have indoor and outdoor options to take advantage of good weather and not be stymied by bad weather.

Principles of Exercise

The following is a summary of exercise principles for MS, including how to manage fatigue.

Individuality

Each person with MS has a unique combination of factors affecting their fitness level and exercise needs. These factors include baseline activity level, exercise tolerance, exercise knowledge and skill base, and gender and age-specific limits on power, flexibility, and aerobic capacity. MS may produce heat sensitivity, fatigue, limited bladder and bowel control, spasticity, ataxia, weakness, pain, and cognitive deficits, all of which exact a toll on the person's exercise capacity and possibly require a modified exercise program. It makes no sense to take a 'cookie-cutter' approach to exercise prescription. Everyone needs an individualized program that takes into account their personal fitness, health, and emotional status.

A first step in creating an individualized exercise program is to determine exercise history, likes, and dislikes. Ask about the person's current exercise program. More often than not, the answer will be that she or he does not have one. In that case, ask about their past exercise experiences. How have they exercised before? Where did they exercise? Do they still have notes about their program, perhaps something written down by the physical therapist or personal trainer who taught them? Was any special equipment involved and do they still have access to it at home, school, or a gym? It is usually easier to get a person to resume an exercise program that he or she followed before than it is to get him or her to embark on a new program. If a person has an exercise program that he or she enjoys, he or she will look forward to it instead of dreading it and this makes it much easier to sustain. Exercise history is a foundation that should be built on, not cast aside. If there is not enough time to talk about all of this during a clinic visit, patients can consult a physical therapist to develop an individualized home exercise program (HEP).

Specificity

Generally speaking, the training response to a given exercise stimulus is specific to the key performance element of the intervention. In other words, physical adaptations to exercise will meet the needs of the specific exercise. Only to a lesser extent will there be carry-over that improves other aspects of fitness and physical function.[10] This principle has been borne out by exercise studies in MS. For example, DeBolt et al. studied the effects of an eight-week lower-extremity resistance-training program in subjects with mild to moderate disability. The intervention produced a 37% increase in leg extensor power, but no significant improvements in balance, mobility, or spasticity.[11] Cattaneo et al. recently published a study demonstrating that a balance rehabilitation program was superior to a non-specific exercise program for reducing the frequency of falls and improving balance in MS.[12]

Exercises should be focused as much as possible on correcting the specific deficits and or meeting the specific goals of the patient. Therefore, if a patient's chief problem is gait instability, the first priority of an exercise program may be selecting weight-bearing balance exercises. If the patient wants to improve walking distance, treadmill training may be utilized with good results.[13] If a well-rounded fitness program is desired, combined training including both resistance exercises and aerobic exercises practiced alternately four times per week may be suitable.[14]

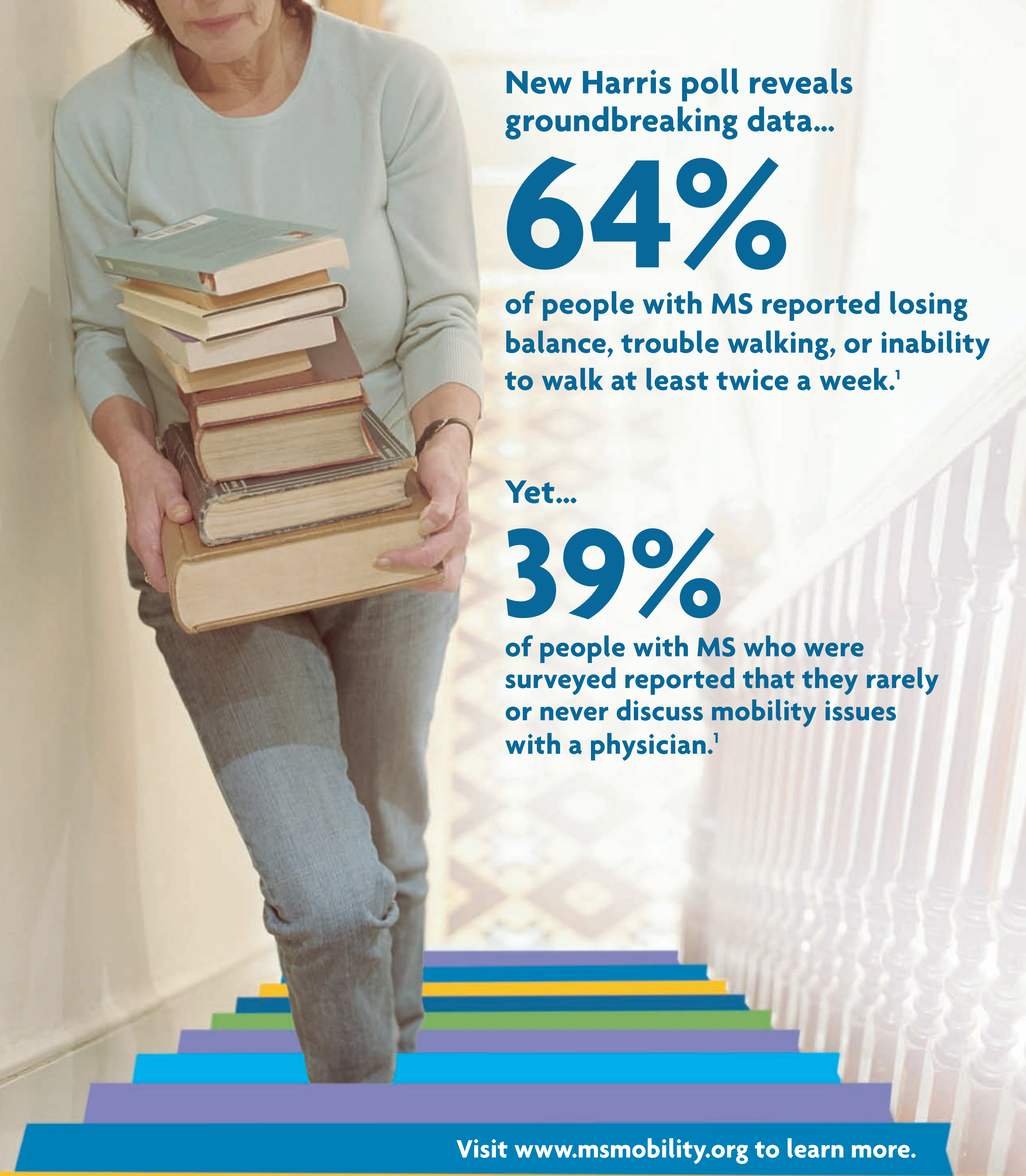
Exercise goals should be established at the beginning of the program. There is a useful mnemonic that provides guidelines for establishing exercise goals: 'be SMART.' The S stands for being 'specific' and not vague in defining goals. The M stands for measurable. Clear-cut goals that are based on something that you can count are better than goals that are qualitative and unmeasurable. The A stands for attainable. We want our patients to feel good about their programs and themselves. Self-efficacy is boosted when goals are achieved. Setting modest goals and gradually re-setting the bar at a higher level allows many opportunities to succeed. The R in SMART stands for 'relevant' to the problem. Keeping in mind the limited amount of time and energy that most people with MS can devote to an exercise program, the goals should address what is most important for the patient. Finally, the T stands for 'time-based.' Set goals in a time-frame. An intermediate term such as two months is a good amount of time to set for achieving the initial exercise goals. An example that combines all of these SMART elements for a person with MS, fatigue, mild ataxia, and osteoporosis would be to start a daily walking program with a pedometer, with the goal to increase the average daily step count by 1,000 by the end of the next month.

Moderate Intensity

We rarely use heart-rate monitoring in MS. To determine how hard someone is exercising, we monitor their breathing using the so-called 'talk test.' If a person can sing while exercising, they are performing mild-intensity exercise. If they can carry on a simple conversation, it is moderate intensity. If they are breathing too hard to talk, it is vigorous exercise.

There are a few good reasons to avoid vigorous exercise in MS. First, most patients with MS are de-conditioned and will have difficulty getting a good workout at a high level of intensity. For a de-conditioned person, vigorous exercise may bear more safety risks related to muscular injury, hypoglycemia, syncope, and falling. As a result, they will find it uncomfrotable, which may increase the likelihood of early drop-out. Vigorous exercise is also likely to exacerbate fatigue and cause a more rapid rise in core body temperature, leading to more problems with heat sensitivity.

In MS, we will usually start an exercise program at mild to moderate intensity and avoid intense exercise. When it comes time to expand an exercise program, we usually do so by increasing the exercise frequency (days per week) or duration of each exercise session by lengthening the time of one exercise or adding new exercises. New exercises may replace old exercises if the patient does not want to spend and excessive amount of time exercising.



New Harris poll reveals groundbreaking data…

64%

of people with MS reported losing balance, trouble walking, or inability to walk at least twice a week.[1]

Yet…

39%

of people with MS who were surveyed reported that they rarely or never discuss mobility issues with a physician.[1]

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[1] **Source:** Harris Interactive. *Experiences with Multiple Sclerosis (MS): Perspectives of People with MS and MS Care Partners* [poll]. Poll commissioned by: Acorda Therapeutics, Inc. and the National MS Society. March 25, 2008.

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Avoiding Exhaustion

Fatigue is the most commonly reported symptom in MS.[15,16] Many people with MS who are not exercising may hesitate to get started out of fear that exercise will make their symptoms worse. Others have experienced over-exercising that did actually heighten their fatigue levels. I recall one patient who had not been exercising for a few years as a result of a bad experience she had had with exercise. She said, "I would go hiking in the woods where I had no choice but to keep going or else there was no way back. When I became fatigued, I would try to ignore it and push on." This 'do or die' approach should be discouraged. Instead, tell MS patients to heed their body's signals. If they are starting to feel tired, it is best to switch to a non-fatiguing exercise such as balance training or strengthening of small muscle groups. They can also take a break, or switch to the cool-down part of the routine. Their tiredness indicates that they had a good work-out, but that they also need to preserve some energy for everything else that they need to do that day.

MS fatigue is not static. It fluctuates from day to day. If someone is having a bad fatigue day, he or she should take the day off or restrict the program to easier elements and stretching. Hopefully, they will soon feel ready to resume their usual program. Additional rules include:

- start low, go slow;
- when in doubt…don't!;
- if it hurts…stop!;
- do not do as much as you possibly can, but as much as you reliably can; and
- exercise should be a challenge, not a struggle.

If properly regulated, exercise fatigue may be less than most people imagine. Smith et al. tested fatigue responses to a single session of combined exercises in 34 subjects with mild to moderate disability.[17] The average duration of exercise was 17.5 minutes. Before exercising, subjects were asked to gauge their fatigue level at that moment and what they thought their fatigue level would be after completing the exercise. On average, they guessed that their fatigue level would roughly double after exercising. Immediately after exercising, the subjects were asked again to rate their fatigue levels. These had, in fact, hardly worsened at all. The study also documented that exercise frequently causes transient symptoms such as numbness in MS patients, but these symptoms resolve within an hour in most cases.

The evidence that an exercise program extended over a period of months reduces fatigue is mixed. Some studies have shown reductions in fatigue levels, while others have shown no change.[18–20] On the other hand, no study has found evidence of exercise making fatigue levels worse. Without exercise, the capacity for physical activity will gradually decline. There really is no choice but to exercise. Again, the key is exercise in moderation with a very gradual ramping up of exercise activity over a period of months.

Sustainability

Study after study has demonstrated the short-term benefits of exercise in MS. Many have limited the observation period to the duration of the intervention. However, studies that have followed up with patients for three, six, or 12 months post-exercise intervention have universally found a wearing-off effect.[1] Physical fitness parameters creep back down to baseline or below baseline. This is analogous to the patient with a chronic disease who stops taking maintenance drug therapy. What effect would we expect that to have on their disease? Put simply, an exercise program should be judged on how well it is sustained over months to years. There are several steps that may help maximize the longevity of an MS exercise program. MS patients should:

- get off to a good start by choosing a good exercise program;
- write down the elements of the exercise program so that they can refresh their memories later;
- keep track of progress by making an exercise log;
- exercise at the time of day when energy is at its highest;
- keep cool by staying well-hydrated;
- practice energy conservation for everyday tasks—budget activities to make sure that the things that must be done get done and less energy is spent on less important activities (occupational therapists can help with this);
- participate in group exercise or have an exercise buddy;
- get enough sleep and get help if not sleeping well;
- cut back on exercise during relapses to avoid injury and allow rest; and
- quit smoking, as smoking and exercise are incompatible.

Exercise for Severely Disabled People

Being confined to short-distance walking or wheeled mobility, a person with severe disability will receive less physical exercise through activities of daily living than his or her more able-bodied counterpart. De-conditioning and problems of restricted range of motion, bone demineralization, pain, spasticity, fatigue, and depression are more likely to occur. Common sense and clinical experience tell us that exercise is more important to this group of MS patients than to any other. Unfortunately, MS patients with advanced disease have received little attention in disease-modifying research; likewise, there has also been very limited exercise research in this patient population.

There really is a lot that can and should be done with exercise for MS patients with severe disablility. First, address any safety issues such as risk for falling. This will often require a physical therapy referral. While providing transfer training and gait training, the therapist can also evaluate exercise needs and establish an individualized program. The program can be practiced, fine-tuned, and re-enforced over a period of weeks of therapy. Sitting or standing balance exercises and upper extremity active range of motion (ROM) exercises can be incorporated into the program. Lower-extremity paralysis may preclude strengthening exercises, but it requires that passive ROM be taught to the patient and their caregivers to treat spasticity and avoid progressive joint contractures. Occupational therapy can be added a hand exercise program in order to maintain to teach a hand exercise program to maintain flexibility and fine muscle strength and control. Many rehabilitation centers have equipment for partial weight-supported treadmill training that can allow greater stability and support for gait training. Patients may advance from this therapy to walking in parallel bars or with a walker. Standing frames can be used to get a non-ambulatory person into a standing position, which may improve vasomotor control and bone density and reduce spasticity. Breathing exercises should be taught to those with paraplegia or tetraplegia. This can be done with an incentive spirometer, positive expiratory pressure device, or by simply practicing deep breathing combined with arm ROM. Most PT centers do not offer aquatherapy, but senior centers, Young Men's Christian Associations (YMCAs), and municipal pools do. Aquatherapy programs get disabled people into a pool to enjoy a different environment where they can mobilize limbs, walk, float, or swim. Arm–leg cycle machines enable non-ambulatory patients to get an aerobic work-out at home. There are several powered cycle machines on the market. These can be used to supplement the patient's cycling efforts or allow for passive ROM of paralyzed limbs. While prescribing an exercise program to a person with advanced physical disability, do not forget to include mental calisthenics. For example, ask the patient to read for 30 minutes a day and then to summarize what they have read by writing it down or discussing it with a friend or caregiver. If they cannot read, they could use audiobooks. Other popular mental calisthenics include crossword puzzles, playing cards and Sudoku.

Final Points

Keep in mind that health insurance coverage for PT and other rehabilitation services is usually good for people with MS. It is better to err on the side of referring patients to rehabilitation services rather than missing an opportunity to make a difference in their safety and fitness. When you see the person again, ask about their experience with PT or what therapy service was prescribed. Ask if they are still following the exercise program that was provided and whether it addressed all of their needs. This gives an opportunity for the patient to brag about what they are doing and for you to praise their efforts. Do not hesitate to send the person back to a therapist if they have stopped following their program or need a refresher. For MS patients who are not disabled, seeing a fitness trainer may help get them involved in exercise. The patient should make sure that the fitness trainer is licensed, and that he or she has some knowledge of the special exercise requirements of people with MS. Learn which therapists in your area have expertise in MS and gather a list of group exercise programs for adults with MS or other physical disabilities in your area. Ask the local chapter of the National MS Society for their list of local exercise groups. By showing MS patients that you think exercise is important, you will give them belief and hope. Exercise is medicine and for MS, it is very good medicine. ■

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NIH Grants Rush University $4.3 Million for Brain Trauma Study

Rush University has received a $4.3 million grant from the National Institutes of Health (NIH) for a five-year study into brain trauma rehabilitation. Rush, along with 10 healthcare facilities in North America, will study over 2,000 brain trauma patients involved in treatment programs covering physical therapy, occupational therapy, speech therapy, psychiatric support, and social support.

Rehabilitation rates will be analyzed to see which program or combination of programs is the most effective. Patients will be also be followed for a full year after being discharged to assess their quality of life and mobility. "Our aim in this study is to isolate individual components of the range of therapies we use to treat our patients and determine how, and to what degree, each is associated with improved function," said Dr James Young, Chairman of the Department of Physical Medicine and Rehabilitation at Rush.

The study won the support of NIH on account of its potential role in healthcare standards throughout North America. Until now, research into rehabilitation programs has relied on comparing random clinical trials. Problematically, each trial often focused on only one therapy, making direct comparison difficult. "From the extraordinary wealth of data we will collect in this five-year analysis, we will be able to offer clinicians the information that can help them evaluate their current treatment practices and select therapies that are most likely to help their patients," Young said. "This is medicine at its best: treatment based on the results of years of clinical practice." ■