



Making the outlook brighter for multiple sclerosis patients

► Allison Averill, M.D.

The course of multiple sclerosis (MS) is highly variable, and patients with the condition, who are generally young and in the prime of life, face a future of uncertainty. Fortunately, drugs approved for treating MS are improving the lives of many of them. These agents—interferon beta-1b, interferon beta-1a, glatiramer acetate and mitoxantrone—have been shown to reduce the number of demyelinating lesions, increase the time between exacerbations and decrease the severity of those attacks in patients with relapsing-remitting MS, the most common type of the disease.

Today, fully 75 percent of patients with MS never require a wheelchair, and 40 percent will

experience little or no disruption of normal activities, according to data compiled by the Multiple Sclerosis Foundation. It remains crucial, however, to manage the wide range of neurological symptoms that MS patients experience during exacerbations, as well as the permanent damage done by progressive or relapsing-remitting MS. Along with medications, a comprehensive rehabilitation program can help to decrease the debilitating effects of MS and optimize function.

Each patient is different

People with multiple sclerosis generally require rehabilitation treatment immediately after a significant exacerbation, to treat the symptoms of that exacerbation.

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Focus on

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To assure the survival of medical rehabilitation

► *Bruce M. Gans, M.D.*



When I first entered residency training in 1973, the prospects for inpatient rehabilitation looked bleak. Medical rehabilitation was struggling to prove itself in an environment characterized by ignorance and hostility. Outpatient capacity didn't exist, inpatient capacity was extremely limited, and patients with strokes or spinal cord injuries were routinely sent to nursing homes to vegetate or die. Our colleagues in neurology and other specialties thought the idea of helping patients achieve greater function and live more productive lives was holding out false and cruel promises to hopeless people.

Medical rehabilitation has since triumphed, despite those obstacles. But I fear our field is heading back to those primitive times.

That's because the very existence of inpatient rehabilitation is being challenged. Medicare's 75 percent rule is a formidable threat, with private insurers more than willing to see if they too can get bargain-priced care without regard for quality or outcomes.

But while those external threats are very real, internal threats are just as ominous. We still don't have expert consensus on standards to guide the placement of patients for rehabilitative services. We continue to lack the scientific evidence we need to differentiate inpatient rehabilitation from other types of care. We still display unacceptably wide practice variations, making the whole field vulnerable to charges of overutilization. Those of us in the Northeast and Mid-Atlantic regions, for instance, have a much higher rate of utilization for joint replacement patients than facilities in the Midwest and Pacific Northwest. And our own ranks are shrinking, as more physiatrists concentrate on outpatient musculoskeletal practice, not hospital-based rehabilitation. We have so successfully broadened the scope of our expertise that outpatient practice now threatens to overshadow the field's historic core of inpatient care.

All these factors suggest a possible future in which inpatient rehabilitation capacity is slashed, many of our jobs disappear, and patients either can't access care or run a much higher risk of poor outcomes.

What can we do to avert such a future? First, we can take the initiative to provide what we've asked the government for to no avail: a consensus panel to create appropriate, credible standards for deciding which rehabilitation setting is right for which patients.

We can push for research to generate the scientific evidence that will support those standards. We can continue to press for change on the local, regional and national levels, forging alliances with both the disability community and consumer groups.

We can remain open to evidence that may show we can provide the same or even better service in other settings. We can continue to recruit the best and brightest practitioners to serve our patients' needs.

And we can exemplify our responsibility as professionals, embracing change while staunchly maintaining the excellence of our art and science.

We have produced remarkable innovations that have revolutionized patient care and given new hope to people with disabilities. Let's act together now to ensure that future patients won't have fewer options because we've allowed medical rehabilitation to be dismantled.

Improving care for patients with lymphedema

► Jeffrey L. Cole, M.D.

Lymphedema is a lifelong condition that can put patients at a higher risk for infection and lead to functional or actual limb loss or even death. Without continual attention, lymphedema patients also face reduced mobility and diminished skills in the activities of daily living as a result of fluid weight gain and joint stiffness. Above all, lymphedema requires that patients be given extensive education in techniques for managing the disease.

Acquired lymphedema is documented in about 30 percent of patients with axillary and/or inguinal node dissection or biopsy, although only 3 percent of patients will have a significant clinical problem. Trauma and recurring infection of the glands can also result in acquired lymphedema.

The lymphedema program at Kessler Institute for Rehabilitation focuses on therapies for reducing fluid retention. Its goal is to reduce the increased volume by at least 50 percent. In a few patients, this has translated to a loss of more than one hundred pounds of fluid.

Three modes of treatment

The program generally consists of 20 sessions that can include three different or overlapping modes of treatment. The first makes use of pneumatic-medicine pumps, which have a multiple-chamber pressure system to force out fluid and open drainage channels. The second is manual lymphedema drainage

(MLD), in which a specially trained therapist uses massage and wrappings to soften and force fluid away from the swollen area. This is followed either by wrapping the area with a compression garment that may be custom-made or purchased over the counter or instructing the patient how to use wrapping that is removed only for bathing until the

for refractory patients. Following the 20 sessions, some patients chose to return on a monthly basis to continue MLD therapy.

Education is an integral part of the program. Patients are given extensive training about their condition and how to use massage and compression wraps. They learn how to avoid swelling as much as possible—and how to dress, employ stretching and range-of-motion exercises to keep joints limber and remove some of the danger from air travel and other high-risk activities.

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To prevent infection

An important goal for therapy and education is to avoid not only recurrent swelling, but also the dangerous infections that can occur. Lymph fluid collection serves as an ideal growth medium for infectious agents, and

underlying venous insufficiency and slow drainage further contribute to infection risk. If an episode of cellulitis does take place, patients are treated aggressively with antibiotic therapy.

With training, effective treatment of lymphedema—and of infections when necessary—patients are better able to meet the challenges of a normal lifestyle with this chronic and demanding condition.

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These “before-and-after” images show how lymphedema can be reduced if patients get the right combination of treatments.

next treatment.

The third mode of care is somewhat controversial and uses a drug called coumarin (5,6-benzo-alpha-pyrone), which is not FDA-approved for this purpose. This agent, used in Europe and Asia, has been reported to activate macrophages to reorganize the fibrin in the distended fluid in a way that reduces the surface area of the threads of the fibrin and thus reduces the sponginess of the tissue. The result is that less fluid is held by the fibrin fibers.

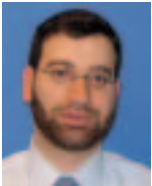
The first two drainage modes are used for all patients, but coumarin is employed only rarely

Getting stroke patients back behind the wheel

Many can return to driving, thanks to the training and adaptive equipment available today

Stroke patients' desire to resume driving is second only to their determination to walk again. At Kessler Institute for Rehabilitation, physicians, therapists and certified driving specialists are all helping to return stroke patients to the road. To do so, they're using extensive assessment and training, as well as a host of low-tech—and low-cost—adaptive tools.

Focus on Rehabilitation inquired about the program recently in a talk with Uri S. Adler, M.D., Kessler's director of stroke services, and Richard W. Nead Jr., Kessler's manager of driving rehabilitation services.



FOCUS: When deciding if patients can resume driving, what cognitive and physical skills do you assess?

ADLER: The two most vital cognitive areas are processing speed—which refers to patients' ability to obtain information and make quick adjustments—and the ability to multitask. From a physical standpoint, we assess patients' visual acuity, strength and fine motor control, and sensation. If they don't have sensation in their feet, for instance, they won't be able to tell how hard they are pressing a pedal.

FOCUS: How soon after a stroke does that assessment begin?

ADLER: The initial evaluation is immediate. Patients' performance in non-driving-related areas will often tell us when it is time for a formal driving assessment. Some patients can be assessed right away, while others need to wait.

NEAD: The sooner physicians deem it appropriate to evaluate patients, the better their chances are of returning to driving. Patients less than 12 months post-stroke can be referred

for additional therapy if they're not doing well after one or two driving lessons. For those more than two years post-stroke, though, we're often limited in the therapeutic interventions we can offer.

FOCUS: What deficits are the easiest and the hardest to correct?

ADLER: Weakness is easiest to correct with adaptive equipment. The hardest is hemineglect and hemianopsia. These patients ignore or don't see half of their environment.

FOCUS: What type of assessment tests do you use?

ADLER: We first assess strength, reflexes, memory, divided attention, ability to multitask and vision. If those results indicate that driving is a possibility, we follow up with a behind-the-wheel test in a car with brakes on the evaluator's side.

Based on those results, we make our recommendations. Perhaps driving is not a possibility in the foreseeable future. Or we recommend further therapy to focus on specific areas to be followed by another evaluation. Or driving lessons, with or without adaptive modifications.



FOCUS: What types of adaptive equipment are available?

NEAD: Patients with right hemiparesis or weakness often need a left foot accelerator, a device that runs from the original accelerator to the left side of the brake. Such individuals may also require a left-side spinner knob on the steering wheel, which allows them to turn the wheel with one hand.

Patients with left hemiparesis or weakness may need a spinner knob as well as a directional alternative, a mechanical crossover or electronic

device that relocates the turn signals to the right side of the wheel. Many stroke patients also have to compensate for some visual deficits with panoramic rear-view mirrors or fender-mounted side-view mirrors.

FOCUS: How long does it take to train patients on these adaptations?

NEAD: It varies based on the individual, but there is usually seven to ten hours' training on an adaptation such as a left-foot accelerator. That allows patients to develop the needed skills and prepares them so we can take them to the Motor Vehicle Commission and get them licensed to use that piece of equipment.

Some patients with minor strokes go by themselves to be tested on a driving course. The advantage of the Kessler program—and other certified programs—is that we assess and train patients in real driving situations.

FOCUS: How do you break the news to patients who can't resume driving?

ADLER: That isn't an easy conversation. You need to show patients objective evidence, such as test results, and give them the assessments of trained specialists and professionals involved. That can be problematic with those who, because of the stroke, don't realize they have anything wrong with them. At the same time, there are stroke patients who realize they are not fit to drive and willingly accept your judgment.

Although patients may at first think that not driving is "the end of the world," we counsel them about the dangers to themselves and others if they continue to drive. We also explore the many different resources available to achieve independence.

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Retooling constraint-induced therapy for more practical help for the stroke patient

► Yekyung Kong, M.D. and Patricia Judd, M.H.A., M.S., P.T.

Constraint-induced therapy (CIT) is an exciting rehabilitation treatment that—unlike traditional therapy, which is based on exercises and compensatory strategies—allows for active use of a limb weakened by stroke. Even people who had a stroke years ago and have little upper extremity control may benefit from CIT. But the original protocol for CIT has proved daunting for patients and family members, and the dropout rate has been high. To make CIT more patient-friendly, therefore, a less stringent form of the therapy was developed and is now an integral part of the long-term stroke program at KIR.

A challenging regimen

At first the protocol for CIT called for constraint of the less-involved limb in a mitt or sling for 90 percent of the waking day for a two-week period. The therapy itself was equally intensive, at six hours a day for the same two-week period. During the therapy, the patient chose two or three important activities, such as eating or tooth-brushing, and the activities were broken down into smaller components, repeated with assistance if needed, then expanded to include the complete activity. The theory behind CIT is that forcing the patient to use only the involved limb, combined with repeated and sustained practice of the functional activity, will facilitate cortical reorganization to enhance motor recovery and allow for maximal functional independence.

Although effective, the program itself was expensive, tedious and



Constraint-induced therapy is difficult by nature, but modifications make the protocol manageable.

frustrating for patients, and it also required significant commitment from both patients and caregivers. Safety issues arose when the patient was at home during the two weeks of constraint. In addition, the protocol was difficult to translate into clinical practice.

To make the method more manageable for patients and family members, researchers at Kessler Medical Rehabilitation Research and Education Corporation collaborated with doctors and therapists at Kessler Institute to develop the modified CIT program that the Institute now employs.

Improved compliance

The new protocol consists of 30 to 60 minutes of physical and occupational therapy, three times a week for eight to 10 weeks. In total, patients wear the constraint device

five hours a day, five days a week, including the time in therapy, and participate in a home program practicing functional tasks. Patients may also initially use other modalities to gain sufficient strength to progress to CIT, and Botox® may be used to combat spasticity that hinders movement of the affected arm and hand.

Studies show results for the new program that are comparable to the old one, with dramatically higher rates of patient compliance and satisfaction. Identical treatment protocols are used at all four Kessler facilities to measure the efficacy of the therapy. Outcome measures include initial and ongoing assessment with clinically validated measures of

motor function. The Stroke Impact Scale is used as well, to assess patient and caregiver perceptions of improvement and quality of life. The measures have demonstrated initial and persistent improvement in the use of the limb with CIT.

Constraint-induced therapy is now a prominent feature of inpatient and outpatient stroke rehabilitation programs and is used for both acute and chronic stroke patients. It is a promising new treatment that helps patients get better control of hand and arm function.

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The 75 percent rule: What comes next?

► *Bruce M. Gans, M.D.*

In February, the House of Representatives finally passed a budget reconciliation act that granted the field of rehabilitation a brief reprieve.

Due to monumental advocacy efforts on the part of the profession, the legislation provides for a one-year moratorium on the phasing in of the 75 percent rule for inpatient rehabilitation. The current 60 percent level of patient admissions—which was slated to jump to 65 percent this summer—will instead remain in effect until July 1, 2007.

The bill did not, however, include other key elements we've asked for in our long-running battle with the Centers for Medicare and Medicaid Services (CMS). Congress failed, for example, to call for appointing an advisory council to work with the CMS to craft a definitive fix to the 75 percent rule. That makes this one-year delay only a stay of execution, not the pardon we sought.

The good news is that the legislation gives us one more year; the question is, what should we do with this brief respite? We certainly need to use this time to continue to appeal to the rationality of legislators and regulators.

A little breathing room

We now have more time to engage the public and the disability community to join with us and press for an equitable fix.

We can use this time to do more as a field to produce the expert standards and evidence we need to determine what type of care is appropriate in different settings. Only when we have those data will public policy be founded on evidence, not bias or rhetoric.

And we should use this time to make sure that other types of facilities are not caring for patients inappropriately, providing services they're not qualified to deliver. We need to use this time to track such abuse—and to document the consequences patients suffer when they are denied needed services or have their access to inpatient rehabilitation curtailed. In that sense, this reprieve is perverse good news: As patients have poorer outcomes and access problems mount, the better the case we'll be able to build.

But even as we move forward on all these fronts, we need to be mind-

**Many smaller facilities
won't have the critical mass to
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ful of what we should *not* be doing during this critical time. We should not, for instance, interpret this one-year respite as a green light to admit patients who really don't belong in our facilities.

That is particularly true for patients with uncomplicated joint replacements. The field has agreed that these patients, if they are otherwise healthy and if alternative care is available locally, can be cared for in other settings. Any failure now to abide by that determination would only convince policy-makers that inpatient rehabilitation needs even tighter constraints.

We must also make sure that we don't put our financial needs before the needs of our patients. The fact is that many smaller facilities won't

have the critical mass to survive even a partial implementation of the 75 percent rule, let alone its full implementation.

We must ensure that institutions do not go beyond their clinical capabilities in an attempt to meet diagnostic mix requirements. For example, facilities should not seek to treat patients with spinal cord injuries when they do not have the experience, skills or services needed.

And we need to make sure we don't cling to unnecessary capacity in our communities, putting our own facility's self-interests before those of our patients and profession.

Instead of engaging in cut-throat—and dangerous—competition for patients, we should cooperate to reduce excess local inpatient rehabilitation capacity.

Tough decisions ahead

That may mean that smaller units will have to choose to close in order that larger units, free-standing hospitals and academic centers are able to stay viable. That surely is a difficult decision, but this is the time to ask ourselves hard questions about how well we are fulfilling our fiduciary responsibility as professionals.

Our efforts to reform the flawed 75 percent rule may well decide what options our patients will have, both now and in the future. At the same time, the integrity of our profession is at stake. Our actions now will determine whether we can sustain inpatient medical rehabilitation, even for patients who meet Medicare's restrictive criteria.

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A brighter outlook for multiple sclerosis patients

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New presenting symptoms may also require rehabilitation treatment.

MS symptoms vary widely, and no two patients are the same. Symptoms are caused by lesions in the myelin sheaths of nerve axons, which leave scars that disrupt neural transmission. The effects vary depending on where in the nervous system a lesion occurs. Issues such as motor weakness, sensory disturbances, ataxia, cognitive dysfunction and the like must all be addressed by the neurorehabilitation team.

Effective rehabilitation treatment therefore requires a broad interdisciplinary approach. At Kessler Institute for Rehabilitation, the neurorehabilitation team usually consists of a physiatrist, psychologists, nurses and physical, occupational and speech therapists, all of whom are trained and experienced in treating neurological conditions. With a coordinated approach by the neurorehabilitation team, most of the wide-ranging symptoms of MS can be alleviated.

Managing symptoms

MS encompasses virtually every aspect of rehabilitation medicine. Weakness, balance problems and poor coordination can be treated with physical therapy that is tailored to each patient's tolerance level. Dysphagia and dysarthria can be improved with speech therapy. Cognitive issues can be addressed with speech and occupational therapy; occupational therapy can also monitor and treat visual syndromes and improve ADLs, including driving. Bowel and bladder control problems can often be effectively treated with nursing care under the guidance of a urologist.

Combating fatigue and improving patient strength and general

condition make up another important component of MS rehabilitation. Fatigue is the most common symptom of MS; it can be treated with medication and physical therapy that is structured with appropriate rest periods.

One of the greatest challenges facing MS patients is depression. Patients must cope not only with the disability and exacerbations caused by the condition, but also with the uncertainty of their prognosis. The loss of a sense of control can lead to serious depressive episodes or chronic depression. There is also evidence that some of the drugs used to treat MS may increase depression. Treating the depressed patient with psychological and supportive counseling, as well as medication therapy, is therefore critical to help overcome this common and distressing complication of MS.

Managing MS patients and treating their symptoms are not always clear-cut, and there is often clinically more than meets the eye. The patient who shows unmistakable symptoms of paraparesis, for example, may also have cognitive problems that are less obvious. Additionally, the clinical picture can become clouded with pseudoexacerbations—symptoms that present as an exacerbation but are caused by another medical problem. One example is an apparent mobility problem that is actually the result of a bladder infection. The rehabilitation team is in an ideal position to identify and address both exacerbations and pseudoexacerbations of MS.

Improving function

Despite the uncertain prognosis for the MS patient, research shows that early treatment is key and can help to slow the progress of the disease. The agents used to treat the



Rehabilitation can help the MS patient maintain strength and balance.

condition have all been approved to treat relapsing-remitting MS and also progressive MS that is associated with exacerbations. Improving the functional status of MS patients is an important goal of both medication and rehabilitation treatment.

While the functional status and the severity of MS symptoms can change drastically in a short period of time, a multifaceted treatment plan with medications and rehabilitation therapy can decrease the number, severity and long-term effects of the exacerbations and increase functionality and independence for the MS patient. With optimal management that includes medical, rehabilitative and psychological support, much can be done to improve the long-term outlook for patients with MS.

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Soothing the agitated brain-injury patient takes the right environment—and a special touch

► Jonathan Fellus, M.D., and Laleh Jamshidi-Azad, C.R.R.N.

For patients with brain injury, agitation is a distinct stage of recovery. In the rehabilitation hospital setting, it can cause significant disruption and risk to patients and staff. Fortunately, much can be done to minimize the restlessness and aggression of the agitated patient.

Limiting environmental stimulation is a critical strategy for reducing and preventing agitation in patients. Restricting television, visitors, noisy roommates and loud equipment is just the beginning. Because the patient has no day-to-day memory, it is not possible to explicitly “teach” more adaptive behaviors. However, agitation is a stimulus-response behavior—a primitive reaction to a perceived threat—and staffers in the brain injury unit at Kessler Institute are taught specific behavioral and environmental strategies. They learn to “talk the patient down,” for example, using body language, tone of voice and other techniques.

Staffers also find out which stimuli reinforce agitation and which help calm the patient. Music, massage, relaxation training and certain visitors may have a positive effect. Other triggers may need to be removed or altered, such as bright lights, loud sounds or a family or

staff member who (usually unintentionally) antagonizes the patient. Rewarding good behavior is part of the strategy as well, including trying to engage and praise patients when they are quiet and compliant. Staff also learn, and teach family members, how to distract an agitated patient and direct attention to a less antagonizing stimulus, an invaluable tactic for helping to soothe the patient. These stimuli and triggers are discussed among staff during behavior rounds. When needed in severe cases, one-on-one sitters can be used as well.

Other behavioral strategies include adapting patient activities. Patients in the special care unit do not leave the unit, for example, but have therapy and meals in the quiet of small treatment gyms and dining areas. As patients improve, they move from the special care unit to the progressive care unit, where they take meals in the main dining room and therapy in the main gym.

Environmental strategies are also important for keeping the agitated patient safe and calm. For instance, brain injury patients often have mobility problems and impulsive behavior, a combination that adds up to a high risk for falling. Enclosure beds with mesh netting can therefore be used to confine the

patient to the bed, but allow for movement and use of the call and television buttons.

In addition, family members are encouraged to bring in photographs and posters to hang in patient rooms. Because confusion and memory problems are a common source of patient agitation, having familiar objects helps to orient the patient. Clocks, calendars and schedules also give the patient useful clues, as does keeping a memory book. The patient who does not remember an activity, such as calling a family member, and becomes agitated as a result, can be shown the entry he or she made in the book.

Managing the agitated patient in an effective way entails patience and experience. A trained staff that understands the special needs of this patient population is indispensable. Nurses, therapists, aides and housekeeping staff must all know their roles and be well versed in strategies for helping to minimize agitation to promote recovery.

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