

**NATIONAL MULTIPLE SCLEROSIS SOCIETY
MS LEARN ONLINE INTERNET PROGRAM**

**IMPROVING INDEPENDENCE
OPTIONS FOR RECREATION AND REHABILITATION**

>>Welcome, and thank you for joining the National Multiple Sclerosis Society's MS Learn Online Internet program. I am Rick Turner, your host and medical correspondent.

Among the first things you are told after being diagnosed with multiple sclerosis are the course of the disease is unpredictable and there is no cure. But this does not mean there is nothing you can do. A disease modifying therapy may be right for you. In addition, people live well with MS by making the most of what they have and using a variety of strategies to maintain function even if problems develop. In short, they manage MS with the rehabilitation approach to keep disabilities from shutting them off from life.

In this webcast, Dr. Susan Bennett is back to talk with us about rehabilitation and recreation opportunities available for people living with MS.

Welcome back, Dr. Bennett.

>>**Dr. Bennett:** Thank you, Rick.

>>**Rick Turner:** Dr. Bennett holds clinical appointments in the Departments of Neurology and Rehabilitation Science at the University at Buffalo, State University of New York where she also serves as Director of the MS Comprehensive Care Center within the Jacobs Neurologic Institute.

This webcast series is titled Improving Independence.

So talk to us Dr. Bennett about the roles recreation and rehabilitation have in maintaining independence and the options that exist for people living with multiple sclerosis.

>>**Dr. Bennett:** Thank you, Rick. First I want to reiterate a comment that you made. The advent of the medications that now are available to slow down the progression of the disease has really given individuals in rehabilitation an

opportunity to help people get better, to improve their function, to improve their strength, to improve their cardiovascular fitness. So really, rehabilitation now is focused on getting individuals better, not adapting to disability. Some times if the disease has progressed to a point where we start to have to deal with more limitations in mobility then we will deal with those.

But honestly, our approach is lets try and get you better, lets try and get you stronger. In doing that we have to do a good comprehensive examination, what I call a differential diagnosis, make sure we identify the correct muscles that are weak or the muscles that are spastic, get on a correct treatment program there, and then work with the individual to establish realist obtainable goals. Then in the end our big push in the Buffalo program is to promote wellness and health. We run a wellness program in our clinic. We have actually been successful in running that with the support of our local chapter for the National MS Society for over 13 years, and we are really proud of that program. Once individuals have completed their short-term rehab we can move them into our wellness program which runs twice a week as a means to keep them strong, fit, and promote that whole concept of health.

>>**Rick Turner:** So just like the name says of your care center, it is a comprehensive approach.

>>**Dr. Bennett:** Absolutely, absolutely.

Just to get into this assessment for a minute, Rick, before we start to talk about the role of various rehab providers, there are different roles that we play within the rehabilitation team; and all of us are going to look at function mobility, not only at home, but mobility within the community itself. Certainly performance of ADLs (activities of daily living) which might be dressing activities, kitchen activities, and such, and then certainly this underlying clinical testing so we find out specifically what is causing some difficulty, so we get on the right rehabilitation approach.

We can actually break down those impairments into two categories. We call them physiological problems which would be weakness, spasticity, numbness or sensory problems, sometimes incoordination or ataxia, balance dysfunction, and fatigue. Then we are also much more aware that there can be some psychological impairments as well. Some problems with memory, cognition, and sometimes behavior.

I would like to talk first about two little case scenarios which I think will help the viewers understand the role of rehabilitation.

The first case scenario is a 20-something female, very common in MS, a young woman who was referred for rehabilitation with an unsteady gait. She also had complaint of thigh pain and spasm in the thigh. When I examined this woman she did have an unstable gait, almost appeared to be limping or having a painful gait, and she tended to bend over towards her left side. When she was sitting and she would stand up, she would favor her right side so not even using the left side of her body. Then during examination I identified yes, there was pain in that thigh muscle, there was stiffness in the thigh muscle, and there was also weakness not only in the thigh muscle but in the hip muscles. Her major complaint was an unsteady gait so I needed to test her balance system. But when I tested her balance system, which we call the vestibular, which is inner ear and then ocular meaning vision, that was fine. No problem there. So my job was to figure out well why is she having problems with walking. Why is she unsteady? Well, based on the examination, the crux of the problem was weakness and spasticity. I put her on an appropriate strengthening program to work on strengthening the muscles as well as stretching those stiffer spastic muscles, and then a lot of specific training or what we call task-specific training to work on improving her gait. Well, I am happy to say that after eight physical therapy visits, she was back to wearing two-inch heels and not having any limp at all, and for a 20-year old, Rick, you can imagine she was pretty happy.

>>**Rick Turner:** I bet she was.

>>**Dr. Bennett:** This other case is very different. Still a 20-something female, works full time, but she is now having difficulty planning activities to be completed throughout the day. Her neurologist did send her to me for an examination, and when I examined her strength was absolutely normal, no limitations in muscle flexibility. She walked without limitation. She could get up and down the stairs, Rick, faster than I could. So physically she was fine. When I looked at her balance, no problem; she could even stand on one leg. But as I was talking with her during the examination and even as she arrived to our clinic, she had to call us several times to get directions. She kept getting lost as she was trying to find us and as we talked during examination she would get forgetful and she would start saying something and then forget and then back to it and such. So she seemed to be having some problems with attention, and certainly there were some problems in organization of her day. In this case the problems were difficulty

planning activities, following directions, certainly multitasking, and some memory deficits.

For her she needed to see an occupational therapist. My colleagues in occupational therapy can prescribe cognitive strategies that help with activity planning throughout the course of the day. They also teach the individual to use a memory log for completion of daily tasks. In this young woman's case, she did not need physical therapy, but you can bet I recommended it because we know that general exercise and wellness is good for general circulation and getting that oxygen and glucose in the blood up to the brain, which from some other studies have suggested that can help with cognitive dysfunction. So she did not need physical therapy, but I did prescribe a wellness exercise program, but I did refer her to one of my colleagues in occupational therapy for a more comprehensive evaluation.

So the summary of these two cases is that you can see individuals will come to us with different types of problems. Our job is to figure out what are those problems and get them on the right course of treatment program and make sure they are working with the right health care provider.

The next series of slides, actually for the viewers, are quotes directly from our National MS Society web site. When we talk about a rehabilitation program our goal again is to restore functions essential to daily living in individuals who have lost these capacities through injury or illness. And our goals for rehabilitation are certainly to be comprehensive in nature.

When we are talking about rehabilitation we usually refer to occupational therapists, physical therapists, and then speech therapists who are also referred to as speech and language pathologists. The OT as I mentioned with that one case, an occupational therapist will focus not only on those cognitive memory issues, but they also focus on specific activities of daily living such as grooming activities, dressing, eating, hand writing, even some driving retraining. Occupational therapists will also work on more fine motor controls; so if you are having difficulty with buttoning or zippering, they can come up with some of those assistive or adaptive devices to help with that task. They also participate in evaluating assistive devices, specifically wheelchairs, and they are great at looking at energy conservation: how to get through the routine of your day and save as much energy for the things that we enjoy doing.

In my role as a physical therapist, certainly we prescribe a lot of stretching and range of motion exercises and exercises to work on strengthening of the arms, the

legs, the trunk. Certainly we play a role again helping the individual identify an appropriate assistive device that might be needed for mobility, maybe an orthotic that might be needed. And then we do a lot on patient and family education because again we want to promote this concept of health and wellness. Maybe a short-term rehab stint is needed to get the individual back to where they were prior to the flare up or exacerbation, and then promotion of how do you stay that way. How do we keep you healthy and promote the whole concept of wellness.

My colleagues in speech and language pathology work a lot in multiple sclerosis with difficulties in swallowing. So there might be problems with weakness or incoordination of the face and tongue muscles. Individuals may also have difficulty with speaking, a dysarthria, and that again is a problem with coordination of muscles of the face and tongue. So the speech therapists play a great role here. The viewer should also note that speech therapists also do cognitive retraining just as the occupational therapists do. In regards to this cognitive retraining which we have been talking about, this really is a new area of rehabilitation specifically in MS, and this is right from the National MS Society web site. "Some rehab centers have innovative programs designed to help." "People compensate for loss of memory or slowed learning ability." "Frequently you may be referred to a neuropsychologist, a speech language pathologist, and/or an occupational therapist" to help identify specifically what the difficulty is and make sure we get you on the right rehabilitation approach.

Finding rehabilitation providers is key, finding someone who knows MS. I cannot stress that enough. Unfortunately I have had people be referred to me that have previously seen some of my colleagues that might specialize more in back injuries, neck injuries, knee injuries, and we cannot know everything, and my colleagues in those areas are great for knees or backs, but they do not know MS. So you want to make sure you get to see a rehab provider that knows multiple sclerosis, and to identify that individual, again, contact your local National MS Society chapter who will be able to refer you to an appropriate rehabilitation provider that understands MS and is going to help you work on improving your function mobility and certainly your quality of life.

>>**Rick Turner:** Dr. Bennett, I wonder how often you get patients who have gone just to their local gym to get physical therapy for an MS condition?

>>**Dr. Bennett:** Absolutely, Rick. That is another great comment. In some of our previous webcasts we have talked about the concern of not pushing through fatigue, not over exercising, because we do not want individuals to exercise and

have ill nor negative effects. We want them to exercise and feel great. Sometimes going to one of these gyms or fitness facilities, working with a trainer who does not know MS, they may push the individual a little bit too hard, and then the individual has a negative thought about exercise instead of thinking about how it can really derive positive benefits for the body. So that is a great point.

A lot of people though, to be honest with you, Rick, they do not like the type of exercise that I have been talking about. They do not like range-of-motion exercises or using resistive bands or using weights. They want to do something that is a little bit more enjoyable. And that is important, finding the right exercise program that you like to do means that you are likely going to be more compliant in doing it. Meaning you are going to adhere to that exercise routine.

So I just want to take a couple of minutes and share with our viewers a couple other types of recreational options that also have terrific value from an exercise component. We are going to talk about yoga, music therapy, which is a new favorite of mine, aquatic exercise, and hippo therapy or therapeutic riding.

Yoga has been around for a long time. There have actually been some very good studies. One that I put a quote on from the UCLA MS Achievement Center “yoga enables patients with multiple sclerosis to control or reduce symptoms, specifically pain and spasticity.” A study has been conducted at the Oregon Health and Science University showing that yoga can also reduce fatigue in patients with MS, and we have talked already about how that fatigue can be a major impairment.

This next slide that the viewers are looking at has an example of a yoga task, and my thanks to a colleague of mine here in Buffalo, Connie Brignole-Sawicki, who was starting to introduce me to yoga. It is just some simple things to think about. Obviously first by sitting up nice and tall in your chair, concentrate on just breathing slowly in and out and really thinking about the cool air coming into your lungs and then the warm air that you are blowing out. All you do for a good two to three minutes is just concentrate on your breathing, nice straight posture and just breathing nice and slow. Then as you are in this position you start to elongate your neck slowly so that actually straightens your back out even more. Then as you neck starts to become elongated or stretched, you work on squeezing your shoulder blades together, hold that and continue with that nice deep breathing. Then to get at those abdominal muscles, that is always a factor for us because when our abdominal muscles are weak that leads to more back injury, you try to think about moving your navel toward your back, hold that and breathe, and that starts to tighten those abdominal muscles. Then the last think that Connie recommends on

this very simple yoga task is as you are sitting there you think about sitting on your what they call sit-down bones, anatomically we call them the ischial tuberosity, but it is those two little bones in our hips that we are sitting on and think about shifting your weight so you are putting most of your weight forward on the bones, and then sit back, and then as you sit back you would actually be more on the buttock area, then you sit forward which give you a nice erect poster and then you sit back. So you are going through this nice yoga routine, and honestly once you have done this for five or ten minutes, you will definitely feel relaxed.

Now music therapy is a new area for us in multiple sclerosis. There has actually been some research done in individuals with Parkinson disease and definitely looking at music as a specific stimulus to increase activity, increase movement, increase arousal. So some research has been done in Parkinson's looking at the benefits of music therapy. Certainly we know when you are sitting at home or sitting in your car and listening to the radio you get a familiar tune that comes on and it has a nice upbeat to it, you are going to start to kind of bounce your head or you might start tapping your foot, you might even start snapping your finger. We know that music naturally just stimulates some physical and emotional responses. We should think about using music while we are exercising. The key concepts here, if you are looking to relax and unwind at the end of the day then you want slow, passive music, something calming. But if you are going to do some exercise, and you want to use music as a stimulus to help you do your exercise, then you want something that is much more upbeat, maybe even turn the volume up a little bit more, something that is going to get you tapping your toes and clapping your hands. That is the type of music we would want that would promote more activity. We have done a short program, again, here in Buffalo with music therapy, and I have to tell you, Rick, one of the greatest things about it is everybody that participates has a huge smile on their face. They just love listening to the music, and they are not even thinking about the fact that they are doing arm exercises and leg exercises while they are listening to the music. We are just all kind of doing rhythmic activity together but we are motivated by the music, which is the stimulus.

>>**Rick Turner:** Just get swept up in it.

>>**Dr. Bennett:** That is right. And, again, we want to have fun while we are exercising, so you want to find something whether it is yoga, whether it is music therapy or maybe aquatic therapy. You want to enjoy the exercise that you are doing.

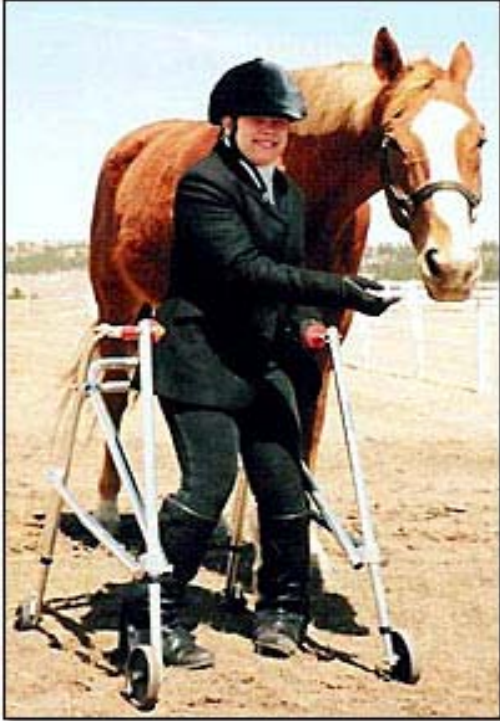
Aquatic therapy we have known for a long time can have terrific value in MS. The whole buoyancy of the water unweights our body. We ran a program here in Buffalo a couple years ago, and it was just remarkable to me an individual who I had been working with who walked with two forearm crutches, so a crutch on either side, and when he would walk he had difficulty advancing each leg forward. When he got in the pool and he was in water just a little bit over waist high without his crutches, Rick, he walked right across the pool, one foot after the other. So that whole concept of the buoyancy of the water which decreases the stiffness or spasticity unweights the body, allows the muscles to be used a little bit more effectively, is just a terrific effect for people with MS. The problem we have to watch for that we encounter is individuals feel so great in the water they do not want to get out. So I would say okay in 15 minutes everybody has to get out. No, just another five minutes. Okay, 20 minutes everybody has to get out, No, just a little... and by the time we got them out, they overdid it because they did not realize how much they were using their muscles, and then they were more fatigued.

>>**Rick Turner:** And maybe being in the warm water you do not have as much awareness of how much you are working.

>>**Dr. Bennett:** Another great point, Rick, because we do have to worry about the temperature of not only the water but also the air in the pool region. If the pool area is hot and humid, that certainly could bring on some symptoms for our individuals with MS. If the water temperature itself is hot, that again could cause some problems, so we have to be sensitive to the air and water temperature, and then not overdoing it, so good points to bring up in regards to that aquatic therapy.

The last one is another type of recreation therapy that has been around for some time referred to as hippo therapy, which is actually a Greek term or also called therapeutic riding. I actually downloaded this picture that the viewers are looking at from a web site called the Pine Creek Foundation where they have run a therapeutic riding program for several years. This young woman, as the viewers will see, is using a walker to get around because of her limitations. She does not have MS. She has another disability, and you see her standing next to her horse, giving him a carrot. The next picture is terrific. Look at the change in her posture. Now she is sitting upright on her horse. Her posture is terrific. The position on the horse allows the pelvis to move forward as it should, the legs are now moved apart in what we call abduction, the knees are slightly bent. Just sitting on a horse is wonderful stretching as well as strengthening for the hip and trunk musculature, and then as the horse is led around the ring by either an OT, speech therapist, or PT, you get that nice rocking motion of the horse which also helps stimulate more

pelvic and leg activity. So therapeutic riding is terrific value in muscle tone, decreasing spasticity, getting movement in the hip and pelvic joints, and then strengthening because obviously their feet are in the stirrups, so they are doing some weight bearing through the stirrups. So another terrific type of exercise.



>>**Rick Turner:** That is also fun.

>>**Dr. Bennett:** Absolutely. Again, it brings a smile on the individual's faces.

So the most important key here, Rick, just to summarize for the viewers, get active. Find something that you like to do because if you like to do it there is a greater likelihood that you are going to stick with that program. And get with something you enjoy doing because the benefits of exercise for all of us are so important and even more so for individuals that are living with MS.

>>**Rick Turner:** Well, Dr. Bennett, this ends our series Improving Independence. It has been an honor to have you with us. Thank you so much.

>>**Dr. Bennett:** Thank you very much, Rick.

>>**Rick Turner:** The National MS Society is proud to be a source of information for you about multiple sclerosis. Our comments are based on professional advice, published experience, and expert opinion, but do not represent individual

therapeutic recommendation or prescription. For specific information and advice consult a qualified physician. If you have a question that was not addressed, please e-mail us at mslearnonline@nmss.org. If you would like more information on multiple sclerosis, click on the resources link on your screen or call the chapter nearest you for an answer to your question. You can reach your chapter by calling 1-800-FIGHTMS. That is 1-800-344-4867. You may also want to check the National MS Society's web site where you will find more information about today's topic and a menu of other web casts available to participate in.

Funding for this program was provided from Biogen Idec.

For the National Multiple Sclerosis Society I am Rick Turner wishing you health and happiness.