

Finally, Treatment for Cognitive Difficulties with MS!!

Dr. Miriam Franco, MSW, Psy.D., MSCS and Dr. Rita Carroll, Ph.D., CPCRT, Founder of Main Line Rehab, An In-Home Cognitive Rehabilitation Program in PA

Cognitive difficulties are common symptoms of MS. It's estimated that 60% of folks with MS experience problems with short term memory and have trouble sustaining concentration and attention. Some experience cognitive decline later as their disease progresses. Some experience changes in cognition early on because of the location of a lesion and some never do. It's only been in the last two to three years that neuro psychologists have been able to identify the specific ways in which cognitive decline occurs within MS as distinct from other diseases. As a result, some cognitive rehab clinics now exist that provide a more radical and broader approach to treating cognitive issues. Large research pilot studies are now underway to document these effects. As a psychologist, I had few if any treatment or resources available to my MS patients for cognitive difficulties until recently. That changed when I met Dr. Rita Carroll of Main Line Rehab in the Philadelphia suburbs where I practice. I was excited to learn that she had developed a program working one on one with persons with MS in their homes to either prevent or delay cognitive decline. Her program is providing exciting, new opportunities to treat cognitive problems that is changing how we think and cope with MS. I invited her to share her impressions and experience with the MS Focus community in the following interview.

Miriam: *You know, Rita, cognitive problems are very common symptoms of MS including short term memory loss, problems sustaining concentration, problems with naming, even sometimes some decreased social judgment. And yet, I find it is rarely discussed by MS practitioners with people with MS. There was an unintentional attitude of: If there is no treatment to offer, why talk about it? For those with MS, it was scary to think about cognitive impairments in addition to having to cope with the other effects of MS on their quality of life. And, it is terribly misunderstood. Because people with MS can be very expressive and not struggle with communication they don't present the same way as do others with diseases that affect thinking.*

Rita: You're right. Some studies are showing it might be as many as 75% experience cognitive issues with MS. But, most people do not know about that aspect of MS. Cognitive issues can have a profound impact on the person with MS and the family, as well. The person with MS may not understand why they are forgetting things, or having difficulty following conversations, or planning their day. Coupled with that, family

members are confused by changes in behavior and don't realize that cognitive changes impact behavior and function. These changes can be frightening and overwhelming, and often overlooked by medical professionals.

Miriam: *As a rehabilitation specialist, what are the typical ways you see MS affecting thinking and memory?*

Rita: Mostly we see an impact on concentration and focus, memory, and executive functions. Concentration and focus is essential to pretty much anything a person does, so strong attention skills are very important. If there are issues in this area, then every other cognitive skill can be impacted.

Memory issues can be more than just forgetting a shopping list or instructions from a supervisor at work. It can be holding information in your head long enough to do something with it, like remembering the cost of your latte at Starbucks, long enough to pull out the cash to pay for it.

Then there are executive functions. Problems with executive functions can impact planning, organizing, adaptability and problem solving. These skills are essential for successfully functioning in everyday life.

Miriam: *So how exactly would one know if they are experiencing cognitive decline? And does it typically occur as the disease progresses?*

Rita: Sometimes the person with MS is aware of the change in thinking. It may take longer to get things done, or they may get feedback at home or at work that they didn't do what was asked, or forgot something. Perhaps, there are difficulties with routine banking, or trouble figuring out how to solve a household problem. Sometimes people with MS have issues with keeping appointments and multitasking. These are some of the common complaints that signal cognitive issues. And these kinds of things can show up suddenly and wreak havoc on how a family functions.

There can be huge variations in the way cognitive issues show up and the progression of the disease. And the potential for a corresponding cognitive decline is different for each person. As the disease can impact various parts of the brain, each person is likely to have a different set of cognitive issues depending on where lesions in the brain are located.

Miriam: *Should everyone get neuro psych testing? Are there other ways to assess this?*

Rita: Neuropsych testing is incredibly helpful when it's available. It helps to document very specific cognitive abilities. When a neuropsych test is done well, it identifies areas of cognitive strength and weakness and can be very helpful if a person embarks on a course of cognitive rehabilitation or just wants to know what their cognitive deficits are.

With that being said, functional assessments can be an even more powerful tool. Cognitive Rehabilitation specialists can evaluate function in the home and community to tease out the cognitive issues that impact function. Interviews using formal and informal measures can round out the assessment.

Miriam: *So is there REAL help?*

Rita: Absolutely. Cognition and function can be retrained through home and community based Cognitive Rehabilitation Therapy (CRT). CRT has been an integral part of rehabilitation for people with head injuries for decades. There is a growing body of evidence that CRT can be an effective tool for improving cognitive skills and that these skills can be generalized to apply to a variety of settings.

Up until recently, most of the CRT for people with MS has been conducted in the rehab hospital or clinic setting. This is great, but CRT can be **so much more effective and relevant when provided in the person's own home and community**. As skills are developed and practiced in a variety of ways, and strategies are fine-tuned, the person has the opportunity to immediately put them into practice in the real world, and receive instant feedback or cueing from the therapist to improve performance. And as the person makes progress there is typically a level of hopefulness restored. This also helps to boost confidence, and promotes community access and engagement.

Miriam: *What exactly is cog rehab treatment? What can it do? What's involved? When should one start it?*

Rita: Cognitive Rehabilitation is direct retraining of skills lost or altered due to a disease or injury. The goal is to improve cognition, compensate for deficits, and restore function, through education, skills training, strategy development, functional application and building awareness.

CRT promotes neuroplasticity which is the brain's ability to reorganize its structure, function and connections in response to internal and external stimuli. And CRT helps to improve cognitive reserve which is believed to be protective against cognitive decline.

Also, CRT can complement the effectiveness of medications, and it can build awareness, confidence and hopefulness.

A lot of the CRT being provided right now is computer based, but this really should only have a small role in the CRT session that ideally includes real life strategy and skill development and application in many settings. CRT should be uniquely tailored to the person's abilities, goals, environment and support system. **This isn't about running someone through a program. Rather it is about seeing each person as an individual with unique needs and creating a personalized course of treatment.**

As for when to start, people often start after the cognitive issues have significantly impacted their relationships, household management or work. Some people with MS are beginning to opt to begin CRT before they experience cognitive issues, as a way to strengthen cognitive skills before issues show up.

Miriam: What's unique about your treatment program--Main Line Rehab-- in the Philadelphia suburbs?

Rita: I think it's the fact that we use evidence based practices for CRT and services are provided in the home and community. We believe that Cognitive Rehabilitation is more effective and efficient when delivered in the environment in which the skills and compensatory strategies will be used—in other words, the person's own home, workplace and/or community. This means that the therapist comes to the person with MS and provides those services in the setting in which the skills and strategies will be utilized. This fast tracks the application and generalization processes and produces strong, relevant outcomes for each person more quickly. A side benefit is that if the person desires, family members and other support people can be educated about the cognitive issues that can arise with MS and also learn how to best support the Cognitive Rehabilitation process as part of a collaborative team.

Oh—and we are also in Pittsburgh area, too.

Miriam: What can we expect to happen in MS community with cognitive treatment for others?

Rita: I am hopeful that we will begin to see dedicated funding for Cognitive Rehabilitation. There is some limited funding available for CRT services through some

state Medicaid waivers. And of course, people can pay privately for these services right now.

Currently we are receiving some funding for short term services through the Greater Delaware Valley Chapter of the National MS Society.

We also received a grant to develop home based CRT services that are specifically designed to meet the needs of the people with MS. Therapy sessions include skills training, strategy development, and functional application. As always, our model includes building awareness as a means for people to better self-evaluate and determine when skills and strategies are best applied.

One of the biggest issues right now is that **CRT, for any diagnosis, is typically not paid for by medical insurance.**

Though there is a strong and growing body of evidence that CRT works, there has been little support for coverage on the insurance front. This situation is further complicated by the wide range of therapists who provide the services. The Society for Cognitive Rehabilitation acknowledges that providers of CRT may have education, psychology, speech, or OT credentials, and the Society offers a certification in Cognitive Rehabilitation.

Going forward, the priority will be to have these services available to all people with MS. Coverage through traditional medical insurance is a goal, and of course, therapists will need to receive specialized training to address the unique cognitive issues for people with MS.

Miriam: How would one go about learning if there are these resources in their own communities?

Rita: I do think that the word is slowly getting out about the need for CRT services and that the payoff can be huge. We have received wonderful feedback from the people participating in our grant, with many stating that they never thought they would be able to return to some of the activities they previously participated in!

The good news is that some medical specialists are becoming aware of CRT and may have some resources. And, of course, MS organizations like the MS Foundation, MSAA and NMSS may have access to resources.