

## CHAPTER 10

# Help with Cognitive Problems: Using Neuropsychological Information Effectively

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### COGNITIVE PROBLEMS PEOPLE WITH MS OFTEN HAVE

According to research in this area, it seems that a substantial proportion of those with multiple sclerosis (MS) will have at least some significant cognitive difficulties within a range of 45 to 65 percent (Rao 1995). There appears to be a pattern to these difficulties. Some areas of ability remain relatively strong, while others may get weaker. For instance, although you may do well on standard intelligence tests (IQ tests), you may have other cognitive problems. You may also continue to have very good language skills, especially if you've had college education or professional or technical kinds of jobs. Because of this ability, it can sometimes be difficult for you to recognize that you are having cognitive difficulties, or how important they are. If you have some "unclear" cognitive concerns, this can be confusing not only to you, but to those with whom you interact.

Note that some people with MS have few or no cognitive problems. For example, if most of your multiple sclerosis lesions are located in your spinal cord, you might have difficulty with muscle control, but you might not have any problems at all with your cognitive abilities. A full neuropsychological assessment should be performed.

Worksheet 21 presents an overview of the areas that may be affected. I've put asterisks (\*) next to the four areas that can be especially vulnerable if you have MS. Checklist 11 explains these four areas in greater detail.

## WORKSHEET 21: SEVEN AREAS COMMONLY ASSESSED IN NEUROPSYCHOLOGICAL TEST BATTERIES

**Sensorimotor Ability.** Do the areas of the brain responsible for controlling the body's muscles function efficiently? Does the brain efficiently process input from the sensory organs? (This is technically not a cognitive function but it's important to measure sensorimotor function to make sure that the brain is getting good information from the outside world.)

**Attention and Concentration.** *Attention* is the ability to focus on individual stimuli. *Concentration* is the ability to maintain that focus in the presence of distractions for an extended period of time.

**Memory.\*** Visual-spatial memory; verbal memory; long- and short-term memory; incidental memory versus memory for rehearsed or practiced items. *Short-term memory* is important for learning new material and efficient functioning. *Incidental memory*, which is memory for things (e.g., in the environment) that did not seem important at the time, is also important for efficient functioning. *Verbal memory* is memory for material that is heard. *Visual-spatial memory* helps in remembering locations and in some types of learning.

**Language Ability.** The ability to understand language and to use it to express ideas.

**Spatial Ability.\*** The ability to deal with two- and three-dimensional formats, perceive whole/part relationships, and perceive field-background relationships.

**Cognitive Efficiency.\*** The ability to perform simultaneous tasks efficiently, or to perform tasks in the presence of competing stimuli. The ability to screen out extraneous stimuli.

**Executive Function.\*** This refers to the ability to deal with abstractions, and to do problem solving, self-regulation, and initiate plans.

The areas most frequently compromised may be evident in the different types of memory, but very much less so in the case of the other functions. When you review the short list of cognitive concerns in checklist 11, below, it can be helpful to check in with your family and friends to get their opinions.

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\* These functions are frequently compromised if you have MS (Clemmons et al. 2004).

## Checklist 11: The Short List of Cognitive Concerns

1. Since you've had MS, have you noticed increased problems with short-term memory? \_\_\_\_
2. Is it more difficult for you now to do several things at once and to process them quickly? \_\_\_\_
3. Are you having difficulty in problem solving, planning, initiating, and evaluating your activities? Is it difficult to think through your problems? \_\_\_\_

Again, you might want to review these questions with a family member or friend to get their perspective!

### *Difficulties with Memory*

People with MS frequently say things about their memory like the following two statements:

*In school, I always used to be able to learn things quickly. Now it seems like I can't remember anything.*

*I can't make up my mind whether my spouse just doesn't listen carefully, or whether he really has some kind of memory problem.*

Memory is a very important ability. If you have difficulty in this area, you're likely to have difficulty with social interactions, job performance, and even the basic activities of daily living. People with MS frequently have difficulty with memory. Even when testing demonstrates that someone's memory appears to be within the average range, a very common complaint is that the person's memory doesn't seem to be as efficient as it once was.

It's very unusual for problems with memory to involve things learned long ago. Memory for skills well-learned, events in personal history, and knowledge developed in the past is often relatively stable. What seems to be affected most is memory for very recent events. If you have MS, often the many new experiences and interactions we all have every day become harder to remember. This, of course, can interfere with learning new tasks or following through with plans or commitments. Memory function can be especially affected if new learning situations involve information that changes frequently. Busy or noisy learning situations can also interfere with your ability to retain new memories.

**The busy parent.** Consider a busy parent, one who works half- or full-time, drives the kids to soccer practice, shops, prepares meals, breaks up children's arguments, and so on during the course of a busy day. Because this person is operating in an environment that constantly changes, her short-term memory abilities are very important. Missing a business report deadline or forgetting an important soccer match causes problems for everyone involved. Not remembering a spouse's business dinner or a slumber party for the kids' friends can create friction in the household and embarrassment or self-esteem problems for the parent.

However, there is some good news about these memory concerns. Some research suggests that the problem is not so much with the actual learning part of making a memory, but with retrieving memories that have already been stored (Rao et al. 1984). For example, you may do better on memory tests when

you have memory cues, or where you have some structure that helps you to remember. This suggests that your memory problems may be problems of retrieving memories.

This is better news than it would be if the memories had not been formed, and stored, in the first place. It also suggests that structuring situations and providing memory cues can make your memory function more efficiently, and that memory practice and overlearning information may be a useful strategy. For instance, suppose you want to remember a work task such as the steps involved in bringing up a certain computer program. It can be useful to repetitively bring up the program, close it down, bring it up again, and so on, until you can do it automatically.

### ***Difficulties with Multitasking/Processing Information***

“Nowadays, I just get swamped by the multiple tasks I have to do that I used to field so easily at my job.” This is a very common report from people with MS who have cognitive problems. It is an example of multitasking challenges. Because multitasking involves processing many tasks efficiently, this ability is also referred to as *cognitive efficiency*. Complaints of falling behind, having difficulty keeping up with the flow, or becoming easily distracted may become predictable for you if you are having difficulty with cognitive efficiency or multitasking. You may find yourself processing information much more slowly than you used to, before you had MS. You may no longer enjoy the busy or even hectic pace of your job.

As stated in the discussion about memory above, you can be operating less efficiently than before. This can be a very distressing situation. You may be feeling overwhelmed by all the details of daily life, but still fondly remember having efficiently organized your family’s affairs while holding down a busy job. Understandably, you may feel a sense of loss and frustration. Equally distressing may be the feeling that you “should” be keeping up and that your difficulties suggest you are lazy or disinterested.

You might want to reread the example of a busy parent’s day a few paragraphs above. If you do read it again, you will see that this, too, could be cited as an example of someone having difficulty with multitasking abilities. Stop and think about this for a minute because this is an important point. Often, people don’t have problems in just one area of cognitive functioning. The problems are likely to be interactive: that is, problems with multitasking cause difficulties with remembering things, and problems remembering things cause less efficiency with multitasking.

You can see how confusing this might become, unless there is a way to identify and measure one’s cognitive abilities. The interactive nature of many cognitive problems, that is, how they affect each other, is even more important in the next area to be discussed: executive functioning.

### ***Difficulty with Executive Functioning***

Difficulties with executive functioning often give rise to comments like these:

*John used to be such a go-getter. Now he hardly ever initiates anything. He makes plans, but he never acts on them, and he seems stuck.*

*I don’t think Sally means to be impolite, but sometimes she doesn’t make good social decisions. She says she is just trying to be friendly, but sometimes people feel her behavior is inappropriate or that she can’t figure out social situations.*

Much research and experience suggests that “executive functioning” is an area in which many people with MS experience at least some difficulties. There are many aspects to executive functioning. *Executive abilities* is the name given to the abilities we use to run our lives effectively, to make good decisions, and to organize our lives. Like a good executive, these abilities help us to manage our affairs and to stay organized. Executive abilities are also important to social problem solving and maintaining socially appropriate behavior. Abstraction, the ability to receive input from the environment and come to general conclusions, is an important executive function. Difficulties with abstraction lead to poor problem solving and poor decision making. Also, weaknesses in this area may make it challenging to appreciate another’s point of view.

As the term “executive” suggests, these are also the abilities that are important to initiating and regulating behaviors. Problems in this area may lead to problems with impulsive behavior or to difficulty in following through with commitments and responsibilities. Previously energetic and dynamic persons may become less organized and self-directed. These changes may be misunderstood by family members and friends. They can be wrongly interpreted as laziness or carelessness.

In addition, when you are having problems with executive functioning, if you find yourself on a wrong course, it can be very difficult to correct and redirect the direction in which you are headed. Unfortunately, as problems with executive functioning increase, it is not uncommon to have greater difficulty understanding the nature of a problem. You may not even realize that there is a serious problem. Because of this cognitive deficit, it may also become more difficult to understand difficulties with spouses, or significant others and associates. This, in turn, is likely to increase the misunderstanding and difficulty with communication.

Again, as discussed above, cognitive abilities are often interactive. If your other abilities, such as multitasking and memory are less efficient, your executive function will suffer, too. Thus, executive functioning may get worse if you have to retrieve information quickly or you must process large amounts of complex information. Success at tasks like operating a complicated computer program or keeping up with the changing needs and moods of children depends on an efficient memory, the ability to multitask, and efficient executive functioning.

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## IDENTIFY YOUR COGNITIVE PROBLEMS WITH NEUROPSYCHOLOGICAL TESTING

When cognitive abilities are being discussed, you might think of IQ tests or intelligence tests. IQ tests can be useful to you in terms of understanding some of your strengths and weaknesses, but they have many limitations. Unfortunately, they don’t measure many of the areas of cognitive ability that are important in everyday life. Also, they were not designed to measure the kinds of problems you may experience with MS. With MS, you can have cognitive difficulties and may still score reasonably well on IQ tests because of old verbal learning, such as vocabulary. Consequently, tests that are more sensitive to specific cognitive problems (i.e., memory) and *new learning capacities* are a better choice than IQ tests or other standard tests used to measure intelligence. These are called neuropsychological tests.

Neuropsychological tests are designed to measure many different kinds of brain abilities. Because we use our brains in order to adapt to our living environment, these abilities are often called *adaptive abilities*. Many different adaptive abilities can be measured by neuropsychological testing. These include such diverse abilities as attention and concentration, different types of memory function, multitasking, problem solving, and several other important abilities.

## *Look for Your Areas of Strength*

It's important to know that although neuropsychological tests are usually given only when people suspect a problem, these tests can be very useful for identifying areas of strength, as well as areas in which there may be deficits. Because of this, they're quite useful in planning. Here are some ways in which neuropsychological testing can provide you with useful information or a basis for making plans. They can help you to:

1. Identify your cognitive strengths and weaknesses.
2. Make better educational and vocational choices.
3. Choose an appropriate type of counseling or psychotherapy.
4. Identify environments and interventions that will accommodate your limitations successfully.
5. Make decisions about your ability to successfully perform activities like financial management, driving, or independent living.
6. Solve your specific concerns regarding "reasonable accommodations," diminished work performance, forgetting, difficulties with problem solving, and improving your communication skills.
7. Establish information about your level of capacity for Social Security or disability pension considerations.

These are just a few of the possible uses of neuropsychological data. Additionally, information from a neuropsychological test battery sometimes provides you with important positive feedback. You may experience a sense of satisfaction when neuropsychological testing points out your areas of relative strength and ability. Even if you are aware that you are having some type of cognitive difficulties, these concerns may be vague and poorly defined. You may feel a sense of relief and validation once your cognitive problems are more accurately defined in measurable terms. Some of your problems that you suspect are cognitive in their origin may, in fact, be more related to physical fatigue or depression. Neuropsychological test results can often put some of your concerns to rest.

## *The Limitations of Neuropsychological Testing*

It's also important to understand that neuropsychological tests do not always provide an accurate picture of a person's functioning. From a statistical standpoint they are very accurate instruments. For instance, if the researcher administers the neuropsychological test battery to one hundred people, there is a strong likelihood that the battery will be able to identify which of these people have difficulty with cognitive functioning and which do not. When a neuropsychologist administers the same battery to a single person, however, many other factors, such as fatigue, motivation, pain, stress, and depression, can affect that person's performance. Cultural differences and many other factors also can affect scores.

Another problem that can occur is sometimes the neuropsychologist doesn't have a good medical or psychosocial history for the person being tested. When that happens, the neuropsychologist may not make an accurate analysis of the meaning of the test results because of the missing information. Finally, sometimes someone might do poorly on the tests, but still perform life activities well due to years of practice.

All of this is just another way to say that you have to be careful about believing that test results always measure your actual capacities accurately. For this reason, it is best to use the results of a neuropsychological evaluation to form a “best guess,” or an hypothesis about someone’s cognitive functioning. Then, we try to see whether the “best guess” is useful in explaining problems you may be experiencing in your daily activities and in dealing with your environment.

In vocational programs, for example, it is quite common to use the neuropsychological evaluation to make a best guess about which types of jobs are most likely to accommodate specific difficulties. Then, a two- to three-month internship or unpaid work experience can be developed with a local company to make sure that the best guess from the evaluation really does match the person’s work capacities. We call this experience “community-based” because it is done in a real-life situation, instead of a counseling office or within an institution. This community-based assessment is often supported by state rehabilitation agencies as discussed in chapter 7. (See also appendix C.)

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## CHOOSING AND WORKING WITH A NEUROPSYCHOLOGIST

If you decide to get neuropsychological testing, this section will help you to choose the right person. It helps to be a good consumer in order to ensure that you are tested by someone who can use and interpret the tests correctly. A *neuropsychologist* is a licensed psychologist with specific training in giving and interpreting neuropsychological tests. Many other psychologists use neuropsychological tests occasionally, but they don’t have the comprehensive training that a neuropsychologist has received. Also, neuropsychological tests are not controlled by neuropsychologists. Any psychologist who wants to buy and use them can do so. Because of this, you will need a plan for choosing the right professional.

Here are some tips that will be useful for choosing and for working with a neuropsychologist.

**You have a right to request a résumé from any neuropsychologist with whom you are considering working.** This résumé should list the psychologist’s education as well as other kinds of training. A person who is practicing as a neuropsychologist should have a degree in psychology. Specific training in using neuropsychological tests is also a must. There should also be supervised training after the person receives a Ph.D. This is often called an “internship.” Many neuropsychologists also have an advanced certification that is called a “diplome certification.” This certification, as issued by the American Board of Professional Psychology, is also referred to as an “ABPP certification.” Neuropsychologists who have ABPP certification are likely to have a very solid preparation to practice as neuropsychologists, although some very good ones have not yet taken this examination.

**Word-of-mouth.** This can be a very effective way to determine if a neuropsychologist has provided services that have proved useful to other people. It would be helpful if you could find individuals who could give you references for neuropsychologists with whom they have worked, e.g., through support groups. Agencies such as local multiple sclerosis associations may be useful places to get this kind of information or to meet people who have had satisfying experiences with neuropsychologists.

**Many state, county, or city mental health organizations have listings of neuropsychologists.** You can look for these lists through psychological or neuropsychological associations, medical school departments of rehabilitation medicine or neurology, and university psychology departments. Other local neuropsychologists may have all their pertinent information available for viewing on their Web sites.

**State rehabilitation agencies may provide neuropsychological testing for people who qualify for services.** Although state agency personnel may be in the habit of referring to specific practitioners for getting neuropsychological testing, it is still important to be a good consumer. Recent legislation and policy trends emphasize “client choice” policies.

### *Make Sure You Get a Personalized Report*

Finding the neuropsychologist with whom you want to work is only half of the job. There are two more tasks you need to do:

1. First, it’s important to make sure that the neuropsychologist has enough medical vocational/educational (transcripts), and social information from your account of your history to make accurate judgments about what your test scores mean. As mentioned above, just having the test scores is not always useful. They mean a lot more when they are used with an understanding of the person’s medical and social history. For instance, if you were raised in another country, or you have hand tremors, you may score differently than other people. It’s important to make sure the neuropsychologist gets this kind of information so that the report can be as accurate as possible.

It is also important to try to remember whether you’ve had psychological or educational evaluations in the past. If this was the case, try to make sure that the neuropsychologist gets copies. Usually, it’s more useful for the neuropsychologist to be able to read this kind of information in its original form. Also, a review of any nationally standardized educational test scores from your high school and/or college transcript can be very helpful.

2. Second, it’s important to provide the neuropsychologist with a letter that has specific questions to be answered. This is also a way to make sure that your report is a personalized report. Imagine for a minute that you are a neuropsychologist writing a report. If the person whom you tested had not given you some specific questions to answer, you may have to guess at which recommendations would be most helpful. Remember the old saying from the early computer programmers: “Garbage in, garbage out”? The higher the quality of your background information and your questions, the more useful the neuropsychologist’s report will be. You can use worksheet 22, below, to prepare the questions to include in your letter.

## **WORKSHEET 22: QUESTIONS FOR YOUR NEUROPSYCHOLOGIST**

*Examples:*

1. In a summary, can you tell me what are my specific cognitive assets and what are my specific deficits?
2. Can you help me figure out a way of talking about my disability-related concerns with others?

3. Do I have the ability to do well in a technical graduate degree/program? Is further academic training in my best interest? Would I do better in on-the-job training?
4. My performance at work has gone down steadily for the past four months. Can you suggest some procedures or equipment that might help me to improve my job performance?

### Your Questions for the Neuropsychologist

Of course, the questions above are just examples. But after reading them, you should have some idea of the kinds of questions you want to ask the neuropsychologist. Also, be sure to get some input from your family and friends. They may come up with some important questions to ask that you might overlook.

1. \_\_\_\_\_
2. \_\_\_\_\_
3. \_\_\_\_\_

You can probably think of other questions to ask because the suggestions above are just generalized examples that different people might use. It's more likely that you will receive a more personalized report from the neuropsychologist if you generate your own questions.

If you have difficulty coming up with questions, think about your life since the onset of MS. Reviewing a typical day (or week) in your life since you began living with MS, and thinking about the difficulties you've been dealing with will probably help you generate specific questions to ask the neuropsychologist.

If you're living with a spouse or significant other, it would be a good idea to make sure that his or her point of view is also given to the neuropsychologist. Sometimes, people we know and care for have very different ideas about the nature of our relationship with them and about what kinds of interpersonal problems exist. For example, a spouse may have questions about how MS affects the couple relationship or he or she may disagree with you about how to best help you.

If you must live with and get along with a life partner, it is a good idea to make sure that your partner has a chance to ask questions too. Sometimes, it's a good idea for each person involved in a relationship to write separate referral letters to the neuropsychologist to ensure that each has the privacy needed to feel safe about honestly saying what they think about the situation. If you live with a life partner, it would be an excellent idea to discuss this suggestion with that person.

In reading the paragraph above, you may have seen a possible problem arising if more than one person becomes involved in writing a referral letter. Usually, the more information a psychologist gets, the better the report will be. When more than one person is involved, however, it's also very important to make sure the person being tested is not made to feel uncomfortable.

If you are the person to receive the testing, you probably understand that the report will be more useful if your life partner also contributes to the questions to be asked. Even so, it would be entirely natural if you were uncomfortable about this. Before you invite other people to include their questions in

a letter, you should talk to them about your possible concerns. There may be times when it is not a good idea for anyone but the person being tested to ask the referral questions. Because people are so different, the question of whether other people should be involved in asking questions of the neuropsychologist has to be decided on an individual basis. Except in unusual situations, the person being tested should have the right to make this decision. If there is a conflict, talk to your physician, social worker, counselor, or an advocate from a local MS association.

### ***Some Examples and Hints on Writing Referral Letters***

You probably don't write referral letters every day, so we are providing some examples of shared information about some of the questions to ask. First, here is how part of a letter from a worker with memory and multitasking problems might look:

I seem to have more and more difficulty learning new procedures and keeping up with the rest of the staff at work. Sometimes I'm exhausted by the end of the day. My memory seems to be a big part of the problem. I think that I can manage if I can take some of the work home, but I need to learn some ways to become more efficient at work. I also need some ways to help my husband understand that I can handle this on my own.

This person's spouse might also write a referral letter, which might include the following concerns:

I am worried because my wife is working harder at her job, but seems to be overwhelmed with it. She often brings work home overnight. She's worried that if she asks for an accommodation at her job that she will hurt her chances for a promotion. She has always been very independent. I'm worried that she thinks that she must be a high achiever for our family to love her. She can help others, but she has a hard time accepting help for herself.

As you can see, both of these people see the problem more or less in the same way, but with some different viewpoints. Can you spot an important counseling issue? The wife is concerned with demonstrating that she is still able to function independently, while her spouse is worried that she is cutting herself off from family support. This type of information can be quite useful to the neuropsychologist for suggesting possible counseling issues and strategies.

Generally, because neuropsychological testing is usually sought when specific problems are suspected, there may be a tendency to focus on problems rather than strengths. A good evaluation should point out areas of relative strength, and then suggest how these can be used in accommodation or communication strategies. It may be helpful to ask specifically for a discussion of your relative areas of strength and how these may be used to maximize your functioning in all of your life's tasks.

### **Operational Questions**

Here's another important thing to think about. You can't expect the neuropsychologist to be an expert in every field. For this reason, it is usually more helpful to ask operational questions rather than general questions. In an *operational question*, you explain or define the object of your question. This makes the question more specific (and helpful).

If you are writing a letter to a neuropsychologist, and you want to know if a person will be able to cook meals, you might be tempted to ask the question this way: “Will James be able to cook meals independently?” This question seems simple enough, but other questions can arise from that seemingly simple question.

A more helpful way to phrase the question about cooking would go like this:

Do you think James will be able to follow a five- or six-step recipe by reading it from a cookbook? Will he have trouble if he has to cook more than one item at a time? Will he be able to cook efficiently if our two children are “helping” him? Should we be worried about safety issues, like his forgetting to turn off a burner?

Here’s another example, this time about a job situation. Suppose you are helping your friend Sally write a question about how well she might do in retail sales. As above, you can just ask the question “How well do you think Sally will do in retail sales?” However, like the example about cooking, it would be more helpful to ask the question by telling the neuropsychologist exactly what your concerns are.

That is, it would be helpful for the neuropsychologist to know how many different essential tasks are required to do the job and how much time is spent on each task over the day. You could copy the job description developed by the company and send that. But even sending a job description developed by the company may be insufficient if the *essential functions* of the job are not clear and outlined as to the effort and the time frames involved. Some job descriptions are very generalized and don’t really describe how the job is done. For job-related evaluations, the neuropsychologist should know the truly “critical” job tasks and the approximate number of hours involved in each. A work supervisor might be the best resource. Here are the key concerns that must be addressed in the referral letter to the neuropsychologist:

### Elements for Referral Letter for Neuropsychological Testing

- Describe problems to be addressed. Be as specific as possible.
- Frame your questions operationally. (See Operational Questions above.)
- Include important medical and social history.
- Request a discussion of strengths as well as weaknesses.
- Request a discussion of accommodation strategies (e.g., procedural or assistive equipment).
- Request a discussion of specific counseling strategies, if appropriate.
- For job functioning concerns, have an accurate description of the job’s key tasks and input from a supervisor or from the person being tested about which tasks are the most challenging.
- If possible, try to have input or separate letters from friends and significant others.

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## COSTS AND FUNDING SOURCES FOR NEUROPSYCHOLOGICAL ASSESSMENT

Neuropsychological testing can be expensive. A full neuropsychological evaluation can take most of a day, and, typically, involves the administration of both a neuropsychological test battery and a measure of intellectual functioning such as the Wechsler Adult Intelligence Scale-III (WAIS-III). It is also standard practice to administer some index of emotional functioning, such as the Minnesota Multiphasic Personality Inventory-2 (MMPI-2). A full neuropsychological evaluation can take an entire day of a psychologist's time or that of a psychometrist, who is an individual trained to administer, but not to interpret, neuropsychological tests. Review of background information, interview time, and report writing take additional time. Depending upon the circumstances and the geographic location, the cost of a comprehensive neuropsychological evaluation can range from \$1,000 to \$3,000 or even more.

If you want to obtain a neuropsychological evaluation, there are a number of options to consider before paying for it from your own pocket. Many medical plans will pay for a neuropsychological evaluation if it is requested by your physician. If this option is available, it would be desirable to involve the referring physician in generating the questions for the referral letter as discussed above.

Alternately, in a job situation, you may be able to request that your employer pay for a neuropsychological evaluation as part of a larger accommodation package in seeking technical assistance. The Americans with Disabilities Act (ADA) stipulates that many employers are responsible for seeking technical assistance in order to help individuals with medical conditions. Although it may feel threatening to disclose your medical condition, our experience suggests that often the energy involved in trying to mask problems with work performance, e.g., working longer hours, can be personally draining. Current rehabilitation legislation also makes it likelier that employers will try to provide you with reasonable accommodation if you request it.

If you are not working or if you are having difficulty maintaining your employment, the state rehabilitation agency is an option for providing neuropsychological evaluations, as well as access to assistive technology and other services. Individual counselors within the state rehabilitation system may or may not have specific training with respect to MS-related issues. For this reason, it may be desirable to provide a state vocational rehabilitation counselor with specific MS-related information, including information about the importance of obtaining a neuropsychological evaluation (see Clemmons et al. 2004 in the References section). In some cases, rather than waiting in a state of limbo, you may simply want to "bite the bullet" and pay for the evaluation yourself.

### *How Much Testing Do You Need? Are There Ways to Cut Costs?*

The advantage of a full neuropsychological battery of tests is that it provides a comprehensive screening. Nevertheless, as suggested above, there appear to be some patterns seen in MS-related cognitive concerns. Because of this, much interest has been shown recently in developing brief neuropsychological screening batteries for MS that focus on these areas (Basso et al. 1996; Beatty et al. 1995; Rao, Leo, Bernardin, et al. 1991; Rao, Leo, Ellington, et al. 1991). Rao, especially, has studied a number of very brief screening batteries for use with people who have multiple sclerosis. As discussed above, these usually involve general areas such as short-term memory, multitasking ability and speed of information processing, and problem solving or executive functioning.

Building on the work of previous authors, Clemmons and colleagues (2004) developed an abbreviated neuropsychological screening battery for people with MS. This can be administered in approximately three hours and provides an estimate of intellectual functioning, as well as good coverage of the areas discussed above in addition to the functions of language, attention, and visual-spatial processing. We've used this battery to provide vocational and other types of counseling for people with MS seen in our vocational program. The battery is useful because it addresses the concerns of mid-career, semi-skilled and skilled professionals who seem to make up the bulk of the MS population.

It should be noted that brief test batteries may sacrifice the desirability of a broader evaluation of neuropsychological abilities to the advantage of saving money or time, while still being helpful. Someone with MS may have difficulties outside the three main areas first discussed. Nevertheless, there are times when it may be expedient to consider the use of a brief or abbreviated neuropsychological battery of tests due to the presenting clinical or time/cost considerations. This would be one of the issues you will want to discuss with the neuropsychologist with whom you are considering working.

The following is a short case history which can show you how all of this works together.

### *Case History: A Consultation with Nora*

Nora, who has a master's degree in nursing, is a supervisor at an infirmary in a state penal institution. She was recently diagnosed with MS and is emotionally stressed. Nora and her husband had discussed not revealing her medical condition to the institution's administrative staff because she values her well-paid position. She is, however, experiencing memory problems and has received two write-ups by the institution's administrator for failing to attend a court hearing and for not scheduling the transfer of an inmate to the infirmary.

Nora knows she is having difficulties remembering nurses' absence requests and other administrative details and she is becoming less and less efficient. A job analysis indicates that her scheduling of nursing staff is a critical function and takes up almost half her work week. Another supervisor is encouraging her to seek disability consultation. With all the stress she is experiencing, Nora is becoming increasingly anxious and irritable at home, as well.

- Would you disclose to the administrator?
- Would you seek assistance, and how?
- How would you pay for the evaluation?

**Outcome.** After discussing all the issues with her husband, Nora talked to her supervisor about her need for accommodation and she scheduled a consultation with the state's disability services unit. This unit, with Nora's permission, sought assistance for assessment and accommodation recommendations from the neuropsychological and vocational rehabilitation unit within the neurology department of a local university. Nora's specific problems, as tested, were:

1. Some problems with her short-term verbal memory, and
2. Slow speed of information processing.

This meant that she was:

1. Having trouble remembering small but important daily facts, and

2. Her memory became even more inefficient when the work pace speeded up and became more hectic (which it often did).

The consultation team, with input from the Internet through West Virginia University's Job Accommodation Network (JAN), recommended a nurse-scheduling software package that reduced her scheduling demands from four hours a day to twenty-five minutes daily. With this extra time and with the aid of a personal digital assistant (PDA), she was able to keep quite organized and to maintain her job proficiency.

Previously, she had been trying to maintain the daily scheduling with a large wall chart and a pack of "yellow stickies." This consultation was kept as a confidential matter with disability services and the software costs were easily absorbed by the institution as part of regular office expenses. The institution's administrator was very enthusiastic about the improvement in Nora's functioning.

Although Nora and her husband did not write a referral letter about what they thought her problems were, the neuropsychologist was someone with a great deal of experience in this type of situation. In addition to the vocational rehabilitation recommendation about the software package to help Nora at her job, the neuropsychologist's report offered suggestions about how to manage the stress that she was experiencing and the growing friction at home. Due to a reduction in her workplace difficulties and the specific recommendations on how to deal with MS as a couple or a team, within a short time, Nora and her husband were happy to report they were experiencing much less stress in their relationship.

One of the reasons that Nora's case has a positive ending was that she was able to reach out for help relatively early. Counselors who provide social and vocational rehabilitation services for people with MS know that frequently it is difficult for people with MS to seek outside help. Sometimes, it can be uncomfortable to admit that a problem has grown large enough that you need to seek outside help, but many MS-related problems eventually do require specialized assistance. The good news is that this generally takes some of the burden off you, as an individual, and can provide new strategies for helping you to maximize your strengths and manage your limitations more effectively.

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## Conclusion

This chapter has reviewed some areas of neuropsychological ability that are important to life functioning, and it has offered you suggestions about finding and screening a qualified neuropsychologist. Neuropsychological testing can be seen either as targeting deficits or as defining the problems to be solved. For anyone who is worried about the possibility of losing some cognitive abilities, the tests can be perceived as threatening. For this reason, the emphasis in this chapter has been that this testing can be very helpful for identifying relative areas of strength. By identifying these areas of cognitive strength, the person who is having difficulties with vocational, social, or other areas of life functioning can begin to develop strategies for adaptation and accommodation. For the person with MS and that person's significant others or employers, early intervention can eliminate quite a lot of frustration and distress.

For those of you with MS, we hope that this discussion will encourage you to explore neuropsychological testing, if you think it might be helpful. For those of you who are significant others, this chapter has suggested ways for you to support and assist your loved one in finding appropriate testing and making the best use of it.