



The Role of Neuropsychology

CFIDS patients are often **resentful** when their doctor suggests a neuropsychological exam—and **downright angry** when their insurance company requires it for disability insurance claims. But this exam can actually **help you in unexpected ways.**

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GUEST CONTRIBUTOR**

Often when a physician suggests a neuropsychological evaluation to CFIDS patients, they think: “My doctor thinks it’s all emotional” or “She thinks I’m crazy, but I’m not making this up.” Nothing could be further from the truth. What doctors are saying is that they have noted that your cognitive ability has been compromised, and they are seeking a better understanding of how your thinking brain has been affected by the illness.

The suggestion to get a neuropsychological evaluation can leave you with questions about the why’s and how’s of the evaluation. A neuropsychological examination, which is also called a neurocognitive evaluation, is administered to assess the clinical relationship between a person’s neurological or brain function and its impact on cognitive and behavioral functions. Its focus is to evaluate the multidimensional impact of neurological

disease, injury and illness on a patient. It can also highlight emotional changes that have occurred due to a patient’s medical or neurological condition.

It should not, however, be confused with a psychological evaluation, which is more limited and largely focuses on the emotions and personality characteristics that have been disrupted by some life event or stressor (divorce, loss of a child, loss of employment, household move, etc.) that directly impacts and limits a person’s emotional functioning and often leads to negative or maladaptive behaviors. While the neuropsychological evaluation will take into account those emotional domains assessed by a psychological evaluation, its primary focus is to understand how CFIDS has impacted the daily functioning of the “whole” person.

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The basics of neuropsychological testing

The neuropsychological evaluation involves taking an extensive history (including review of medical records) and comprehensively assessing cognitive and behavioral functions using a set of standardized tests, tasks and procedures. It takes approximately 8 to 12 hours of face-to-face contact with a qualified neuropsychologist who has a specialty in CFIDS. During the process, the patient will undergo tests related to general intelligence; effort; reaction time; attention and concentration; speed of processing different types of both visual and verbal information (ranging from simple to complex); a wide range of memory functions; ability to perform multitasking, planning, organizing and prioritizing tasks, problem solving; language usage and verbal and written communications; and sequential thinking and reasoning through simple and complex problems.

The purpose of the testing is to understand how you're presently using your cognitive abilities to get through the day and what problems you're encountering. The tests assess why and how your decline in thinking ability has negatively affected the way you handle the vocational, academic, economic, family, interpersonal and personal demands of everyday life.

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The testing time can vary depending on a patient's medical condition, medication regimen, energy level or travel time on the day of testing. For CFIDS patients it's best to test over a series of days, normally two to four hours per session. CFIDS patients don't have the stamina to sustain more than four hours of testing, and even that amount of time in a single session will require a number of refresher breaks. Any time beyond that in one session becomes so taxing for CFIDS patients that results of the neuropsychological evaluation are likely to be meaningless, and patients won't have the stamina to put forth their best effort. Often, CFIDS patients will need approximately one week between sessions to effectively recover from the testing procedures.

Using the results to benefit you

The results of the neuropsychological evaluation are used in a variety of ways to benefit CFIDS patients. You should use it to:

1 Create an effective treatment planning. A treatment plan is designed to address the cognitive weaknesses that have been uncovered by the evaluation. Treatment typically involves cognitive remediation with a qualified neuropsychologist who specializes in CFIDS. Cognitive remediation, a treatment intervention that was originally used with patients who suffered brain injury, is now widely used for patients who are affected by neurological illness, attention-deficit disorders and other medically involved illnesses. This method teaches CFIDS patients compensatory strategies that will help improve cognitive problems. Most often, the treatment plan will also include psychotherapy to help you deal with the significant emotional losses that have accrued because of the devastating effects of CFIDS (loss of job/work; reduced interaction with a spouse, significant other, family or friends; financial problems; or depression, mood changes and anxiety).

2 Support your disability claim. Many CFIDS patients become so disabled by the illness that they can no longer work and must seek some form of compensation to provide for even basic living expenses. This is done by seeking compensation from Social Security and/or from a private disability insurer (if you have a preexisting policy at the time of illness onset). Apart from medical records, these funders will usually require a neuropsychological evaluation that documents the cognitive and emotional declines that justify your need for disability benefits.

3 Justify job accommodations. Like many CFIDS patients, you may still be able to carry on your functional duties and daily roles, but the effects of this illness—especially reductions in your level of physical and mental energy—require you to reduce the demands of your roles in the workplace and at home. If your competence to perform is limited, you can use the results of a neuropsychological exam to seek accommodations from supervisors and family members to assist you. This may include such things as reducing your work schedule, taking some assignments home, limiting the complexity of tasks, redefining your job role and extending time limits for task completion.

4 Educate all your medical specialists. Unfortunately, some medical specialists are not aware that the psychological presentation of the CFIDS patient is neurologically/organically based, and they may ascribe your functional status solely to emotional problems. Furthermore, they may not have a precise understanding of the differences among the fields of psychology—for instance, neuropsychology

vs. clinical psychology vs. experimental psychology. Consequently, they may refer you inadvertently for a psychiatric or psychological evaluation when your failures are cognitively based. A thorough neuropsychological report can help such physicians understand the basis of a patient's presentation as well as provide further understanding of the cognitive domains that are negatively affected. This allows physicians to offer better and more precise referrals in the future for you.

5 Educate your family members and significant others. CFIDS is not only a systemic illness that disrupts your physical and psychological life, it's also one that invades and disrupts all your external support systems. A CFIDS patient's decline in personal functioning is impacted by the frustrations and burdens the illness places on those most needed for support. The findings of the neuropsychological evaluation can be used to help educate those individuals and help them better understand the nature and complexity of the deficits you experience. It can guide them in

how to interact with you to reduce stress and reconstruct more positive vocational and social roles and interactions.

When tests should be performed

A neuropsychological evaluation should be ordered by your physician as soon as a CFIDS diagnosis is made so that a baseline of cognitive functioning can be established early in the medical treatment. This has advantages both to the patient and the physician since it helps both understand the nature and degree of cognitive deficits and how they impact your life. By having this information early in the process, you can gain greater insight into your thinking, feelings and behavior so you can lessen the emotional consequences that can result from uncertainty.

The knowledge derived from the evaluation often verifies patients' internal assumptions about their functional deficits. The physician can use the information to track a patient's cognitive and psychological progress and make any regimen or medicine changes that will enhance the patient's performance. Serial neuropsychological evaluations should be conducted one year after the first evaluation to evaluate treatment response and then approximately every two years thereafter.

Choosing a neuropsychologist

It's usual practice for a physician ordering a neuropsychological evaluation to provide you with the name and contact information of a qualified neuropsychologist who has developed a specialty in CFIDS. If your doctor doesn't provide a referral, ask for one. Since this evaluation is usually uncharted territory for a CFIDS patient, there are a number of things to keep in mind when contacting and interviewing a

Did You Know?

- If you file a claim for Social Security or long-term disability insurance, you may be required to take a neuropsychological exam. (See related story on page 6.) It's important to use this evaluation to your advantage. A neuropsychologist who specializes in CFIDS can be a crucial ally in that process.
- A neuropsychological evaluation can also help you secure needed workplace accommodations from your employer so you can continue working on a full-time or part-time basis. (See related story on page 10.) The information can also help your family members understand the cognitive and functional impairments that impact family life in stressful ways.
- Neuropsychological testing is not the same thing as a psychological evaluation. If your doctor refers you to a neuropsychologist, don't assume your mental state is being questioned.
- A neuropsychological evaluation isn't cheap. It typically costs between \$2,500 and \$3,500.

proposed neuropsychologist:

1 Interview the neuropsychologist by phone prior to making an appointment. Ask about the doctor's experience with CFIDS patients, how many patients he has evaluated and how many patients he has treated for CFIDS following evaluation.

2 Clarify fees and payment schedule. It's important to know the cost of the entire evaluation before making an appointment. This should include the clinical interview, all testing sessions, the finished report and the feedback session. The feedback session is a face-to-face meeting with the neuropsychologist to explain and clarify any questions you may have about the results of the evaluation.

Professional charges vary according to geographic area and how the reports will be used. Reports used for disability purposes tend to be more extensive due to the requirements of the disability funders and are usually more expensive. While the face-to-face portion of the neuropsychological evaluation takes 8 to 12 hours, the time required by the neuropsychologist to complete the scoring, data analysis, report writing and feedback will normally double that amount for a total of approximately 20 to 24 hours of work. Costs typically vary from \$2,500 to \$3,500.

You should also be aware that many neuropsychologists don't take insurance, but they do provide an invoice you can file with your insurer for reimbursement. While most insurers cover approximately 80 percent of the fee, some cover the entire cost. You will need to discuss this with your insurer, espe-

cially if you require preapproval for services.

3 Clarify the number and duration of sessions. It's important to know how many sessions you need to plan for and how long each session will be. You should explain to the neuropsychologist about your energy level and what times are best for you during the day. Most CFIDS patients have a specific period of time each day when they function best, and this needs to be shared with the neuropsychologist for scheduling purposes.

A neuropsychological examination, which is also called a neurocognitive evaluation, is administered to assess the clinical relationship between a person's neurological or brain function and its impact on cognitive and behavioral functions.

4 Discuss terms of the written report and feedback. You will want to know how long it will take after the completion of testing before the final report will be issued. You'll also want to know if the report will be provided at the feedback session or if you will receive it prior to the feedback session so you can make notes and discuss particular concerns at the session. If you wish to bring a parent, spouse or significant other to the feedback session, you should inform your neuropsychologist's office so they can make space accommodations.

5 Find out what to bring. You'll want to know what you must bring to each session, such as glasses, hearing aids, medication, refreshments and form of payment. Also ask what medical records the doctor will need and if you should send them prior to the first appoint-

ment or bring them with you. Inquire if any other information is needed, including insurance forms if the doctor takes or participates in an insurance plan. Be sure to bring a list of all medications and dosages you're taking at the time of your first session, as well as the full contact information for all insurers, doctors, therapists, lawyers and agencies with whom you are working.

Far from something to avoid like the plague, a neuropsychological evaluation can actually be very useful in improving your quality of life. It's helpful for CFIDS patients to view this evaluation as a beneficial and necessary adjunct to advance your holistic treatment and rehabilitation. The testing will be stimulating

and interesting, and the detailed information that's gathered will contribute to a better understanding of the impact of CFIDS on your life and therapeutic outcome. ■

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