

Multidisciplinary Assessment for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS),
Fibromyalgia (FM) and Environmental Sensitivities

ETeam Description

The ETeam consists of:

**Michelle DeLisle Cory Fagan, Robert Hadden, Diana Monea,
Chris Rozell, Eleanor Stein & Anne Woolliams**

Specialized multidisciplinary assessment for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Fibromyalgia & Environmental Sensitivities

One of the most frustrating experiences for people with ME/CFS, FM or Environmental Sensitivities (ES) is the absence of objective findings that support the subjective illness experience. Some symptoms such as pain and fatigue are internal experiences. Other symptoms such as irritable bowel and sleep disorder are overlooked as benign by many practitioners because they are not progressive or lethal. None of the symptoms or diagnoses can be proven through conventional testing. Patients often express frustration that all their test results are “normal” yet they feel so horrible. Many individuals are financially disadvantaged by their inability to validate their condition to disability insurers.

There are an increasing number of tests which can validate the symptoms experienced by people with ME/CFS, FM and ES. The exhaustive report by the Institutes of Medicine released in 2015 recommends diagnosis utilizing objective measures including cognitive and exercise testing (Institute of Medicine, 2015). The ETeam has been offering these tests for almost 20 years, long before the IOM report. The ETeam is gradually growing our skill set and team membership to offer as many valid, objective tests as possible. All the tests we use are evidence based.

One of the challenges in developing a protocol to measure cognitive and other dysfunction in ME/CFS, FM, ES is that the normal and abnormal ranges overlap. An individual who prior to illness or exposure functioned at a high or elite level could suffer a significant decline in abilities and still score in the “normal range” on many tests. Therefore, it is necessary to compare scores both with large data bases and with estimates of the individual's own performance prior to illness. It is also important to know what to look for. In ME/CFS, FM and ES not all functions are equally affected. The ETeam protocols shine a spotlight on the areas of function most likely to be affected.

Background Information

Cognitive function is measurable and there are many studies describing the common cognitive deficits in people with ME/CFS and FM. (Cvejic, Birch, & Vollmer-Conna, 2016; Dick, Verrier, Harker, & Rashiq, 2008; Leavitt & Katz, 2008).

Kinesiologists Staci Stevens, Mark Van Ness and colleagues have developed a 2-day exercise test protocol which shows unique findings in some patients with ME/CFS who experience post exertional malaise (PEM). PEM is the core symptom of ME/CFS and is not identified up on conventional exercise and functional capacity tests. A subgroup of people with ME/CFS show an inability to replicate physical work produced on the second day of a 2-day protocol despite maximal effort. This is not found in any other known illness, even severe lung or heart conditions. When present, failure to replicate exercise capacity is an objective and unique marker of ME/CFS (Ciccollella & Davenport, 2013). Since being first reported, the Stevens protocol has been replicated by several independent research groups (Keller, Pryor, & Giloteaux, 2014; Nelson et al., 2019; Vermeulen & Vermeulen van Eck, 2014).

Quantitative EEG is an objective measure of brain function in real time. Dr. Pierre Flor-Henry and colleagues have shown the ability to validate clinical diagnoses of ME/CFS, FM and some psychiatric conditions by comparing individual results to a large data base of results (Flor-Henry, Lind, & Koles, 2010). More recently Marcia and Mark Zinn of Stanford University have shown that patients with ME/CFS have increased delta rhythm and decreased in alpha rhythm in many brain areas (Zinn, Zinn, Valencia, Jason, & Montoya, 2018). This is an indication of under-activation of the brain and central nervous system dysregulation. Although qEEG, in the clinical setting, may not confirm a specific diagnosis, it can validate subjective complaints using a test which cannot be faked or malingered.

Protocol Components

The medical and psychiatric assessments will be completed by Eleanor Stein MD FRCP(C). She will undertake a focused history of the presenting symptoms and a careful review of symptoms to rule out other causes of the problems. This includes a psychiatric interview to establish whether psychological and/or psychiatric issues are a part of, secondary to or independent of the physical health problems. She will make DSM-5 (psychiatric) diagnoses if appropriate and will rate the degree of disability using the WHODAS 2.0. This assessment provides context to aid in the interpretation of the other assessments. The detailed report may include recommendations for further testing, general management suggestions and recommendations specific to each individual. The report will be sent to the patient and the referring physician. Dr. Stein provides follow up to the referring physician by phone on request.

The psychological assessment including cognitive tests will be administered by Dr. Michelle DeLisle, or Mr. Robert Hadden M.Ed. M.Sc., R.Psych both with extensive experience in psychometrics and other aspects of psychological evaluation. Cognitive effects are among the most disabling symptoms of those suffering from ME/CFS, FM & ES. Psychometric testing can provide valid and reliable data. Well-established, standardized tests and procedures are used to provide objective

measurement of verbal and nonverbal performance, memory, working memory and processing speed.

The cognitive evaluation will begin with a screening consisting of complete questionnaires, online cognitive test and an interview. You will receive a report summarizing the findings. If indicated and depending on your goals you will be offered a more in depth, individualized assessment. The in-depth cognitive assessment is the most time-intensive component of the multidisciplinary assessment. Testing sessions can be arranged to suit one's schedule and energy level. A report of findings is provided with recommendations for optimizing cognitive function.

Dr. Diana Monea (optometrist) will conduct a complete eye-health assessment.

The effects of ME/CFS and FM on vision are frustrating and chronic. Since 80% of what we learn is through vision, visual impairments effect every waking moment and may impact work, study or parenting. Visual symptoms may include dry eyes, sensitivity to lights, fluctuating and fading of vision, eye pain, loss of vision or color vision changes. The visual consultation involves digital documentation of the corneal map for dryness, retinal photos for signs of eye disease, refractive testing, and visual fields to determine any visual loss. All assessment results are stored digitally and can be sent to your treating professionals. Additional tests such as an ocular CT are available if needed or requested.

Dr. Anne Woolliams Au. D (audiologist) offers hearing, auditory evoked potential testing and tinnitus assessments. The effects of ME/CFS and FM on the auditory-vestibular system can be subtle to severe. ME/CFS, FM and ES can affect balance, equilibrium, auditory processing and tinnitus (ringing in the ears). Dr. Wooleams is one of few audiologists in Canada trained in assessment and treatment of tinnitus.

Chris Rozell MC, R.Psych (psychologist) offers QEEG and Psychophysiologic Stress Testing. QEEG is a form of assessment which measures the electrical activity of the brain in real time. The goal is to determine the type and level of activity at each brain location and measure the connectivity between brain locations. Psychophysiology Stress Testing - Using the Thought Technology system monitors an individual's heart rate, breathing rate, sweat response, muscle responses, and temperature while completing a number of exercises that are designed to be challenging. The level of each physiological response provides objective evidence that may relate to symptoms and can provide clear goals to make treatment more efficient/effective. Mr. Rozell provides a detailed report including recommendations for treatment.

Cory Fagan M.Sc. offers the Two Day CPET (Stevens) protocol for ME/CFS and incremental blood lactate testing. Mr. Fagan is a kinesiologist and owner of TCR Sport Laboratory in Calgary. Although TCR's primary clientele are athletes, Mr. Fagan has a background and interest in chronic illness including cancer survivors and patients with ME/CFS and FM. Incremental Blood Lactate testing determines anaerobic threshold and exercise capacity. Cardiopulmonary Exercise testing is the gold standard

to determine exercise capacity. It includes objective measures of effort. Clients can attend for a traditional one-day test or the specialized two-day exercise test protocol (Stevens Protocol). The two-day protocol, if positive, offers confirmation of post exertional malaise the core symptom of ME/CFS. Mr. Fagan provides a detailed report including recommendations for incremental training based on individual capacity.

Referrals

You can contact the ETeam yourself, but you will need a referral from a physician or nurse practitioner before proceeding with the assessment. For medico-legal assessments, the referral must come from your legal representative. In most cases we will be able to confirm whether you have clinical and objective findings consistent with ME/CFS, FM or ES. However, testing cannot prove the cause of your condition nor can it predict whether your symptoms will improve with time. We don't find objective evidence of dysfunction in everyone.

The Procedure

For most clients, the first step is a phone call to our ETeam admin, Kaza Smith at (587) 392-5066. You will be sent information about the team and a client registration package. If after reading the information and costs you want to go ahead, you and/or your physician will talk to Dr. Stein by phone to determine if you have one of the diseases that is the focus of our expertise and if there is a reasonable chance we can answer your questions. She will help you select the tests which may be most helpful to answer the clinical questions you have. If you decide to go ahead with the ETeam process, you will be sent questionnaires and instructions regarding how to gather the information we need.

After you complete and return the questionnaires, you will receive an email from Michelle DeLisle, our psychologist with a link to complete an online cognitive test. Then Dr. DeLisle will arrange a virtual meeting by phone or zoom to gather information about your cognitive problems. She will indicate whether the cognitive screening suggests that

more in-depth assessment may help provide objective evidence consistent with your subjective impairments and/or answer further questions you have about diagnosis. If you have additional conditions or questions, please mention them during this phone call.

The remainder of the assessment is all in-person at the various ETeam offices in Calgary. Kaza will book your assessment appointments according to your schedule and energy. For those from out of town, you will need to be in Calgary for four - five days depending on the number of assessments you are undertaking and your energy levels. After you have completed the entire assessment, the team members will exchange

information and discuss their findings with each other. Please allow 4 – 6 weeks for this process.

Outcome

You and your referring practitioner will receive an ETeam package. This consists of reports from each ETeam professionals you meet with and an executive summary integrating the information. The assessment will include diagnoses, test findings and management recommendations. The information you receive may validate what you already know about yourself but have been unable to quantify or describe in objective terms. The report will include suggestions to manage and compensate for your symptoms. You may contact any team member (except Dr. Stein) for clinical follow up if you wish. Dr. Stein is available to your referring physician for follow up.

Payment

You will receive an itemized cost sheet when you finalize your assessment plans and before you provide the final consent to go ahead. The cost varies depending on the tests you decide upon. The medical and psychiatric assessment (Dr. Stein) is covered by Canadian provincial health care plans. The other assessments are not covered. Most private insurance plans will pay a portion of these costs. We can provide you with a list of the test procedures and time involved to submit to your insurer ahead of the assessment so you know what will be covered. In most cases there will be a substantial outstanding fee that will be billed directly to you, the client.

The cost sheet explains who to pay and when. In brief, the fee for cognitive screening is due at the time of your interview with Dr. DeLisle. The fees for additional tests are payable to the professional at the time of your meeting with them. The ETeam administrative fee is due when your ETeam package is mailed to you.

Location

The ETeam professionals are all located in central Calgary, Alberta. Two of our members have offices in other cities as well (Anne Woolliams in Edmonton and Diana Monea in Regina). After booking your appointments, you will be sent a spread sheet with each appointment time, location and the contact for that professional.

After you decide to go ahead, we will book your assessment far enough in advance to allow you time to answer the questionnaires, complete 2 weeks of symptom observations and write a medical history. We request receiving your information about 3 weeks ahead of your assessment. This is most important if you are traveling from out of town. We read the information in advance and may suggest changes to the assessment

plan if needed. We are generally in contact with you by phone and email during this time to answer your questions.

We are excited to be offering this much-needed service and look forward to hearing from you.

Dr. Ellie Stein on behalf of the ETeam

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