

Client Information

The ETeam consists of:

Gerard Alberts, Stuart Donaldson, Cory Fagan, Robert Hadden, Diana Monea, Chris Rozell, Eleanor Stein, Anne Woolliams

One of the most frustrating experiences for people with ME/CFS, FM or MCS 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 MCS. The ETeam is gradually growing our skill set and team membership to offer as many valid, objective tests as possible. All of 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, MCS and toxic exposure 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 the individual’s own performance prior to illness. It is also important to know what to look for. In ME/CFS, FM and MCS not all functions are equally affected. The ETeam protocols shine a spot light on the areas of function most likely to be affected.

Background Information

Dr. Kaye Kilburn, a professor emeritus at the University of Southern California has had the opportunity to administer standardized tests to large groups of people exposed to known chemical toxins (e.g., sulfur dioxide leaks). In his book “Chemical Brain Injury” he outlines the test profiles of individuals exposed to a number of known chemical toxins (Kilburn, 1998). His approach is not only to measure whether some aspects of functioning are below the normative range but also to compare aspects of cognitive and sensory function that are expected to be affected with those that are not affected. Dr. Kilburn's protocol aids in the interpretation of commonly used standardized tests.

Psychologist Dr. Nancy Didriksen runs a busy private practice in Dallas, Texas and has personally examined thousands of patients primarily with MCS and related conditions. Dr. Didriksen has given many presentations about which tests are the most sensitive in these illnesses and what deficits can be expected. Her protocol is based on the World Health Organization recommendations for the detection of chemical exposure. There is a considerable published research on the cognitive dysfunction in ME/CFS and FM (Dick *et al*, 2008;Bower *et al*, 2005;Thomas & Smith, 2009;Majer *et al*, 2008). We have combined tests from this large literature for the ETeam cognitive battery. All of the tests are commonly used and well standardized.

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 (Van Ness *et al*, 2007;Ciccollella *et al*, 2007). The Stevens protocol has been replicated by two independent research groups since being first reported (Van Ness *et al*, 2010;Vermeulen & Vermeulen van Eck, 2014;Keller *et al*, 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 *et al*, 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 (presented at the 2014 IACFS/ME conference). This is an indication of under-activation of the brain and central nervous system dysregulation. Although qEEG in the clinical (as opposed to research) setting may not confirm diagnosis, it can validate subjective complaints using a test which cannot be faked or malingered.

Protocol Components

The selection of protocol components will be decided in conjunction with the client based on individual presentation and history. Please read this list carefully and be prepared to discuss with our team which symptoms and tests are of most interest to you. Of course we will give our professional opinion.

Cognitive Testing: Mr. Gerard Alberts or Mr. Robert Hadden, registered psychologists administer the cognitive testing. Both psychologists have an extensive experience in psychometrics and other aspects of psychological evaluation. Well-established, standardized tests and procedures are used to measure cognitive function and identify problems such as: poor short-term memory, attention and concentration problems, slowness in mental processing, problems with word finding, and more.

This testing is the most time-intensive component of the multidisciplinary assessment. It takes several hours to complete, which can be very tiring for the client. Testing can be arranged to suit one's schedule and energy level. However we suggest testing for several hours daily to replicate a typical life/work situation. The intensive ETeam testing protocol allows observations of post exertional malaise. A report of cognitive findings is provided with recommendations for improving workplace performance and/or quality of life.

Dr. Stewart Donalson PhD and Chris Rozell MC (Myosymmetries)

Quantitative EEG (QEEG) Brain Map: QEEG is a form of assessment which measures the electrical activity of the brain in specific locations. The goal is to determine the type and level of activity at each location, and measure the degree of connectivity between locations. With this objective information, one can gain improved understanding of a person's functioning, and can potentially explain symptoms that an individual experiences.

Psychophysiology Stress Testing: Using the Thought Technology system, we monitor an individual's heart rate, breathing rate, sweat response, muscle responses, and temperature while they complete a number of exercises that are designed to be challenging. The level of each physiological response provides us with objective evidence that may relate to symptoms and can provide clear goals to make treatment more efficient/effective.

Treatment informed by these test results includes **Neurofeedback and Brain Counselling.**

Neurofeedback is a form of biofeedback treatment which is used to shift the electrical patterns in the brain in order to improve functioning. Some areas may be hyperactive, while other areas may be underperforming.

Brain Counselling: As psychologists we often use classic counselling techniques such as cognitive-behavioural therapy and solution-focused therapy. When these techniques are combined with QEEG, the process can be improved because the objective data related to the functioning of the client's brain provides another level of understanding/insight. By matching the QEEG results to the person's symptoms and comparing the findings to scientific research, we can often explain why a client is feeling/thinking/behaving a certain way. The client can then understand their own challenges with attention and other cognitive processes, which enhances the mindfulness based restructuring of the brain.

Exercise Testing: Cory Fagan, MSc is a kinesiologist and owner of TCR Sport Laboratory in Calgary. Although Cory's primary clientele are athletes he has a background and interest in chronic illness including cancer survivors and patients with ME/CFS and FM. Incremental Blood Lactate testing assists patients in determining their anaerobic threshold and exercise capacity. Cory can provide recommendations for incremental training based on individual capacity. Cardiopulmonary Exercise testing is the gold standard to determine exercise capacity. It is possible to objectively measure whether someone has given a maximal effort. These results cannot be faked. Clients can attend for a traditional one day test or the specialized two day exercise test protocol. The two day protocol, if positive offers confirmation of post exertional malaise the core symptom of ME/CFS.

Visual and eye exam: Dr. Diana Monea (optometrist) conducts the visual component of the protocol. The effects of toxic exposure/CFS/FM on vision are frustrating and chronic. Since 80% of what we learn is through vision, visual impairments affect every waking moment and can be debilitating as one tries to work, study or parent. 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, visual fields to determine any visual loss, and color vision assessment. All assessment results are stored digitally and can be e-mailed if necessary to treating professionals. This consultation is a complete eye-health assessment.

Medical and Psychiatric exam: Dr. Eleanor Stein is a psychiatrist with a special interest in with ME/CFS, FM and MCS. She will undertake a focused history of the presenting symptoms and a careful review of systems to rule out other causes of the problems. She will also conduct 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 diagnoses if appropriate and will rate overall disability using the WHODAS 2.0. This assessment will also include recommendations for further testing if appropriate. Dr. Stein uses conventional medical/psychiatric treatments as well as functional medicine approaches to rehabilitation. All ETeam clients will receive a copy of Dr. Stein's manual: *Let Your Light Shine Through: Strategies for Living with ME/CFS, FM and MCS*. The manual contains referenced self management and medication recommendations.

Audiology Exam: Dr. Anne Woolliams (audiologist) conducts the audiological component of the assessment protocol. The effects of toxic exposure/CFS/FM on the auditory-vestibular system ranges from subtle to severe. CFS/FM can cause significant balance and equilibrium problems, hearing loss, auditory processing dysfunction, and tinnitus (ringing in the ears). The auditory-vestibular system is one of the most sensitive systems within the body to toxins and may begin to show signs of significant destruction before any other signs of toxicity may be seen. The audiological assessment may include direct measures of the integrity of the auditory-vestibular system. Hearing thresholds—the softest sounds, which can be heard—are measured, as well as the state of the cells within the inner ear and how effectively sound is transmitted from the inner ear to the level of the brainstem. These sensitive evaluative procedures allow us to measure the function of the auditory-vestibular system and correlate the results with the severity of damage to the ear from toxic exposure/CFS/FM.

Who can refer

You can contact the ETeam yourself but you will need a physician's referral before proceeding with the evaluation. Our equipment and test selections are designed specifically to assess cognitive dysfunction and related symptoms in people with ME/CFS, FM and MCS and certain toxic exposures. If you do not have problems with thinking or remembering, the ETeam may not be the best use of your resources. We will not accept referrals for unrelated disorders affecting cognition such as head injuries or neurological disorders.

The Procedure

For most clients the first step is a phone call to the ETeam office. One of the ETeam psychologists Gerard Alberts or Robert Hadden will contact you to discuss whether your symptoms fit the profile of people we feel we can help. They will also discuss the protocol and the fees. In most cases there will be a follow up phone call with Dr. Stein to discuss the choice of tests that will best meet your needs. Be sure to advise us of your time schedule and energy

limitations. Also let us know if there is a chance your test results may be used in any legal action. If your assessment is for medico-legal purposes, you must be referred by your lawyer and the fee schedule will reflect the increased work required.

After agreeing to an ETeam assessment, you will be sent a patient package including questionnaires. These must be completed and returned at least 3 weeks prior to your assessment. We will postpone your assessment until this information is received. Your medical history alerts us to possible conditions we may need to test for and may influence our recommendations for test selection.

Once we have received and reviewed your medical information, you will be advised of your appointment times and the contact information for each ETeam professional. If you have to change an appointment time please contact the ETeam office directly. To avoid delays in your assessment, please give maximal notice of appointment changes.

The ETeam protocol requires approximately 12 - 15 hours of in person assessment time with the various team professionals. For out of town patients the tests can generally be completed in one week but including the 2 day exercise protocol may involve an extra day's stay.

After you have completed the entire assessment, the team members will exchange information and meet to discuss their findings. Please allow up to two months for this process especially if your assessment is right before a holiday. When your results are complete, you and your referral source (physician or lawyer) will receive a detailed written assessment including individual reports from each ETeam professional, copies of test results and a summary of the main findings.

You will then meet with Gerard Alberts or Robert Hadden in person or by phone for a follow up appointment to discuss the findings and recommendations. You are welcome to book follow up appointments with any of the ETeam professionals if you wish further feedback or follow up.

Outcome

The objective of the ETeam protocol is to reliably measure the cognitive, sensory and exercise function in people with ME/CFS, FM, MCS and toxic chemical and mold exposure. The written 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 also include recommendations to manage and compensate for your symptoms. In some cases we may recommend further testing. In some, but not all cases, cognitive deficits are reversible with optimal management/treatment.

Payment

The medical component of the assessment (Dr. Stein) is covered by Canadian provincial health care plans. The psychological, visual, audiological and exercise assessments are not covered. Most insurance plans will pay a portion of these costs. Upon request we can provide you with a list of test procedures to submit to your insurer so that you will know the ultimate cost to you. In most cases insurance will not cover the entire amount.

The fees differ for patients who are resident of Alberta, resident of a province other than Alberta and for medico-legal assessments. Please indicate your situation so that we can give you the correct fee information. Half of the total fee is payable at the time you sign the informed consent to undertake the ETeam protocol and half is payable when you receive the final report.

For medico-legal assessments, the informed consent is signed by your lawyer and the lawyer pays the ETeam directly. In all other cases you are responsible for the fee. It is your responsibility (not ours) to get any reimbursement that you may be eligible for through insurance, WCB or out of province health care plans. We will provide you with all documentation you require to obtain reimbursement.

Location

The ETeam is located in Calgary, Alberta. If you will be coming from out of town to participate, we will attempt to book all of your appointments within one week. You will need to book at least a month ahead and have your paperwork back to the ETeam office 3 weeks before your scheduled appointments. Pre and post contact such as answering your questions about the protocol, informed consent and follow up can be done by phone and email.

We are very excited to offer you this much needed service.

For more information contact the ETeam at: (403) 254-8400 eteam@shaw.ca

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