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Clinicians Can Help People With Severe ME/CFS, Even Unseen

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People who are severely ill with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) are often too sick to leave home, but clinicians can still support them in many ways, experts say.

Approximately 250,000 people in the United Kingdom (0.2% to 0.4%) have ME/CFS — where it's called "ME." As many as 2.5 million in the United States have it. Those numbers are expected to dramatically increase with the addition of people with long COVID. An estimated 25% of patients with the condition are so severely impaired that they are housebound or bedbound to the point where they're unable to attend medical office visits. There are very few data about them because they're typically unable to participate in studies.

Speaking at the recent virtual meeting of the International Association for Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (IACFS/ME), patient advocate Helen Baxter, of the UK charity 25% ME Group, presented a case series of five patients bedbound with ME/CFS who became severely malnourished because of delays in the placement of feeding tubes. The delays occurred because it was not recognized that the patients were unable to eat. The inability to eat may be due to a variety of factors, including gastrointestinal dysfunction, dysphagia, nausea, or lack of sufficient energy to eat or drink.

A report of those cases was included in a special issue of *Healthcare* devoted to the topic of severe and very severe ME/CFS. The issue, which was published in April 2021, included 25 articles on the pathophysiology of severe ME/CFS, ways that clinicians can support patients who are too sick to make office visits, and psychosocial aspects of the condition that result from physical debilitation.

Two additional articles by specialist physicians aim to counter the skepticism about ME/CFS that has long persisted among some in the medical community.

"ME/CFS is under-researched and has historically received insufficient funding for research, particularly when compared to other chronic conditions, such as multiple sclerosis. And most of the research that has been done about it has focused on patients who are able to attend clinics. Patients with severe ME/CFS have largely been excluded from research due to the severity of their illness and are often described as 'hard to reach.' Consequently, research into severe ME is very limited," Baxter said.

Asked to comment, Lucinda Bateman, MD, founder and director of the Bateman Horne Center, Salt Lake City, Utah, told *Medscape Medical News*, "It's a big gap, even in the knowledgeable community. The research is totally skewed towards people who can get up and go participate in research.... I don't think most clinicians have any idea how sick people can get with ME/CFS."

Cardiopulmonary exercise testing (CPET), which is commonly used in research, is intended to elicit objective biomarker responses. Such testing, which is considered the gold standard for determining disability, is impossible for the most severely ill patients with ME/CFS and is potentially harmful to these patients because of the hallmark postexertional malaise (PEM) phenomenon, Bateman noted.

"If we want to use CPET for research, we have to remember that it harms people to some degree and that we're only studying the people who aren't as sick.... It's one of the reasons I've been aggressively pursuing medical education about orthostatic testing, because it's a clear objective marker, not as deleterious, and potentially leads to treatment options," she said.

Misdiagnosis, Treatment Delays Led to Life-Threatening Malnutrition

The five patients that Baxter presented had become severely malnourished and dehydrated. There was evidence of clinical inertia for each of them.

"All were judged to have anorexia nervosa, and psychiatrists were involved, which was an added delay to starting tube feeding.... In each case, the doctors resorted to making inappropriate psychological diagnoses without positive evidence of psychopathology, failing to recognize the significance of the malnutrition," Baxter said. (Urgent tube feeding would have been warranted even had anorexia nervosa been the correct diagnosis, she pointed out.)

Once the problem was finally recognized, "all participants saw an improvement in their situation following the allocation of a home enteral nutrition dietician."

At the IACFS/ME conference, Baxter described the painstaking methods used for gathering information, which were described in the same journal. These involved a combination of online, telephone, and text communications with patients or their caregivers. Efforts were made to avoid overtaxing the patients and triggering PEM.

"An early warning system needs to be put in place for patients with severe ME so that when they or their representatives become aware of the development of problems with oral intake, prompt action is taken and tube feeding started, thereby avoiding undernutrition in patients with very severe ME," Baxter and colleagues write.

Indeed, co-author and semiretired pediatric ME/CFS specialist physician Nigel Speight, of Durham, United Kingdom, told *Medscape Medical News*, "In most of my patients, I used tube feeding early simply to avoid using unnecessary energy and causing stress to the patient."

Speight added, "Patients can also die from sheer weakness leading to lack of respiratory drive. Also, and very understandably, some commit suicide."

Caring for the Patient With Severe or Very Severe ME/CFS

Appearing in the special issue is an article entitled, "Caring for the Patient with Severe or Very Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome." It was authored by a multidisciplinary group led by Jose G. Montoya, MD, of the Jack S. Remington Laboratory for Specialty Diagnostics, Palo Alto Medical Foundation, Palo Alto, California.

In that article, four levels of severity are defined: mild, moderate, severe, and very severe. Included in the “severe" category are patients who are mostly homebound and whose activities of daily living are limited. They may have severe cognitive difficulties. Patients in the "very severe" caregory are bedbound and are unable to care for themselves.

Clinical features include more extreme versions of the core ME/CFS criteria: profound fatigue/weakness, PEM, unrefreshing sleep, orthostatic intolerance, and cognitive impairment. Additional symptoms in those with severe/very severe ME can include extreme hypersensitivity to light, sound, touch, and/or odors. Even small amounts of physical, mental, emotional, and orthostatic stressors can trigger PEM and increased weakness.

The authors recommend a "patient-centered, collaborative approach that is grounded in compassion and respect for the patient in all interactions," and they provide lists of steps providers can take. These include seeing patients at home if possible and considerations regarding that care, such as partnering with the patient's caregivers and other healthcare providers, who may include physical and occupational therapists, home health nurses, and social workers who understand the condition. Home visits by optometrists or ophthalmologists and dentists may be required.

Documenting limitations in activities of daily living is particularly important for helping patients to obtain homecare and disability benefits, Montoya and colleagues say.

Clinicians should investigate any medical problems that may be amenable to treatment, including orthostatic intolerance, pain, sleep difficulties, comorbidities, or gastrointestinal problems. For patients with pain, bloating, and diarrhea who are found on assessment to have mast cell activation disorder (MCAD), a trial of sodium cromoglicate may be tried, Baxter told *Medscape Medical News*.

Nonmedical problems that may be contributing to the patient's morbidity should also be assessed, including a lack of caretaking, social services, transportation, food, and/or supportive devices, such as wheelchairs, bedpans, feeding tubes, and catheters.

The article provides additional detailed recommendations regarding pharmacologic treatments, follow-up visits — in-person or virtual — and hospitalization, as well as recommendations for energy conservation and management.

A section titled Practical Considerations for Busy Providers includes advice to be aware of any regulatory or insurance requirements for providing home visits and to maximize reimbursement by diagnosing any comorbidities, such as postural orthostatic tachycardia syndrome, Ehlers-Danlos syndrome, or MCAD.

Speight, who authored an article in the special issue on the management of ME in children, called the article by Montoya and colleagues "absolutely excellent" and added his own advice, which included not "overinvestigating to cover your back but at the expense of causing stress to the patient" and considering a trial of immunoglobulin.

Importantly, Speight stressed, "avoid referral to psychiatrists unless specifically indicated for additional psychiatric morbidity, in which case, make clear that the psychiatrist accepts [that the] basic illness is medical."

He also advised that clinicians stop using the term "chronic fatigue syndrome" because it suggests the illness is mild and/or psychosomatic. "Maybe the US should embrace the term ME once and for all," he said.

Baxter, Speight, and Montoya have disclosed no relevant financial relationships. Bateman is conducting research for Terra Biological LLC.

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