

## Guest Editorial

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# Research, recommendations and lived/personal experience with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

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This edition of *WORK: A Journal of Prevention, Assessment and Rehabilitation* features research, recommendations and lived/personal experience with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), a chronic, debilitating disease that affects 1 to 2.5 million Americans. Personally, this project has been an exciting opportunity and a great learning experience. My role as the special edition editor merges my background as an occupational therapy practitioner and my experience as caregiver of a child with severe ME/CFS. In my wildest dreams, I would never have imagined this path. But as I have come to realize, paths aren't always choices, they are callings and we go where we are needed. I am extremely grateful to Karen Jacobs, Editor-in-Chief, for this opportunity.

In February 2015, my young child got flu-like symptoms and never returned to health. The search for medical answers and relief from excruciating symptoms has been an overwhelming experience for my child and the entire family. She has never had a moment without pain, bone crushing fatigue, brain fog and utter intolerance to exertion. From that morning 5 years ago, she never returned to school or any of her childhood activities. ME/CFS is universally described by patients as having run a marathon with the flu and a hangover and then getting hit by a bus.

ME/CFS leaves individuals with a shell of their former lives. Their days are reduced to prioritizing basic needs: brush teeth or chat with my sister?; make a healthy sandwich or just have cereal so I can check

emails later?; take my weekly shower today or go to the doctor appointment? There is never enough energy for the wants, wishes and pleasures of daily living when you have ME/CFS. The disease is on a continuum of severity and no one knows when they will move up or down the scale and where the landmines are hidden. With trial and error, people with ME/CFS learn the self-protection skill of pacing, also known as living within the energy envelope. Pacing and performing activities within the energy envelope keep patients from “crashing” or being flooded with crushing ME/CFS symptoms. Because ME/CFS does not have identified biomarkers, lacks research in evidence-based treatment guidelines and is incorrectly thought of as a disease of deconditioning, the most common treatment approach has been graded exercise therapy (GET). But when practitioners know about the multi-system impairments, the hallmark symptom of post-exertional malaise, and the crash cycle, the GET “push through/mind over body” assumptions are recognized as a harmful treatment approach for people with ME/CFS.

I have met so many people with ME/CFS who have had to fight years for a diagnosis, spent thousands on medical care and symptom relief, and are constantly being told their illness is exaggerated. In today's viral pandemic environment, knowing that the majority of ME/CFS cases are triggered by viral and other infections, I worry about the many people who could end up with ME/CFS after Covid-19. Sadly, there are still no biomarker tests or FDA approved medi-

cations that would improve diagnosis and quality of life for the millions who are missing from the lives they love.

I hope you are enlightened by this issue of *WORK* focusing on research, treatment care and patients' lived experience with ME/CFS. Please continue to learn about ME/CFS by visiting the many advocacy groups (such as MEAction, Solve ME/CFS Initiative and the Massachusetts ME/CFS & FM Association) and research centers (such as Open Medicine Foundation, Bateman-Horne Center and the NIH-funded ME/CFS Research Network). People with ME/CFS are fighting every day to return to their activities of daily living and are very grateful for health advocates to join in the fight to bring awareness to ME/CFS.

Karen Jacobs, thank you for this opportunity to share with your readers the challenges ME/CFS brings to daily living activities and the degree to which it strips away the foundation of those living with this disease. Stephanie Lancaster and Lily Williams, I appreciate your skills and guidance with this project. Thank you to all the authors and reviewers who have spent so much time and effort to make this ME/CFS edition happen. I know you are all busy conducting your own research and educating future ME/CFS scientists. Thank you from all the ME/CFS warriors around the world for your expertise.

Peace and good health,

Amy Mooney, MS OTR/L

*Guest Editor*