Centers for Disease Control and Prevention
CDC 24/7: Saving Lives, Protecting People™

CDC Features

ME/CFS International Awareness Day

May 12th is the Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) International Awareness Day. On this special day, we highlight how you can support the millions of people who suffer from ME/CFS.

ME/CFS is a serious, long-term illness that affects many body systems. People with ME/CFS have severe fatigue and sleep problems. ME/CFS symptoms may get worse even after minor physical, mental, or emotional tasks or effort. This phenomenon is known as post-exertional malaise (PEM). Other symptoms can include problems with thinking and concentrating, pain, and dizziness. Often, people with ME/CFS may not be able to do their usual activities. Many adults with ME/CFS are unable to work and long-term unemployment often brings further hardship. When children have this illness, their education is often affected.

May 12 honors the birthday of Florence Nightingale, an important social reformer, statistician, and the founder of modern nursing. *(c) illustrated by Nigel Buchanan*

May 12th honors the birthday of Florence Nightingale, an important social reformer, statistician, and the founder of modern nursing. Despite being virtually bedridden with a painful and fatiguing illness resembling ME/CFS or fibromyalgia, she established the Nightingale Training School in 1860. This May 12th, 2020, marks her 200th birthday and the 28th year of ME/CFS International Awareness Day.

What Can You Do?

Educate. For awareness day, take time to learn more about this illness by visiting any of the links below in the "More Information" section. If you or a loved one has ME/CFS, share your personal stories about how this illness has affected you and take the time to listen to others' stories.

Support. On May 12th, wear **blue** to raise awareness and show support for people with ME/CFS, their families and caregivers, and researchers who study ME/CFS. Use social media to spread information about ME/CFS and to highlight people who suffer from this illness.

It is time to start the conversation – fewer than 1 of 5 people with ME/CFS have been diagnosed by a healthcare provider. Look for ME/CFS educational events and pass the information to your neighbors and friends. Use ME/CFS awareness day to discuss this illness with your family, friends, and healthcare providers.

What Can Healthcare Providers Do?

ME/CFS affects up to 2.5 million Americans. It affects all ethnic and racial groups, including African Americans and Hispanics. Doctors, nurses and other medical personnel can learn more about the disease on the healthcare provider section of CDC's ME/CFS website, which includes recommendations from the 2015 Institute of Medicine (IOM) report . For information about ME/CFS in Spanish, please check out our en Español website.

Stay Informed. Check out the following educational videos and continuing medical education courses:

- Educational videos
- Diagnosing ME/CFS – The Experts Weigh In
- ME/CFS: Test Your Strengths and Gaps in Knowledge
- ME/CFS: A Case-Based Learning Module

ME/CFS changes people's ability to perform daily tasks that were previously easy for them. Communicate with patients and show them that you understand and believe them. Acknowledge how they feel. Encourage them to share their stories. Consider adding extra time to their office visit, by even one minute. Spending that extra 60 seconds asking how patients are doing generally, not just medically, may help you to build stronger relationships with your patients.

Listen. ME/CFS is a real and complex illness that is difficult to diagnose. Each patient is unique and requires an individualized treatment program that best meets their needs. As a healthcare provider, you can listen to them and communicate with them in order to deliver effective care. Check out our website, "Voice of the Patient" to read patients' stories shared in their own words.

For pediatric ME/CFS, the fact sheet for healthcare providers can be found on CDC's ME/CFS website.

What Can Families Do?

Speak up for your loved one. Be active in helping your family member manage their illness and encourage them to do the same. Talk with your family's healthcare provider about your loved one's needs and concerns. Educate others involved in your loved one's life about ME/CFS so that they may help when needed.

Educate yourself. Learn as much as you can about ME/CFS and about how the illness affects your family member. It can be a challenge to go to school or keep working when you have ME/CFS. Accommodations can be made available to people with ME/CFS at work or school. Check out the website of the U.S. Department of Labor for job accommodations . Look up CDC's fact sheet for parents and guardians [240 KB] on how you can manage with your child's illness.

Socialize. Social activities are essential for the well-being of people with ME/CFS and their families. Yet children and adults with ME/CFS may struggle to stay involved in family or social activities. Sometimes, physical participation in activities may not be feasible. Consider using technology to engage with others. For example, invite your friends to watch a movie or listen to a song online with you. When planning activities for people with ME/CFS, start slow and add more gradually to avoid PEM.

What Can Schools Do?

Understand. Educate school staff about ME/CFS in order to help them better empathize with students suffering from the illness. Each child with ME/CFS may experience different symptoms, and the duration of their symptoms may differ as well. Take time to understand each student's individual illness and challenges. Recognize that ME/CFS can affect all aspects of a child's life, from academic performance to social activities.

Collaborate. A key to helping students with ME/CFS is to work as a team. This team may include parents, teachers, administrators, school nurses, other education professionals, and healthcare providers. The team approach can provide flexibility with educational plans and school resources that are customized to meet the student's needs.

Accommodate. ME/CFS is a disabling and complex illness. It affects how students learn and participate in school. Teachers and administrators may need to use creative strategies to foster supportive learning environments for students with ME/CFS. Accommodations might include time extensions on exams and assignments, scheduled rest periods throughout the school day, and combined school and home tutoring. For more information, please check out our fact sheet for education professionals. [201 KB]

More Information

- CDC ME/CFS Website
- NINDS/CDC Common Data Elements (CDEs) for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Disability and ME/CFS
- CDC's Public Health Matters Blog: America's Hidden Health Crisis: Hope for Those Who Suffer from ME/CFS
- NIH Director's Blog: Moving Toward Answers in ME/CFS, March 2017
- NIH ME/CFS website external icon
- FDA Voice of the Patient [267 KB]
- ME/CFS clinical trials

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