



# Accommodating University Students with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

## A Guide for Colleges and Universities

Lily Chu<sup>i</sup>, Lynn R Fuentes<sup>ii</sup>, Olena M Marshall<sup>iii</sup>, Arthur A Mirin<sup>iv</sup>

<sup>i</sup> Independent Consultant, Burlingame, CA

<sup>ii</sup> CEO, Transformation Teaching, LLC, Sedona, AZ

<sup>iii</sup> Doctoral Candidate, Educational Leadership, DePaul University College of Education, Chicago, IL

<sup>iv</sup> Independent Researcher, Castro Valley, CA

### Overview

This guide is an abridgement of our journal article *Environmental Accommodations for University Students Affected by Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)*,<sup>1</sup> which was originally designed to educate occupational therapists about how they could help university students with ME/CFS. Recommendations from the article were also adapted to highlight steps faculty, staff and administrative professionals can take to provide support and accommodations for students afflicted with this highly debilitating disease.

While many of our suggestions are applicable to chronic illnesses in general<sup>2</sup>, the lack of familiarity with ME/CFS underscores the importance of having a resource specifically oriented toward this disease. Universities might recommend that students and families use this guide to help educate their physicians and occupational therapists to better enable them to advocate on behalf of the student.

As of August 2020, at least 51,000 cases of COVID-19<sup>3</sup> and 60 deaths have been associated with universities and colleges across the United States. Although many of those afflicted may have been asymptomatic or experienced mostly mild symptoms, some people, though no longer at risk of spreading the disease, have continued experiencing symptoms weeks and months afterwards. This chronically affected group includes adolescents and young adults.<sup>4</sup> As pointed out by Dr. Anthony Fauci, Director of the National Institute of Allergy and Infectious Diseases: “[COVID-19 survivors] have things that are highly suggestive of myalgic encephalomyelitis and chronic fatigue syndrome - brain fog, fatigue, difficulty in concentrating so this is something we really need to seriously look at because there

very well might be there is a post-viral syndrome associated with covid-19.<sup>15</sup> A study of survivors of a similar coronavirus (SARS-CoV)<sup>6</sup> showed that 27% of survivors developed ME/CFS. Consequently, it is reasonable to expect that COVID-19 will result in a significant number of students being diagnosed with ME/CFS or experiencing ME/CFS-like symptoms in the near future. In addition to helping students who are already diagnosed with ME/CFS, the recommendations made herein may help universities and colleges anticipate the COVID-19 related needs of afflicted students. Even if a student eventually recovers completely from COVID-19, implementing the accommodations we suggest will help and not harm them in the interim.

### Disease characteristics and background

ME/CFS is a chronic, complex, disabling disease that affects between 1 and 2.5 million Americans<sup>7</sup>. Those afflicted include men, women, and children of all races, ethnicities and socioeconomic backgrounds. Onset often occurs between the ages of 10 and 19 and usually follows an infection. For example, up to 14% of people afflicted with Epstein-Barr virus (EBV) mononucleosis will develop this condition<sup>8,9</sup>. In 2015, the American College Health Association found that 1.5% of college students were diagnosed with EBV mononucleosis each year<sup>10</sup>, which corresponds to 0.2% potentially developing ME/CFS annually. With an estimated college student population of about 20 million<sup>11</sup>, up to 40,000 students could be newly affected by ME/CFS annually<sup>12</sup>. The total number of students affected may be higher due to ME/CFS following other infections, enrollment of students already affected by ME/CFS, and the persistence of ME/CFS over time.

ME/CFS has one of the highest morbidity rates among known diseases<sup>13</sup>. Its hallmark symptom is *post-exertional malaise* (PEM) - a delayed, prolonged, and sometimes unpredictable exacerbation of symptoms and loss of stamina following mental or physical exertion. An estimated 25-29% of people with ME/CFS are bedbound or homebound, 35-69% are unemployed, and 84-91% remain undiagnosed. The cause of ME/CFS remains unknown and there is no FDA-approved treatment specifically for ME/CFS. However, proper care can improve the patient's health, function and quality of life.

ME/CFS sufferers have limited physical and cognitive energy and often require rest breaks throughout the day. Too much energy expended in too short a time period risks a PEM episode (referred to as a "*crash*" by some sufferers), which can result in anywhere from hours to weeks of incapacitation. Those afflicted must take care to not exceed their *energy ceiling*.

This guide (together with our journal article) focuses on environmental accommodations within post-secondary education. Ideally, these accommodations will work in conjunction with appropriate medical care<sup>14</sup> and with behavioral measures<sup>15</sup> that students can take in their own lives (e.g., planning activities ahead of time, prioritizing tasks, delegating when possible, etc.).

## Recommended accommodations

The following are accommodations that we recommend for university students. Please consult our full journal article for elaboration and rationale.

### *Awareness of the fluctuating nature of ME/CFS*

1. Be aware of the waxing and waning nature of ME/CFS and its unpredictability

### *Negotiation of accommodations in advance*

2. Ensure that affected students are aware of the need to register with the disability office as early as possible
3. Advise student to schedule an appointment with an academic advisor/consultant early in their university years
4. Encourage students to communicate with instructors prior to beginning a class
5. Encourage students to request assignment flexibility when possible, emphasizing mastery over quantity of work
6. Help students minimize travel. Consider
  - a. Support for participation from off-campus sites
  - b. Provision of teleconference capabilities
  - c. Online courses and/or placement of class materials online
  - d. Housing close to campus
  - e. Dorm rooms that are private, handicap-accessible, and/or close to shared amenities
  - f. Handicapped parking permits
  - g. Transportation to and between classes

### *Actions universities can take to accommodate students*

7. Encourage lecture notes and/or recordings when lectures are not online or otherwise available for review; if no recordings are available, allow students to record lectures on their own
8. Allow examination accommodations, especially when requested ahead of time. Some examples are:
  - a. Additional time
  - b. Scheduled and/or spontaneous rest breaks
  - c. Allowance of food and drink (provided by the student) as needed to effectively manage their condition
  - d. Alternative testing modalities (e.g., online, oral)
  - e. Scheduling exams so that students can take advantage of their higher energy times
  - f. Spacing out examinations (e.g., allowing two two-hour final tests to be taken on separate days rather than the same day)

- g. A quiet place to take exams (e.g., disability office) or the use of earplugs or noise-cancelling headphones
- 9. Permit flexible scheduling when possible and the ability to miss or leave classes without penalty when medically necessary
- 10. Organize easily accessible rest areas on campus and include the right to take opportunities for rest where and when needed
- 11. Furnish ergonomic furniture and devices, such as desks, chairs, computers, keyboards, computer mice.
- 12. Incorporate as much flexibility as allowable for students who have a work assignment, such as a teaching assistantship, or another type of work-like experience such as an experimental learning course requirement. Examples of accommodations include:
  - a. Teaching remotely
  - b. Scheduling class at a convenient time
  - c. Facilitating remote office hours
- 13. Facilitate the use of wheelchairs, mobility aids, and other power-driven mobility devices (OPDMDs), as provided for in the Americans for Disabilities Act, where legal and consistent with applicable university policies

Universities should inform students and their families about these accommodation options and how to access them.

*Advocating for students at a systemic level*

- 14. Provide awareness training to relevant university staff
  - a. Educate faculty and staff about non-traditional disabilities (e.g., share this Guide and associated infographic<sup>16</sup> with staff)
  - b. Prepare orienting information for faculty and student-facing staff who encounter students with ME/CFS
  - c. Educate campus-based medical providers, psychologists and counselors about the physiological basis of ME/CFS so that inappropriate suggestions for more activity or psychological treatment are not offered
- 15. Arrange for support services, ideally:
  - a. An advisor trained to advocate for students with ME/CFS
  - b. A guide directed at students with ME/CFS that teaches them self-advocacy, their rights on campus, what accommodations are available, what accommodations to ask for, and how to ask
  - c. A pamphlet for faculty that the student could provide at the beginning of the term
  - d. Opportunities for interaction with other afflicted students
  - e. Counseling staff who are aware of the needs of students with ME/CFS
  - f. Health center staff who are familiar with ME/CFS
- 16. Ensure that the various university offices that serve students with ME/CFS are working synchronously and in harmony with each other

---

<sup>1</sup> Chu L, Fuentes LR, Marshall OM, Mirin AA. Environmental Accommodations for University Students Affected by Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). *Work* 2020; 66(2):315-326. DOI: [10.3233/WOR-203176](https://doi.org/10.3233/WOR-203176)

<sup>2</sup> Author Fuentes (formerly Royster) founded the Chronic Illness Initiative to support students with chronic illness needs at DePaul University and partnered with author Marshall to document that program. See Royster L, Marshall O. The Chronic Illness Initiative: Supporting College Students with Chronic Illness Needs at DePaul University. *J Postsecondary Education* 2008;20(2):120–5. Available from: <https://files.eric.ed.gov/fulltext/EJ825778.pdf>.

<sup>3</sup> Tracking coronavirus cases at US colleges and universities. *NY Times*. Available from: <https://www.nytimes.com/interactive/2020/us/covid-college-cases-tracker.html>. Accessed 8 September 2020.

<sup>4</sup> Covid is Making Younger, Healthy People Debilitatingly Sick for Months. Now They're Fighting for Recognition. *BuzzFeed*. 25 August 2020. Available from: <https://www.buzzfeednews.com/article/briannasacks/covid-long-haulers-who-coronavirus>.

<sup>5</sup> Official Press Conference: Covid-19 conference highlights (Thursday, 9 July). Available from: [https://www.youtube.com/watch?v=UMmT48IC0us&feature=youtu.be&t=1999&mc\\_cid=1549d1d6f3&mc\\_eid=4e8eedfd25](https://www.youtube.com/watch?v=UMmT48IC0us&feature=youtu.be&t=1999&mc_cid=1549d1d6f3&mc_eid=4e8eedfd25). Additional information on Dr. Fauci's comments may be found in [Healthline](#), [Medscape](#) and [Business Insider](#).

<sup>6</sup> Lam MH-B, et al. Mental Morbidities and Chronic Fatigue in Severe Acute Respiratory Syndrome Survivors. *Arch Intern Med*. 2009; 169(22):2142-2147. DOI: [10.1001/archinternmed.2009.384](https://doi.org/10.1001/archinternmed.2009.384).

<sup>7</sup> National Academy of Medicine, National Academy of Sciences. Beyond Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Redefining an Illness; 2015. Available from: <http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>.

<sup>8</sup> Jason LA, Katz BZ, et al. Predictors of Post-Infectious Chronic Fatigue Syndrome in Adolescents. *Health Psychol Behav Med*. 2014;2(1):41-51. DOI: [10.1080/21642850.2013.869176](https://doi.org/10.1080/21642850.2013.869176).

<sup>9</sup> Hickie I, et al. Post-infective and Chronic Fatigue Syndromes Precipitated by Viral and Non-viral Pathogens: Prospective Cohort Study. *BMJ* 2006; 333:575. DOI: <https://doi.org/10.1136/bmj.38933.585764.AE>.

<sup>10</sup> Spring 2015 Reference Group Executive Summary, American College Health Association. Available from: [https://www.acha.org/documents/ncha/NCHA-II\\_WEB\\_SPRING\\_2015\\_REFERENCE\\_GROUP\\_EXECUTIVE\\_SUMMARY.pdf](https://www.acha.org/documents/ncha/NCHA-II_WEB_SPRING_2015_REFERENCE_GROUP_EXECUTIVE_SUMMARY.pdf).

<sup>11</sup> College Enrollment in the United States from 1965 to 2018 and Projections up to 2029 for Public and Private Colleges. *Statista*. Available from: <https://www.statista.com/statistics/183995/us-college-enrollment-and-projections-in-public-and-private-institutions/>.

<sup>12</sup> Actual figures could be higher due to enrollment of already-sick students, affected students continuing to be sick, and ME/CFS onset following other infections or events. Or they could be lower due to already afflicted students having chosen not to enroll in college.

<sup>13</sup> Hvidberg MF, Brinth LS, Olesen AV, Petersen KD, Ehlers L. The Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). *PLoS One* 2015;10: e0132421. DOI: <https://doi.org/10.1371/journal.pone.0132421>.

<sup>14</sup> U.S. ME/CFS Clinician Coalition. Diagnosis and Treatment. Available from: <https://mecfsciniciancoalition.org/clinical-management/#diagnosisandmanagement>.

<sup>15</sup> ME/CFS and Fibromyalgia Self-Help. Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia. Available from: <http://www.cfselfhelp.org/>. Accessed 8 September 2020.

<sup>16</sup> Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS). Available from: [https://www.canva.com/design/DADINygTjT8/9esrzVs9DWpkH7CdQm9fqg/view?utm\\_content=DADINygTjT8&utm\\_campaign=designshare&utm\\_medium=link&utm\\_source=sharebutton](https://www.canva.com/design/DADINygTjT8/9esrzVs9DWpkH7CdQm9fqg/view?utm_content=DADINygTjT8&utm_campaign=designshare&utm_medium=link&utm_source=sharebutton).