

#MILLIONS MISSING

FACT SHEET

Myalgic Encephalomyelitis (ME):

- ME is a multi-system disease that causes profound metabolic dysfunction and is accompanied by physical and cognitive limitations.
- People experience symptoms on a spectrum from severe to mild, but [75% of people with the disease are unable to work](#) and [25% are homebound or bedridden](#).
- ME/CFS affects all races, ethnicities, genders, and ages—although [75% of those with ME/CFS are women](#).
- Most cases of ME are initiated by an infection. Approximately 80% of people with ME report an infectious onset, whether it was SARS-CoV-2, MERS, swine flu, Epstein-Barr, or a bacterial infection, and never recovered.
- ME/CFS affected more than 1 million Americans, more than MS or HIV/AIDS; and there were an estimated 15-30 million people with ME worldwide, before the pandemic.
- Only 5% of adults recover from ME/CFS. Children and adolescents are more likely to recover, but their symptoms may return in adulthood.

Long COVID & ME:

- The pathway to recovery or diagnosis for people with Long COVID will not be uniform. Some will recover, some will have organ damage and a subset are expected to develop chronic illnesses like ME/CFS, autonomic disorders and autoimmune conditions.
- Many of those living with Long COVID are reporting symptoms that resemble ME/CFS, most notably post-exertional malaise, a worsening of symptoms after exertion.
- Preliminary studies are now showing that nearly [half of people with Long COVID are presenting with ME/CFS](#).
- It is estimated that due to COVID-19, [5-7 million people will be diagnosed with ME/CFS in the United States](#) (an increase from 1.5 million).

