

Recovery Position Statement



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Statement

The general consensus is that full recovery from ME/CFS is not common. However, the research into recovery is plagued by methodological issues, making clear conclusions difficult. There is an urgent need for high-quality, longitudinal research, utilising objective measures of functioning, to determine the long-term prognosis and likelihood of recovery from ME/CFS.

Long-term prognosis for people living with ME/CFS is difficult to predict. While some living with the illness may improve over time, the general consensus from ME/CFS experts is that full recovery from ME/CFS (a return to pre-illness functioning) is not common[1],[2]. Prognosis is better for young people (children and adolescents) and those with mild forms of the illness than it is for those middle-aged and older, and for those who are more severely unwell[1],[3].

Background

Recovery vs improvement

The research literature about recovery from ME/CFS is inconsistent, making firm conclusions about recovery rates difficult. In particular, most studies of recovery don't include a return to pre-illness function as part of their definition of "recovery" and would be more accurately considered studies on rates of improvement than recovery[1].

Improvement vs adaptation

In addition, most studies of recovery use subjective ratings of improvement, rather than objective measures (such as return to work rates or objective tests of symptoms or functioning, like a 2-day cardiopulmonary exercise test) to determine recovery[4],[5].

Subjective ratings of improvement, or measures of symptom reduction, don't differentiate between improvement in health and adaptation to the illness. Many patients learn to live within their energy limits over time (so as to avoid triggering post-exertional malaise and making their condition worse), which may make them less symptomatic, but not necessarily any more functional[4],[5]. For this reason, using subjective ratings of symptoms is misleading as a measure of recovery. Recovery from ME/CFS must be measured using objective measures, such as actimeters or return to work rates[5].

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Supporting Australians Living with ME/CFS

Recovery vs remission

Finally, like multiple sclerosis, there is evidence that ME/CFS can take a relapsing/remitting course[6],[7], making it difficult to determine whether cases of recovery are more accurately in remission, and at risk of relapse in the future.

Without a biomarker for ME/CFS, the notion of recovery is complex, however it should include more than just symptom reduction, and patient views of recovery should be incorporated into the definition of recovery[8].

Evidence

Full recovery from ME/CFS (that is, a return to pre-illness functioning) is considered to be rare. While recovery rates are difficult to estimate, they are generally thought to be just 5-10%[1],[9]. The illness may take a relapsing-remitting course for some, and in up to 20% of cases the illness worsens over time[1]. Prognosis is better for young people (children and adolescents) and those with mild forms of the illness than it is for those middle-aged and older, and for those who are more severely unwell[1],[3].

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1. Friedberg, F. *et al.* (2014). *ME/CFS: A Primer for Clinical Practitioners*. International Association for chronic Fatigue.
 2. Baraniuk, J. (2017) BMJ Best Practice. Chronic fatigue syndrome. <https://bestpractice.bmj.com/topics/en-us/277>.
 3. Rowe, P. C. *et al.* (2017) Myalgic encephalomyelitis/chronic fatigue syndrome diagnosis and management in young people: A primer. *Frontiers in Pediatrics* vol. 5 Preprint at <https://doi.org/10.3389/fped.2017.00121>.
 4. Adamowicz, J. L., Caikauskaite, I. & Friedberg, F. (2014) Defining recovery in chronic fatigue syndrome: a critical review. *Quality of Life Research* vol. 23 Preprint at <https://doi.org/10.1007/s11136-014-0705-9>.
 5. Twisk, F. N. M. (2014) A definition of recovery in myalgic encephalomyelitis and chronic fatigue syndrome should be based upon objective measures. *Quality of Life Research* 23.
 6. Morris, G. & Maes, M. (2013) Myalgic encephalomyelitis/chronic fatigue syndrome and encephalomyelitis disseminata/multiple sclerosis show remarkable levels of similarity in phenomenology and neuroimmune characteristics. *BMC Medicine* 11.
 7. Jason LA, T.-H. S. and N. MFC. (2006) The Face of CFS in the US. <https://www.researchgate.net/publication/236995875> 1–8.
 8. Devendorf, A. R., Brown, A. A. & Jason, L. A. (2020) Patients' hopes for recovery from myalgic encephalomyelitis and chronic fatigue syndrome: Toward a "recovery in" framework. *Chronic Illness* 16.
 9. Friedberg, F., Sunnquist, M. & Nacul, L. (2020) Rethinking the Standard of Care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. *Journal of General Internal Medicine* vol. 35 Preprint at <https://doi.org/10.1007/s11606-019-05375-y>.