Inquiry of the Capability and Culture of the National Disability Insurance Agency

Submission of - Call for Change Australia to the Joint Standing Committee on the National Disability Insurance Scheme

Who we are

Call for Change is a grassroots community of people with ME/CFS calling on the government to investigate the violence, neglect, abuse and exploitation of people with ME (PWME). In 2022 we submitted evidence to the Disability Royal Commission and started a change petition which has currently gained over 4400 signatures https://www.change.org/callforchangeaustralia

What is ME/CFS

Myalgic encephalomyelitis (ME) sometimes called Chronic Fatigue Syndrome (ME/CFS) is a chronic, inflammatory, physically and neurologically disabling disease.

According to the International Consensus Criteria a patient will meet the criteria for Myalgic Encephalomyelitis if they have:

A - Postexertional neuroimmune exhaustion

B - at least ONE neurological impairment symptom from THREE categories:

1. Neurocognitive Impairments
2. Pain
3. Sleep Disturbance
4. Neurosensory, Perceptual and Motor Disturbances

C - at least ONE immune/gastro-intestinal/genitourinary impairment from THREE categories:

5. Flu-like symptoms may be recurrent or chronic and typically activate or worsen with exertion

6. Susceptibility to viral infections with prolonged recovery periods
7. Gastro-intestinal tract disturbances
8. Genitourinary disturbances
9. Sensitivities to food, medications, odors or chemicals, and

D - at least ONE energy metabolism/ion transport impairment symptom.

10. Cardiovascular
11. Respiratory
12. Loss of thermostatic stability

Intolerance of extremes of temperature

Lived experience of the NDIA's capability and culture as a participant with ME/CFS

There is a culture of nontransparency within the NDIA regarding Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), and the use of guidelines for assessing access requests which are informed by outdated treatment recommendations. This is creating an unfair disadvantage to the ME/CFS community and their ability to access the scheme.

According to documents obtained under the Freedom of Information Act, by Call for Change Australia on behalf of the ME/CFS community, the NDIA have an official document, "'Research – Theory and Practice'" that is clearly used internally to advise on the assessment of access requests for those with disability related to ME/CFS (FOI 21/22 – 0693, pp. 1 -23) .This document is based on guidelines and the advice of a professor that have outdated position on ME/CFS treatment interventions. The NDIA has failed to seek co-design in relation to ME/CFS and has not engaged with ME/CFS consumers in their development of assessment guidelines. The Agency should be consulting with the ME/CFS community as the most appropriate experts on the subject matter of ME/CFS. Had this occurred the ME/CFS community would not have recommended the Agency's choice in consultant. According to correspondence between myself and a NDIA representative "the

Agency receives approaches from several peak bodies. For ME/CFS this has been predominantly Emerge and to a lesser extent ME/CFS Australia. The Agency consistently engages with a range of Peak Bodies" (personal communication, November 17, 2021). However, they provided no information on who the other "peak bodies" are and went on to say "there was no tender process involved in the above process. The Agency communicates and engages with all Peak bodies that seek to connect with us. The NDIA accesses information as needed from a range of various sources "(personal communication, November 17, 2021).

The Agency also failed to seek a second opinion from any other practitioner with expertise in ME/CFS and surmised that it was unnecessary due to the professors so called credentials. Additionally, the professor was financially compensated by the Agency for his advice which brings into question the impartiality of the information he provided (FOI 21/22-1057, p. 6). The professor was a co-contributor of the 2002 The Royal Australasian College of Physicians (RACP) Chronic Fatigue Practice Guidelines that recommends Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) for the treatment of ME/CFS (RACP, 2002). These recommendations were reiterated to the NDIA in a "Report in response to a request for information and advice regarding chronic fatigue syndrome" (FOI 21/22 – 1057,pp. 12-17.). Recent evidence has suggested that CBT and GET is not only unlikely to positively affect the impairments caused by ME/CFS but can also cause harm to patients and exacerbate symptoms (see Appendix for evidence summary). This evidence has resulted in other guidelines revising their treatment and management advice for ME/CFS (the RACP guidelines are in the process of being updated however this will take several years and the meantime the NDIA continues to rely on the 2002 guidelines).

The Centre for Disease Control (CDC) The CDC have removed GET and CBT as treatment options for ME/CFS. Their website states there is no cure or approved treatment for ME/CFS and that standard exercise recommendations for healthy people can be harmful for patients with ME/CFS (Centers for Disease Control and Prevention, 2021).

The National Institute for Health Care and Excellence (NICE) The NICE guidelines states "do not offer people with ME/CFS physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories as perpetuating ME/CFS". They have deemed the quality of evidence for CBT and GET to be “very low” to “low” quality due to risk of bias, indirectness and imprecision”. NICE concludes “that it is unethical to treat ME/CFS with ineffectiveness, non-evidence-based and potentially harmful ‘rehabilitation therapies” such as CBT/GET” (NICE, 2021) Furthermore, their review of evidence found that “there is little scientific credibility in the claim that psycho-behavioural therapies are a primary treatment” (NICE, 2021).

According to correspondence with myself and the NDIA, the Agency use the RACP and NICE guidelines collectively with other expert opinion to assess if an applicant with ME/CFS has trialled all relevant interventions to meet the permanence criterion as per s24 and s25 of the NDIS Act 2013 (personal communication, November 17, 2021). This is despite the conflict between the guidelines on recommended treatment and their stance on the effectiveness and safety of CBT and GET. The Agency stated that they will continue to use the above guidelines “in the absence of any further evidence-based guidance clarifying treatment recommendations for ME/CFS” (personal communication, November 17, 2021). It appears that the significant body of recent peer-reviewed literature regarding ME/CFS treatment interventions has escaped the Agency’s attention.

The Agency’s current guidelines for the assessment of ME/CFS is having a detrimental effect on consumers ability to gain access to the NDIS. Further Freedom of Information obtained by Call for Change Australia (FOI 22/23 – 0733) has revealed that 71% of access requests from those with ME/CFS related disability are rejected (reasons were not provided in documentation). According to anecdotal evidence from the ME/CFS community the main reason for rejection is not meeting the access criteria for permanency of impairments. The NDIS consider impairments to be permanent only after available and appropriate evidence-based treatment options have been pursued. The NDIS continues to consider that CBT and GET are an appropriate intervention. ME/CFS consumers are having to address CBT and GET in their requests and prove they have previously participated or trialled the interventions despite evidence of its ineffectiveness and possibility to cause harm. ME/CFS consumers are therefore disadvantaged when it comes to successfully gaining access to the NDIS. Many have had to pursue internal reviews and external reviews to the Administrative Appeals Tribunal. This creates unnecessary burden, contributing to the severity and longevity of impairments experienced by those with ME/CFS and increasing their support needs while they attempt to survive without adequate care. The NDIA is incapable of making an appropriate assessment of the eligibility criteria for ME/CFS consumers by its reliance on outdated recommendations and advice from a so-called expert with questionable credibility.

My own journey with ME/CFS has spanned 10 years, which has included 3 years attempting to get access to the NDIS which I was finally successful in obtaining. However, the Agency refuses to recognise my ME/CFS related disabilities, which are severe and require substantial support, and I have now had a case before the AAT for over 3 years. I previously trialled CBT and GET, and on all occasions, it resulted in Post Exertional Malaise (PEM) – the worsening of ME/CFS symptoms/impairments following physical or cognitive activity. PEM can cause permanent decline in functional capacity thus increasing disability impairments and consequently support needs. Forcing applicants to first attempt CBT and/or GET before deeming ME/CFS impairments permanent will cost the NDIS more in the longer term as ME/CFS consumers may need more substantial supports than if they had not participated in CBT and/or GET.

In summary Call for Change Australia has found:

- There has been a significant increase of applications for access to the NDIS (FOI 22/23 – 0733).
- 160 PWME are recognised and have access to the NDIS (FOI 22/23 – 0733).
- 80 PWME have access to NDIS funding but their ME/CFS is not recognised under the scheme (FOI 22/23 – 0733).
- 1 participant recognised for ME/CFS was exited from the scheme but no explanation for why was provided (FOI 22/23 – 0733).
- The NDIS only started recording ME/CFS patient numbers after our initial FOI. Before then, no data was held.
- According to the NDIA they falsely assert that the condition is only deemed permanent after "5 years” and that most patients will “recover” in 1 year (FOI 21/22-

1057, p. 14). This claim is made despite recent biomedical research and patient surveys stating otherwise.

- The NDIA is currently using the International Statistical Classification of Diseases and Related Health Problems-10 not the most recent ICD-11. We were told by the agency that they would update to ICD-11 in 2022/2023 but this is yet to occur (personal communication, November 17, 2021). This is important because in ICD-11 ME/CFS is classified as neurological (diseases of the nervous system) and has been removed completely from other fatigue (psychosocial) (WHO, 2019)
- Based on advice the NDIA required patients to do Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT) to qualify (the current NDIA Technical Advisory Branch recommendations say patients must do 12-26 weeks of GET 3-5 times per week with 5-16 CBT sessions) (FOI 21/22-0693, p. 16)
- The NDIA are still using the outdated 2007 National Institute of Health Care Excellence (NICE) guidelines. We pressed them on why they haven't updated this to the 2021 guidelines and were instead given a non-authored opinion piece as a reference https://www.rcplondon.ac.uk/news/medical-leaders-sign-joint-statement-response-nice-guidance-mecfs. In short, the NDIA are choosing to rely on the advice of lobbyists with a financial vested interest rather than an independent government regulator such as NICE
- Through our FOI's we found the NDIA had only reached out and consulted with only one person for access recommendations (The NSW fatigue clinic director - Professor Andrew Llyod)
- The NDIA are using the recommendations they funded the UNSW fatigue clinic to provide to deny patients access to the scheme. No public tender was made, no other ME clinicians or researchers were invited to give advice, and no consultations were done with the ME community
- Of the research documents the NDIA TAB team are currently using only one of the references is up-to-date date and relevant (the 2021 NICE guidelines). The remainder are either 15 – 20 years out of date or retracted via a Cochrane review. Below is a list of evidence the NDIS are currently relying on (please note that only two are from the

last 5 years, one of which was dismissed by Cochrane itself as using outdated evidence and poor research methodology).

RACP Clinical practice guideline: Chronic Fatigue Syndrome 2002.

This is a paper that the National Health and Medical Research Council (NHMRC) admits is 20 years out of date (ME/CFS Advisory Committee,2019), was failed to be updated by its own researchers in 2007, is based on poor or out of date evidence and was rejected by the ME/CFS community at the time of its publication.

NICE ME/CFS Diagnosis and Management Guidelines 2021

There is presently a culture of cherry-picking evidence and recommendations at the NDIA. The Agency quote inflammatory and outdated statements from the 2007 NICE guidelines, (which recommends the use of GET/CBT) yet are also meant to be using the most up to date evidence they have on hand (at the time the 2020 NICE draft guidelines) that completely invalidates the use of GET/CBT for ME patients! The 2021 NICE guidelines now supersede and replace any of these old recommendations (which also disavows the use GET/CBT and neurolinguistic programming as treatment options for ME participants)

Hughes Chronic Fatigue Syndrome and Occupational Disruption in Primary Care

This study is 13 years out of date. The NDIA used this study to validate the use of GET/CBT as doctors in the study stated, "cognitive behavioural therapy and graded exercise therapy was more beneficial than medical care for CFS/ME" (Hughes, 2009). Yet the NDIA has ignored other recommendations/conclusions made in the same study "currently, there is little research evidence to support any particular interventions for people with CFS/ME" and that "57% of people with CFS/ME (in the study) reported that they had received unhelpful advice and/or treatment from their GP" (Hughes, 2009).

Price et al Cognitive Behaviour Therapy for CFS in Adults

This study is now outdated and 19 years behind current research (Price et al, 2008). Cochrane has made the following statement regarding the study "this 2008 review predates the mandatory use of GRADE methodology to assess the strength of evidence, and the review is no longer current. It should not be used for clinical decision-making. The author team is no longer available to maintain the review” (Cochrane, n.d.)

Larun et al Exercise Therapy for CFS

Cochrane itself has now discredited and reviewed this study (Larun et al, 2019) and made a damning statement about its research "this amended review is still based on a research question and a set of methods from 2002, and reflects evidence from studies that applied definitions of ME/CFS from the 1990s. Having heard different views expressed about the evidence base for this condition, we acknowledge that the publication of this amended review will not resolve all the ongoing questions about this globally important health topic. We have decided, therefore, that a new approach to the publication of evidence in this area is needed; and, today we are committing to the production of a full update of this Cochrane Review, beginning with a comprehensive review of the protocol, which will be developed in consultation with an independent advisory group that we intend to convene. This group will involve partners from patient-advocacy groups from different parts of the world who will help us to embed a patient-focused, contemporary perspective on the review question, methods and findings.” (Cochrane, October 2019)

Not one biomedical research article or guideline has being recommended or used to inform the Agency’s access assessment process for ME/CFS. This leaves the burden of proof on participants to not only refute the above but submit research papers that are more up-to-date as part of their access request. This demonstrates a clear culture of bias, cherry picking, and denial rife within the capabilities of the NDIA. This demands a review that is codesigned with the MC/CFS community who continue to be denied access due to institutional neglect.

I respectively request that we be invited to present evidence to the committee of this inquiry and implore the NDIA to:

- Consult with the ME/CFS community and individuals and trust that they are the experts of their own experience.
- Consult and seek advice from other medical practitioners with expertise in ME/CFS to inform internal practices.
- Consider recent international peer-reviewed literature regarding CBT/GET and updated best practice guidelines for treatment interventions to better inform the assessment of ME/CFS access requests.
- Be transparent regarding currently used policy, procedures, and guidelines for the assessment of ME/CFS access requests.
- Provide information to those requesting access for ME/CFS about what treatment interventions they are expected to attempt to satisfy the disability requirements for access as per the NDIS Act 2013, especially if their access request is rejected.

We understand this is a late submission but we would like to be given a special exemption due to our limited capacity to respond in the timeline given. This was due to circumstances relating to our disability and available energy to participate.

Kind regards

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References

Centers for Disease Control and Prevention. (2021, January 28). *Myalgic Encephalomyelitis/Chronic Fatigue Syndrome – Treatment*. CDC. https://www.cdc.gov/me-cfs/treatment/index.html

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Cochrane (2019, October 2). *Publication of Cochrane Review: 'Exercise Therapy for chronic fatigue syndrome.* Cochrane. https://www.cochrane.org/news/cfs

Hughes JL. Chronic Fatigue Syndrome and Occupational Disruption in Primary Care: Is There a Role for Occupational Therapy? *British Journal of Occupational Therapy, 72*(1)https://doi.org/10.1177/030802260907200102

Larun L, Brurberg KG, Odgaard-Jensen J, Price JR (2019. Exercise therapy for chronic fatigue syndrome. *Cochrane Database of Systematic Reviews*, *10* (10). doi: 10.1002/14651858.CD003200.pub8.

ME/CFS Advisory Committee (2019). *Report to the NHMRC Chief Executive Officer.* *https://www.nhmrc.gov.au/about-us/publications/mecfs-advisory-committee-report-nhmrc-chief-executive-officer*

National Institute for Health and Care Excellence. (2021). *Myalgic encephalomyelitis (or encephalopathy)/ chronic fatigue syndrome: diagnosis and management*. https://www.nice.org.uk/guidance/ng206/evidence/i-multidisciplinary-care-pdf-333546588756

Price JR, Mitchell E, Tidy E, Hunot V. Cognitive behaviour therapy for chronic fatigue syndrome in adults. Cochrane Database of Systematic Reviews [Internet]. 2008; (3). Available from:https://doi.org//10.1002/14651858.CD001027.pub2.

Working group of The Royal Australasian College of Physicians (RACP). (2002). Clinical practice guideline: Chronic Fatigue Syndrome. *The Medical Journal of Australia, 176*(9), 17-55. https://www.mja.com.au/system/files/issues/cfs2_2.pdf

World Health Organization. (2019). *International statistical classification of diseases and related health problems* (11th ed.). https://icd.who.int/

Appendix - Evidence Summary

1. Vink, M., & Vink-Niese, F. (2022). Is It Useful to Question the Recovery Behaviour of Patients with ME/CFS or Long COVID?. *Healthcare, 10*(2), 392. doi: 10.3390/healthcare10020392

Main Findings/Conclusion: "Our review shows that more patients are unable to work after treatment than before treatment with CBT and GET. It also highlights the fact that both treatments are unsafe for patients with ME/CFS. Therefore, questioning the recovery behaviour of patients with ME/CFS is pointless. This confirms the conclusion from the British National Institute for Health and Care Excellence (NICE), which has recently published its updated ME/CFS guideline and concluded that CBT and GET are not effective and do not lead to recovery".

2. Vink, M., & Vink-Niese, F. (2020). Graded exercise therapy does not restore the ability to work in ME/CFS – Rethinking of a Cochrane review. *Work, 66*(2), 283-308. doi:10.3233/wor-203174

Main findings/Conclusion: "GET not only fails to objectively improve function significantly or to restore the ability to work, but it is also detrimental to the health of ≥ 50% of patients, according to a multitude of patient surveys. Consequently, it should not be recommended."

3. Vink, M., & Vink-Niese, F. (2019). Work Rehabilitation and Medical Retirement for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Patients. A Review and Appraisal of Diagnostic Strategies. *Diagnostics, 9(*4), 124. doi:10.3390/diagnostics9040124

Main Findings/Conclusion: "Cognitive behavioural therapy and graded exercise therapy do not restore the ability to work. …Patients who are given a period of enforced rest from the onset, have the best prognosis. Moreover, those who work or go back to work should not be forced to do more than they can to try and prevent relapses, long-term sick leave and medical retirement."

4. McPhee, G., Baldwin, A., Kindlon, T., & Hughes, B. (2019). Monitoring treatment harm in myalgic encephalomyelitis/chronic fatigue syndrome: A freedom-of-information study of National Health Service specialist centres in England. *Journal Of Health Psychology, 26*(7), 975-984. doi: 10.1177/1359105319854532

Main Findings/Conclusion: “Clinics were highly inconsistent in their approaches to the issue of treatment-related harm. They placed little or no focus on the potential for treatment-related harm in their written information for patients and for staff. Furthermore, no clinic reported any cases of treatment-related harm, despite acknowledging that many patients dropped out of treatment. In light of these findings, we recommend that clinics develop standardised protocols for anticipating, recording, and remedying harms, and that these protocols allow for therapies to be discontinued immediately whenever harm is identified.”

5. Vink, M., & Vink-Niese, A. (2018). Graded exercise therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective and unsafe. Reanalysis of a Cochrane review. *Health Psychology Open, 5*(2), 205510291880518. doi:10.1177/2055102918805187

Main Findings/Conclusion: «Because of the failure to report harms adequately in the trials covered by the review, it cannot be said that graded exercise therapy is safe. The analysis of the objective outcomes in the trials provides sufficient evidence to conclude that graded exercise therapy is an ineffective treatment for myalgic encephalomyelitis/chronic fatigue syndrome.»

6. Geraghty, K., & Blease, C. (2018). Myalgic encephalomyelitis/chronic fatigue syndrome and the biopsychosocial model: a review of patient harm and distress in the medical encounter. *Disability And Rehabilitation, 41*(25), 3092-3102. doi: 10.1080/09638288.2018.1481149

Main Findings/Conclusion: “It is important health and rehabilitation professionals seek to avoid and minimize harms when treating or assisting ME/CFS patients. There are conflicting models of ME/CFS; we highlight two divergent models, a biopsychosocial model and a biomedical model that is preferred by patients. The ‘biopsychosocial framework’ applied in clinical practice promotes treatments such as cognitive behavioural therapy and exercise therapy, however, the evidence for their success is contested and many patients reject the notion their illness is perpetuated by dysfunctional beliefs, personality traits, or behaviours. Health professionals may avoid conflict and harm causation in ME/CFS by adopting more concordant ‘patient-centred’ approaches that give greater prominence to the patient narrative and experience of illness.”

7. Wilshire, C., Kindlon, T., Courtney, R., Matthees, A., Tuller, D., Geraghty, K., & Levin, B.(2018). Rethinking the treatment of chronic fatigue syndrome—a reanalysis and evaluation of findings from a recent major trial of graded exercise and CBT. *BMCPsychology, 6*(1). doi: 10.1186/s40359-018-0218-3

Main Findings/Conclusion: "Results; On the original protocol-specified primary outcome measure – overall improvement rates – there was a significant effect of treatment group. However, the groups receiving CBT or GET did not significantly outperform the Control group after correcting for the number of comparisons specified in the trial protocol. Also, rates of recovery were consistently low and not significantly different across treatment groups. Finally, on secondary measures, significant effects were almost entirely confined to self-report measures. These effects did not endure beyond two years. Conclusion: These findings raise serious concerns about the robustness of the claims made about the efficacy of CBT and GET. The modest treatment effects obtained on self-report measures in the PACE trial do not exceed what could be reasonably accounted for by participant reporting biases."

8. Geraghty, K., Hann, M., & Kurtev, S. (2017). Myalgic encephalomyelitis/chronic fatigue syndrome patients' reports of symptom changes following cognitive behavioural therapy, graded exercise therapy and pacing treatments: Analysis of a primary survey compared with secondary surveys*. Journal Of Health Psychology, 24*(10), 1318-1333. doi: 10.1177/1359105317726152

Main Findings/Conclusion: "Findings from analysis of primary and secondary surveys suggest that cognitive behavioural therapy is of benefit to a small percentage of patients (8%-35%), graded exercise therapy brings about large negative responses in patients (54%-74%), while pacing is the most favoured treatment with the lowest negative response rate and the highest reported benefit (44%-82%)."

9. Goudsmit, E., & Howes, S. (2017). Bias, misleading information and lack of respect for alternative views have distorted perceptions of myalgic encephalomyelitis/chronic fatigue syndrome and its treatment. *Journal Of Health Psychology, 22*(9), 1159-1167. doi: 10.1177/1359105317707216

Main Findings/Conclusion: “The bias and selective discussion of the literature as evident in articles and discussions on CBT and GET reflects a lack of respect for the scientific process in general, and for colleagues with a different view in particular. This disempowers clinicians and researchers and distorts our understanding of the illness-as-lived. More rigorous peer review is essential, and the current editorial polices which operate in certain British journals must be challenged. PACE-Gate is not just an example of flawed research. It is simply the latest in a series of studies which promotes one school of thought. We find this hard to reconcile with best practice and evidence-based medicine.”

10. Ghatineh, S., & Vink, M. (2017). FITNET’s Internet-Based Cognitive Behavioural Therapy Is Ineffective and May Impede Natural Recovery in Adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. A Review. *Behavioral Sciences, 7*(4), 52. doi: 10.3390/bs7030052
Main Findings/Conclusion: “Our reanalysis shows that their post-hoc definition of recovery included the severely ill, the unblinded trial had no adequate control group and it used lax selection criteria as well as outcomes assessed via questionnaires rather than objective outcomes, further contributing to exaggerated recovery figures. Their decision not to publish the actometer results might suggest that these did not back their recovery claims. Despite these bias creating methodological faults, the trial still found no significant difference in recovery rates («~60%») at LTFU, the trial’s primary goal. This is similar to or worse than the documented 54-94% spontaneous recovery rates within 3-4 years, suggesting that both FITNET and usual care (consisting of cognitive behaviour and graded exercise therapies) are ineffective and might even impede natural recovery in adolescents with ME/CFS”.

11. Geraghty, K., & Blease, C. (2016). Cognitive behavioural therapy in the treatment of chronic fatigue syndrome: A narrative review on efficacy and informed consent. *Journal Of Health Psychology, 23*(1), 127-138. doi: 10.1177/1359105316667798
Main Findings/Conclusion: “In CFS, CBT is a psychotherapy treatment offered in the absence of clear disease aetiology. While clinical trials and systematic reviews show that CBT brings about short-lived benefits for some patients, there is little evidence that CBT is a cure for CFS or restores full functional ability over the long term. Patients should be

informed of the rationale behind CBT, potential benefits and possible adverse reactions, prior to entering treatment. CBT may generate negative outcomes for some CFS patients if they blame themselves for lack of improvement, or if they wrongly perceive that they are suffering from psychological illness."

12. Loades, M. (2015). The Cognitive Behavioral Treatment of Depression and Low Self-Esteem in the Context of Pediatric Chronic Fatigue Syndrome (CFS/ME): A Case Study. *Journal Of Child and Adolescent Psychiatric Nursing, 28*(4), 165-174. doi: 10.1111/jcap.12125
Main Findings/Conclusion: "Therapy was effective in remediating the young person's mood difficulties, but appeared to exacerbate their CFS/ME symptoms."

13. Vos-Vromans, D., Evers, S., Huijnen, I., Köke, A., Hitters, M., & Rijnders, N. et al. (2017). Economic evaluation of multidisciplinary rehabilitation treatment versus cognitive behavioural therapy for patients with chronic fatigue syndrome: A randomized controlled trial. *PLOS ONE, 12(*6), e0177260. doi: 10.1371/journal.pone.0177260
Main Findings/Conclusion: "In conclusion, this study provides evidence that MRT (multidisciplinary rehabilitation treatment) is more effective in reducing long-term fatigue severity than CBT in patients with CFS."

14. Vink, M., & Vink-Niese, A. (2019). Cognitive behavioural therapy for myalgic encephalomyelitis/chronic fatigue syndrome is not effective. Re-analysis of a Cochrane review. *Health psychology open, 6*(1), 2055102919840614.
https://doi.org/10.1177/2055102919840614
Main findings/Conclusion: "Seven patients with mild chronic fatigue syndrome need to be treated for one to report a small, short-lived subjective improvement of fatigue. This is not matched by an objective improvement of physical fitness or employment and illness benefit status. Most studies in the Cochrane review failed to report on safety or adverse reactions. Patient evidence suggests adverse outcomes in 20 per cent of cases. If a trial of a drug or surgical procedure uncovered a similar high rate, it would be unlikely to be accepted as safe. It is time to downgrade cognitive behavioural therapy to an adjunct support-level therapy, rather than a treatment for chronic fatigue syndrome."

15. Kindlon, T. (2011). *Reporting of Harms Associated with Graded Exercise Therapy and Cognitive Behavioural Therapy in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome* [PDF]. Dublin: International Association for ME/CFS. https://www.researchgate.net/publication/216572185_Reporting_of_Harms_Associated_with_Graded_Exercise_Therapy_and_Cognitive_Behavioural_Therapy_in_Myalgic_EncephalomyelitisChronic_Fatigue_Syndrome

16. Invest in ME Research. (2018). *The Status of Research, Treatment and Perception of Myalgic Encephalomyelitis (ME) in UK* [PDF]. Eastleigh. http://investinme.org/Documents/Fact%20Sheets/Status%20of%20Research,%20Treatment%20and%20Perception%20of%20Myalgic%20Encephalomyelitis%202018.pdf