

## Violation of the Dutch Code of Ethics for Psychologists with current CFS guideline

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*Authors:* M. Bloks (General Health Psychologist, not practicing because of ME/CFS). In association with: B. Khouri (General Health Psychologist)

Scientific understanding of Chronic Fatigue Syndrome (ME/CFS) has changed and given rise to an essential paradigm shift. We observe that this shift has, at present, not reached the Dutch CFS guideline and, subsequently, the fields of work of medics and allied health professions, including psychologists. A new guideline for adults is in development but completion has been postponed to 1 May 2026 at the latest. No revision of the guideline for children has been announced. This is concerning because new insights make plausible that an essential segment of the patient population currently subsumed under the CFS umbrella is at risk of harm by professional adherence to the current (dated) CFS guideline.

### 1. Paradigm shift

CFS is a heterogeneous illness entity known to consist of a subgroup suffering from the symptom PEM (Post Exertional Malaise). PEM indicates the presence of the severe, chronic multisystem disease ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome), described in the advisory report on ME/CFS by the Dutch Health Council (Health Council, 2018). This disease requires targeted diagnostics and a fundamentally different approach than the one recommended in the current CFS guideline, specifically because of the presence of PEM, also known as PESE (Post Exertional Symptom Exacerbation).

The new 2021 NICE guideline for ME/CFS defines PEM as follows:

The worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. Symptoms can typically worsen 12 to 48 hours after activity and last for days or even weeks, sometimes leading to a relapse. (NICE, 2021a, p. 59)

A relapse implies a persistent and clear exacerbation of ME/CFS symptoms requiring significant and prolonged adaptation of energy management. A relapse can last years (NICE, 2021a) and is sometimes permanent, according to statements relayed by patients.

PEM arises through physical disturbances triggered by exceeding exertion tolerance levels imposed by the disease on patients with ME/CFS. It is fundamentally different from a physical response to incremental increases in activity after deconditioning (see i.a. Geraghty et al., 2019; VanNess et al., 2018; Davenport et al., 2022). These citations are just a few examples of biomedical information available on this subject. Due to lacking a medical background, we will not expand on this here.

There is no curative treatment for the disease ME/CFS at this time. Treatment is, therefore, aimed at symptom management. Because PEM plays a central role in the disease ME/CFS, the basis of recommended non-pharmacological treatment consists of teaching patients to adapt their levels of activity to the energy that is available at the moment, allowing them to use the energy available without exceeding their limits and triggering PEM. A crucial component of this is teaching patients how to recognize their limits and how to cope with (temporary) exacerbation of symptoms of the disease.

It can take weeks or even years before these goals are accomplished and a state of equilibrium is reached (NICE, 2021a; CDC, 2021).

Sustaining this state is not guaranteed because many factors can pose an amount of stress on the patient which exceeds their energy limit. Some examples are: viral infections, loss of a loved one, unremitting heat and noise. In very severe cases of ME/CFS – where the threshold for exceeding the energy limit is very low – mere physical contact, the sound of human speech, and turning in bed can be triggers (CDC, 2019). Research indicates that subtypes can potentially be identified based on disease progression, comparable to a disease like MS (Stoothoof et al., 2017). As such, some patients may never reach a state of equilibrium.

When a patient who is stable wants to make an effort to increase their physical capacity, it is essential that a specialist in ME/CFS exercise physiology is involved (NICE, 2021a; CDC, 2021) given biomedical abnormalities found in ME/CFS. The general principle with this form of care is that it is not curative and thus amounts to symptom management for a chronic illness. The specialist needs to be able to recognize PEM, adapt treatment to the patient in a way that does not exceed their limits, and cease treatment when it turns out to be unfeasible. The latter is important because increasing physical capacity will certainly not be possible for every patient. The patient needs to be informed about this by the specialist (informed consent). It is also pertinent that the patient is informed by the specialist about the importance of not triggering PEM due to the risk of deterioration (NICE, 2021a; CDC, 2021).

The NICE guideline states in this context:

The committee concluded any programme using fixed incremental increases in physical activity or exercise (for example, graded exercise therapy), or physical activity or exercise programmes that are based on deconditioning and exercise avoidance theories, should not be offered to people with ME/CFS. The committee also wanted to reinforce that there is no therapy based on physical activity or exercise that is effective as a cure for ME/CFS. (NICE, 2021a, p. 78)

Adequate diagnosis of PEM and adjusting treatment accordingly has become more relevant in recent years as approximately half of Long COVID patients develop the chronic, multisystem disease ME/CFS (Davis et al., 2023). This has increased the number of patients with ME/CFS significantly and will continue to do so because new Long COVID patients are still joining the ranks as SARS-CoV-2 continues to circulate.

## **2. Violation of the Dutch code of ethics for psychologists**

Because knowledge in the field lags behind scientific developments mentioned above, most colleague psychologists do not have access to the knowledge and skills needed to treat ME/CFS patients. In our opinion this leads them to inadvertently violate the code of ethics of the NIP (NIP, 2015) in the event that they apply the current guideline to patients who meet the CFS criteria without excluding the presence of PEM and, thus, the disease ME/CFS. Downstream effects of this violation of the basic principle of expertise are violations of all the other basic principles of the code of ethics. We will expand on this here.

### **2.1. Expertise**

Contemporary insights into ME/CFS failing to reach continuing education and scientific psychology literature on CFS has rendered too many psychologists unaware of the medical nature of the disease ME/CFS. The most glaring is the profession's general lack of awareness of the existence of PEM and its

therapeutic consequences. Psychologists will, in following the current, dated, CFS guideline, take charge in the treatment of a biomedical disease and treat it with cognitive behavioral therapy for CFS (CBT for CFS).

This therapy modality is based on the cognitive behavioral model for CFS. In this model and its underlying theory it is assumed that CFS symptoms are perpetuated by a combination of cognitive, behavioral and social factors. This theory asserts that the onset of illness often involves a period of severe fatigue and other complaints that can occur with CFS, such as pain. The patient attributes these complaints – justifiably or not – to a physical disease. In order to recover, patients rest and become less active, causing them to become deconditioned and sensitized to as well as anxious about signals of fatigue.

According to this theory, the disease has resolved, but the complaints are perpetuated by an undue focus on the symptoms and the avoidance of activity (with or without a boom-bust pattern) because the patient allegedly has dysfunctional beliefs about their own health. This can cause the patient to believe they are still ill or to have catastrophizing thoughts about unsubstantiated noxious effects of physical activity.

The patient experiencing a low sense of control over these complaints also contributes to the perpetuation of CFS complaints according to this theory. It is assumed that factors such as secondary gains and social rewards may also perpetuate these complaints (Deary, Chalder & Sharpe, 2006; Wiborg et al., 2012; Geraghty et al, 2019).

The cognitive behavioral model for CFS forms the basis of treatment described in the protocol ‘Cognitive Behavioral Therapy (CBT) for CFS’ (Knoop & Bleijenberg, 2010; Heldoorn, van Es & Knoop, 2013) and similar modalities like FitNet and Fit after COVID. Here, in the interest of legibility, we will summarily refer to these modalities as ‘CBT for CFS’.

In the modality CBT for CFS, psychologists will encourage patients to increase their activity levels in order to expand their exertion tolerance levels; not knowing that in patients with ME/CFS the presence of PEM makes exacerbation of the disease a real possibility. This, because the physical limits are likely to be exceeded at some point along the incremental increase of activity levels. It can be expected that, based on the CBT for CFS protocols and a lack of medical knowledge, the psychologist in question will not recognize these limits nor PEM. As a result, the psychologist is unable to assess the exertion tolerance levels of ME/CFS patients.

In conclusion: in lacking medical training and using CBT for CFS protocols based on dated views about ME/CFS, psychologists who adhere to the current CFS guideline will overestimate and misjudge their role in the treatment of a patient with ME/CFS. They will not be able to delineate their role appropriately, with all the consequences that this entails. In doing so, they violate, in our opinion, article 101-106 of the code of ethics for psychologists.

## **2.2. Responsibility**

One of the main points of this basic principle is ‘Prevention and limiting harm’. Harm in the form of (permanent) deterioration following CBT for CFS has been reported by ME/CFS patients and healthcare professionals alike (Davis et al., 2021; Vink & Vink-Niese, 2018, 2022, 2023; Kindlon, 2017). These findings have, up until this point, been dismissed by proponents of CBT for CFS. They state that studies into the effectiveness of CBT for CFS performed by them did not yield any reports of harm. These

reports were also not found in their re-analyses of these studies specifically aimed at assessing iatrogenic harm (Sharpe, Chalder & White, 2022; Heins et al., 2010).

This position has been challenged because iatrogenic harm was not typically assessed in studies and, whenever it was, subjective measures and/or inappropriate measures were used to assess deterioration resulting from CBT for CFS (Vink & Vink-Niese, 2018, 2022, 2023; Kindlon, 2017; Marks, 2022).

Studies into the effectiveness of CBT for CFS were graded at the drafting of the new ME/CFS guideline by NICE with the use of GRADE. The conclusion was that the quality of these studies is low to very low, among other things due to the combination of expectancy bias and subjective measures (NICE, 2021b; NICE, 2021c). With regard to the ReCOVer study (Kuut et al., 2021), a number of similar points of criticism have been raised (Biere-Rafi et al., 2021) about the quality. Conclusions from these studies about the presence or absence of iatrogenic harm can, therefore, be expected to be of low to very low quality as well. The same goes for re-analyses of these studies specifically aimed at assessing iatrogenic harm (like Heins et al., 2010).

Sharpe, Chalder & White (2022) explain these reports of iatrogenic harm as a result of adhering too stringently to the therapy by the therapist or as a result of misdiagnosis. They do not substantiate this claim with scientific research of adequate quality. Such a claim is also inconsistent with the denial of iatrogenic harm and does not resolve the internal inconsistency between CBT for CFS interventions and the rationale of the disease ME/CFS.

In view of the lack of adequate assessment of harm as a result of CBT for CFS we contend that the dismissal of the many reports of harm by patients and professionals is not justified. More so, because of continually emerging biomedical research which makes plausible and comprehensible that exceeding exertion tolerance levels can exacerbate ME/CFS symptoms (Davis et al., 2021; Biere-Rafi et al., 2023; Vink & Vink-Niese, 2023; VanNess et al., 2018). These citations are just a few examples of available science on this matter.

In conclusion: the failure to keep professional expertise up to date thwarts the psychologist's ability to act responsibly towards ME/CFS patients. After all, adhering to the dated guideline and continuing education will pose a risk of harm to patients with ME/CFS and therefore PEM.

Besides physical harm, the likelihood of psychological harm is also real. Because CBT for CFS operates on a flawed theory, it fails to teach the patient to recognize and adequately interpret symptoms and bodily signals relevant to ME/CFS. Conversely, it is likely that the patient will learn (to an extent) to ignore and/or wrongly interpret these. This essentially teaches the patient to not trust their own ability to assess an essential part of themselves.

If the treatment does not yield the desired progress, chances are that the patient will unfairly hold themselves responsible because the protocol of CBT for CFS explicitly cultivates a positive expectation in which the amount of progress is to a significant degree a function of the patient's efforts (Knoop & Bleijenberg, 2010; Geraghty et al., 2019). A patient will struggle to obtain professional, social and societal support if the narrative of the disease is wrong and it is assumed that the patient has control over their illness trajectory (Health Council, 2018). Harm from inappropriate treatment can also lead to medical trauma (van Hemert, 2021).

The application of a treatment in a patient group which carries a real risk of harm as a result of this treatment is, in our opinion, a violation of article 23 and 25 of the code of ethics. A dated treatment which inflicts harm damages trust in the psychologist and violates article 18 of the code of ethics. Article 14, 15 and 16 are also difficult to observe when acting on dated views.

### **2.3. Integrity**

Entering into a professional relationship which may cause harm to the patient cannot comply with the basic principle of integrity. First of all, entering into such a relationship is not professional nor ethical, thus violating article 39 of the code of ethics. The psychologist will also set unrealistic expectations for the ME/CFS patient regarding the possibilities of improvement or recovery as well as the patient's control over this (see paragraph 2.2). This is not in line with article 45 because it is diametrically opposed to the premise that ME/CFS is a severe, chronic multisystem disease for which no proven effective treatment exists (NICE, 2021a; CDC, 2021). The patient will be misled, which psychologists are supposed to avoid as per article 42.

### **2.4. Respect**

As explained above, the ME/CFS patient treated with a CBT for CFS protocol will not be adequately taught to listen to their own bodily signals. This fails to teach the patient to adequately give words to what they are experiencing and to adequately manage their body and themselves. This constitutes autonomy deprivation instead of autonomy cultivation, causing the psychologist to violate article 59 of the code of ethics.

From the standpoint of dated views, it is plausible that the psychologist does not sufficiently respect the knowledge, insights, and experiences of the patient with regard to ME/CFS because the psychologist will label these (to a degree) as perpetuating factors instead of as a reality of the disease. This also includes the belief of the patient that there is a medical cause for the complaints, the experience of PEM, and the observation that the complaints increase with the CBT for CFS treatment. By inappropriately labeling these thoughts and experiences as perpetuating factors, article 56 is violated. Finally, a patient who experiences PEM will also feel inadequately supported by their psychologist who aims to correct these presumed perpetuating factors and does not recognize the signals of PEM. This violates article 57. Chances of violating article 65 are also real if the patient's interpretation of their disease is labeled as a perpetuating factor.

Finally, article 63 outlines that the psychologist has to inform the patient, among other things, of the methods of assessment and treatment options, what can be expected and what are possible side effects or alternatives. As has been argued here in numerous ways: this is impossible when acting upon dated views.

## **3. Which psychological modality is appropriate for patients with ME/CFS?**

Psychological treatment can be applied in ME/CFS as a tool to learn how to cope with this chronic illness. Psychological treatment is indicated when there are psychological factors that impede acceptance of the chronic illness, coping adequately with it, and remaining within one's limits to avoid triggering PEM as a component of this coping (NICE, 2021; Biere-Rafi et al., 2023). In accordance with the NICE guideline for ME/CFS, we subscribe to the opinion that, for this to work, it is important that the patient learns to understand the disease and to recognize and interpret their own bodily signals. This will require a certain focus on the disease and its respective symptoms (especially at the onset).

## **4. Adaptation guideline for ME/CFS patients needed at short notice**

The fact that we, as (former) practicing clinical psychologists, only found this information once we ourselves became ill, indicates a gap in information provision in this area. We deem it necessary, through writing, to bring attention to this. The Health Council made the following recommendations in its report on ME/CFS in 2018:

“Those responsible for training and continuing education of healthcare providers ensure that in training and education the serious, chronic multisystem disease ME/CFS and what caregivers can do for patients with this disease are addressed.” (Health Council, 2018, p.6).

To date, this does not seem to have sufficiently come to fruition. Subsequently, it is impossible for psychologists to be informed of the latest developments that allows them to comply with article 100 (maintaining and developing professional expertise) of the code of ethics for psychologists.

While the current CFS guideline for adults is set to be revised, the completion of this process has recently been postponed to 1 May 2026 at the latest. No date has been announced for a revised pediatric and adolescent guideline. Until further notice, psychologists will unfortunately continue to violate the code of ethics when they use CBT for CFS on ME/CFS patients. This is unacceptable for patients and for the respectability of the profession. For psychologists this situation can be damaging as well due to exposure to the risk of moral injury.

We would like to point out that the Dutch Society of General Practitioners took action in 2018 by withdrawing the CFS guideline from the database ‘Guidelines and practice’ on their website because they found it to not be compliant with the advice of the Health Council regarding the onset of the disease, the characterization, diagnostics and treatment. Unfortunately, no appropriate alternative has been found that ensures ME/CFS patients receive the healthcare they need. This has left patients in healthcare limbo. Our plea is that responsible parties provide an interim solution which is up to date with the state of the art.

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