My Reasonable Adjustment for Work and Education Plan
Guidance for Employers / Tutors

1. A Guide to the Reasonable Adjustment for Work and Education Plan

This Reasonable Adjustment for Work and Education Plan is a personalised, practical tool designed to foster a supportive and productive partnership between an individual managing Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) or Long Covid, and their employer or educational institution.

This document aims to facilitate open, constructive dialogue about what helps the individual stay well, what might cause their symptoms to worsen, and what support can be put in place to enable them to thrive.

The purpose of this plan is not to present a list of demands, but to create a shared understanding. It is a proactive tool that empowers the individual to articulate their needs and self-management strategies, while enabling managers, HR representatives, and educators to provide effective, reasonable support. By working together, it is possible to create an environment where a valued employee or student can continue to contribute their unique skills and talents, maintaining both their wellbeing and their productivity.

It is crucial to recognize that ME/CFS and Long Covid are fluctuating diseases. An individual's capacity and support needs can change from day to day or week to week. Therefore, this reasonable adjustment plan should be treated as a living document. It provides a solid foundation for an initial conversation and agreement, but it should be reviewed regularly—for example, on a quarterly basis—to ensure it remains relevant and continues to meet the needs of both the individual and the organisation.

Finally, this plan is a personal and confidential document. The individual who completes it owns the information within. It should only be shared with their express permission and handled with the same level of confidentiality as any other sensitive health information, such as an Occupational Health report. Establishing this trust is fundamental to fostering the open communication required for a successful partnership.

2. Understanding the Functional Impact of ME/CFS and Long Covid

To effectively use this plan, it is essential for all parties to have a foundational understanding of ME/CFS and Long Covid, as complex diseases focusing not just on the symptoms themselves, but on their profound impact on an individual's ability to function in a work or educational setting. A significant percentage of individuals with Long Covid meet the diagnostic criteria for ME/CFS, and both conditions share a core set of debilitating symptoms. This plan, therefore addresses their overlapping functional challenges.

These conditions are often described as "invisible illnesses." An individual may not look sick, yet they may be experiencing severe, disabling symptoms that significantly limit their capacity for daily activities, including work and study.

This invisibility can create a communication gap. An observer, such as a manager or

educator, might see a person who appears well one day and be unable to comprehend their incapacitation the next. This can lead to misinterpretations, such as assuming a lack of motivation or unreliability. This reasonable adjustment plan is designed to bridge that gap. It acts as a clear, objective reference point, translating the complex, internal experience of the illness into a structured framework for support. By explaining the core mechanics of the condition, it provides a rational basis for the seemingly unpredictable fluctuations, making the invisible impacts "visible" on paper and fostering genuine understanding.

Post-Exertional Malaise (PEM)

The defining characteristic of ME/CFS, and a common feature of Long Covid, is Post-Exertional Malaise (PEM). PEM is not simply feeling tired after an activity. It is a pathological and severe worsening of all symptoms following even minimal physical, cognitive, or emotional exertion. The exertion that triggers PEM is often activity that the individual could easily tolerate before their illness. People experiencing a PEM "crash" often describe it as feeling like they have a severe case of the flu, have been "hit by a truck," or are being "poisoned".

A critical and often misunderstood feature of PEM is the characteristic delay between the trigger and the onset of the crash. The worsening of symptoms typically manifests 12 to 72 hours after the triggering exertion. This delay is fundamental for managers and educators to understand, as it explains why an employee might seem fine after a demanding day of meetings but be unable to function one or two days later. The cause and effect are not immediately apparent, which can lead to confusion without this context.

PEM can be triggered by a wide range of activities, including:

- **Physical Exertion**: Walking, commuting, climbing stairs, showering or even getting out of bed.
- **Cognitive Exertion**: Concentrating in a long meeting, reading a complex document, writing a report, or multitasking. Some patients may have much lower thresholds and triggers can include having a brief conversation or reading a simple text.
- **Emotional Exertion**: Dealing with stressful situations, difficult conversations, or high-pressure deadlines.
- **Sensory Overstimulation**: Being in a loud, bright, or busy environment.

Because of the nature of PEM, conventional advice to "push through" fatigue or engage in graded exercise therapy (GET) is not only ineffective but is strictly contraindicated. Such approaches can cause significant harm, leading to prolonged relapses and potentially irreversible disease progression.

The Concept of the "Energy Envelope"

The most effective way to understand and manage life with PEM is through the "energy envelope" theory, sometimes explained using the "spoon theory" analogy. This concept proposes that an individual with ME/CFS or Long Covid has a strictly limited and often drastically reduced amount of available energy each day—their "energy

envelope" or their allotted "spoons".

Every single activity—physical, cognitive, and emotional—draws from this limited energy reserve. Staying within the confines of this energy envelope allows the individual to remain as functional as possible. However, exceeding the limit, even by a small amount, triggers PEM and leads to a "crash" that can last for days, weeks, or even longer.

Crucially, this energy envelope is not static. It can fluctuate significantly from day to day, influenced by factors like sleep quality, symptom severity, and prior activity levels. This inherent unpredictability is why a rigid, one-size-fits-all approach to work or study is often unsustainable. It underscores the profound need for dynamic, flexible support that can adapt to the individual's changing capacity.

Cognitive Dysfunction ("Brain Fog")

Cognitive dysfunction, commonly known as "brain fog," is another prevalent and disruptive symptom. It is not a reflection of an individual's intelligence or capability, but rather a significant impairment of executive function. In a work or educational setting, brain fog can manifest as:

- Difficulty with concentration and focus, especially for prolonged periods.
- Problems with short-term memory and information recall.
- Sluggish or slowed information processing.
- Difficulty finding the right words during conversations or in writing.
- Challenges with multitasking and organising complex thoughts.

These cognitive challenges are often exacerbated by physical fatigue and can be a direct result of overexertion, making them a key component of a PEM crash.

Sensory and Temperature Sensitivities

Many individuals with ME/CFS and Long Covid develop new or worsened hypersensitivities to their environment. This can include:

- **Light Sensitivity (Photophobia)**: Bright or fluorescent lighting can cause headaches, eye pain, and sensory overload.
- **Sound Sensitivity (Hyperacusis):** Loud or sudden noises, or the constant hum of a busy office, can be overwhelming and painful.
- **Smell/Chemical Sensitivity:** Strong perfumes, cleaning products, or other scents can trigger nausea, headaches, and other symptoms.
- **Temperature Dysregulation:** Difficulty tolerating heat or cold, which can exacerbate overall symptoms.

An overstimulating sensory environment is not just a matter of discomfort; it can be a significant energy drain and a direct trigger for PEM, while also making it extremely difficult to concentrate. The cut-off for intolerances to be triggered vary from person to person and fluctuates within individuals. For some, and especially during crashes or periods of higher symptoms severity, intolerance to otherwise normal levels of exposure to sound, noise and other stimuli can cause significant symptoms and

incapacity.

3: Pacing – The Cornerstone of Proactive Self-Management

Given the central role of Post-Exertional Malaise (PEM), the single most important self-management strategy for individuals with ME/CFS and Long Covid is pacing. Pacing is an active, evidence-supported approach that involves carefully balancing all forms of activity with rest to stay within the limits of one's "energy envelope".

It is not about avoiding activity altogether; rather, it is a strategic way to remain as consistently active and productive as possible without triggering a debilitating crash. This concept reframes the individual not as a passive recipient of care, but as the expert manager of their own complex disease. Effective pacing requires constant self-monitoring, data analysis (through tracking symptoms and activities), and iterative adjustment. When an individual completes this Wellness Action Plan, they are presenting the conclusions of their own careful analysis. A request for an adjustment, such as needing to work from home after a day of intense meetings, is not an arbitrary preference. It is a strategic, evidence-based decision derived from their personal data, which shows that such a day depletes their energy and stretches the envelope to a point where the additional exertion of commuting would guarantee a PEM crash. This perspective lends significant credibility to their requests, transforming them from "wants" into well-reasoned "needs" for maintaining health and productivity.

Pacing must be applied to all forms of exertion, as any type of effort can drain the limited energy reserve. This includes:

- **Physical Pacing**: Breaking down physical tasks, alternating activity and rest sitting and standing, and planning for the energy cost of commuting.
- **Cognitive Pacing:** Limiting time spent on high-concentration tasks, taking breaks from screen time, and avoiding multitasking.
- **Emotional Pacing:** Recognising the energy drain of stressful interactions and building in time to decompress.
- **Sensory Pacing:** Limiting time in overstimulating environments and using tools like noise-cancelling headphones or sunglasses to reduce sensory input.

Practical pacing strategies that an individual may use, and which workplace adjustments can support, include:

- **Breaking Down Tasks:** Dividing a large project into smaller, more manageable steps that can be completed over time.
- **Alternating Activities:** Switching between high-energy tasks (e.g., a team meeting) and low-energy tasks (e.g., quiet low-intensity administrative work).
- **Scheduling Proactive Rest:** Taking short, frequent rest breaks throughout the day, before fatigue sets in, is more effective than waiting for exhaustion to hit.
- **Planning for Exertion:** For a known demanding event (e.g., a presentation, a conference), the individual may plan for extra rest before the event ("radical rest") and schedule protected recovery time afterwards to mitigate the subsequent PEM.
- **Using a Symptom and Activity Diary:** Many individuals track their daily activities and corresponding symptoms to identify their personal limits, patterns, and PEM

triggers. This helps them make more informed decisions about how to budget their energy.

Section 4: Your Role in Securing Support – Reasonable Adjustments

In the UK (under the Equality Act 2010) ME/CFS and Long Covid can be considered disabilities if they have a substantial and long-term adverse effect on an individual's ability to carry out normal day-to-day activities. This means that employers and educational institutions have a legal duty to consider and make "reasonable adjustments" (or "reasonable accommodations") to prevent the individual from being at a substantial disadvantage.

This Reasonable Adjustment for Work and Education Plan is designed to be a key tool in this process. It helps facilitate the "interactive process" or collaborative discussion required to identify and agree upon what adjustments are reasonable and effective. By providing clear, structured information about the individual's condition and needs, the plan helps the organization fulfil its legal and ethical responsibilities while supporting a valued member of its community. The goal is to find practical, mutually beneficial solutions that enable the individual to manage their health while continuing to perform their role effectively.