

ME, CFS AND LONG COVID HEALTH AND CARE PASSPORT

SECTION 1: CRITICAL INFORMATION AT A GLANCE

Personal Information

Name:	I Prefer to be Called:
Date of Birth:	NHS Number:
Address:	Hospital Number:

Emergency Contact

Name:	Contact Number:
Relationship:	

MY CURRENT STATUS

Selection	Status	Meaning
<input type="checkbox"/>	GREEN: I am at my BASELINE	I am managing within my energy limits but remain at risk of PEM.
<input type="checkbox"/>	AMBER: I am STRUGGLING / AT RISK OF A CRASH	My symptoms are worsening. Please minimise ALL exertion immediately to prevent a crash.
<input type="checkbox"/>	RED: I am in a CRASH / SEVERE RELAPSE	Assume I have zero available energy. All interaction is potentially harmful. Please follow my emergency care plan as set out in this section,

MY CURRENT SEVERITY

Selection	Severity	Meaning
<input type="checkbox"/>	Mild	I may need support for some tasks and may have difficulties with mobility.
<input type="checkbox"/>	Moderate	I have reduced mobility, and I am restricted in all activities of daily living.
<input type="checkbox"/>	Severe	I am confined to the house, need help with all activities, sensitive to light and sound.
<input type="checkbox"/>	Very Severe	I am confined to bed, hypersensitive, dependent on care, need help with personal hygiene, eating.

WARNING: This patient has ME, CFS or Long Covid. The defining symptom is Post-Exertional Malaise (PEM), a severe worsening of all symptoms after minimal exertion (physical, cognitive, sensory). PEM is often delayed by 24-72 hours. Encouraging the patient to "push through" will cause harm. Please help me stay within my energy limits to prevent a severe relapse.

MY DIAGNOSIS AND SYMPTOMS

My Specific Diagnosis:
Date of Diagnosis:
Diagnosed By (Clinician/Service):
MY SYMPTOMS:

OTHER CO-MORBIDITIES

Diagnosis	Diagnosed By	Diagnosis Date	Additional Information

My Designated Advocate for Communication and Care Planning:

Name:	Contact Number:
I give my full consent for this person to be involved in discussions about my care and to help make decisions on my behalf if I am unable to do so.	
Patient Signature:	Date:

MEDICATION – CRITICAL

I am often highly sensitive to some types of medication and anaesthesia

- Please consider starting any new medication at a low dose and increase slowly, monitoring for adverse effects.
- I may be sensitive to specific brands due to fillers/binders. Please try to maintain brand consistency if possible.
- My current medications, supplements, and their dosages are listed on a separate, attached sheet. Please do not alter or stop this regimen without consulting my specialist or GP.
- For information on anaesthesia, please consult guidance from the Royal College of Anaesthetists and The ME Association

EMERGENCY CARE PLAN FOR A SEVERE CRASH/RELAPSE

This section describes the care I need when I am in a severe crash. In this state, I may be unable to speak, move, tolerate any light or sound, or eat or drink.

This plan was completed in advance by myself / my carer.

The most critical support you can provide is to create an environment of profound rest and minimal stimulation. Please:

KEY SIGNS THAT I AM IN A CRASH (tick all that apply)

<input type="checkbox"/> Extreme muscle weakness / paralysis-like feeling	<input type="checkbox"/> Increase in debilitating fatigue
<input type="checkbox"/> Inability to speak or form words	<input type="checkbox"/> Increase in orthostatic intolerance symptoms
<input type="checkbox"/> Increase in pain / headaches	<input type="checkbox"/> Heightened problems with memory and concentration
<input type="checkbox"/> Pale skin / grey complexion	<input type="checkbox"/> Heightened sensitivity to sensory stimuli
<input type="checkbox"/> Inability to tolerate being touched or moved	<input type="checkbox"/> More issues with digestive function
<input type="checkbox"/> Inability to chew or swallow food	<input type="checkbox"/> Other:
<input type="checkbox"/> Disrupted sleep patterns	<input type="checkbox"/> Other:

SECTION 2: COMMUNICATION AND COGNITION (MY 'BRAIN FOG')

When communicating with me, please (tick all that apply)

- Speak slowly and clearly, using simple language.
- Allow me extra time to process information and formulate a response.
- Ask one question at a time and wait for my answer.
- Provide all important information (e.g., treatment plans, discharge instructions) in writing.
- Understand that my memory is poor. Please do not assume I will remember previous conversations.
- I may have difficulty finding the right words or forming sentences.

SECTION 3: MOBILITY AND ORTHOSTATIC INTOLERANCE

My mobility is (tick all that apply):

- Fully mobile, but severely limited by energy levels.
- I use a walking aid (e.g., stick, rollator)
- I use a wheelchair for (select all that apply):
 - all mobility
 - distances
 - energy conservation.
- I am mostly or entirely bedbound.

I have Orthostatic Intolerance (e.g., POTS, Orthostatic Hypotension).

This is a physical condition, please note (tick all that apply):

- I may feel dizzy, nauseous, or faint when sitting or standing up.
- I need to transition from lying to sitting to standing very slowly.
- I may need to lie flat for periods of time, including during conversations or assessments.

This is a medical necessity.

- I may need to elevate my legs.
- I need to maintain a high fluid and salt intake

SECTION 4: HOW TO SUPPORT MY ENERGY MANAGEMENT (PACING)

Pacing is my primary and most important management strategy. Your support is essential for my stability and recovery.

Please help me stay within my energy limits by:

- Asking first:** Before any task or examination, please ask me or my carer what I feel able to manage at that moment.
- Clustering care:** Please group essential tasks (e.g., taking blood pressure, giving medication, asking questions) together into short periods, and then leave me for long periods of uninterrupted rest.
- Prioritising deep rest:** Please ensure I have long periods of undisturbed rest, especially in a dark, quiet room. This is when my body attempts to recover.
- Understanding rest:** For me, "rest" means lying down with minimal to no sensory input. It does not mean watching TV, reading, or talking, as these are all cognitively draining activities.
- Breaking down tasks:** Please help me break down essential activities into smaller, more manageable steps (e.g., washing my face now, and brushing my teeth in an hour).

SECTION 5: PERSONAL CARE AND NUTRITION

Personal Care

Please understand that personal care activities use a significant amount of my limited energy.

I may need help with:

- Washing Dressing Toileting Eating/Drinking

I may not be able to manage the following daily and may only be able to tolerate a minimal wash.

Please discuss what is possible with me or my carer

- Shower Full Bed Bath

Nutrition

My dietary needs/allergies/intolerances are:	I frequently experience:
<input type="checkbox"/>	<input type="checkbox"/> Nausea
<input type="checkbox"/>	<input type="checkbox"/> Loss of appetite
<input type="checkbox"/>	<input type="checkbox"/> Difficulty swallowing
<input type="checkbox"/>	<input type="checkbox"/> Other digestive issues
<input type="checkbox"/>	<input type="checkbox"/> Other:
<input type="checkbox"/>	<input type="checkbox"/> Other:

SECTION 6: MY SENSORY NEEDS – AVERTING OVERLOAD IS CRITICAL

I have severe sensory hypersensitivity. Overload can cause pain, distress, and trigger a significant relapse (PEM).

Please help me by controlling my environment.

SENSITIVITY	MY SEVERITY (PLEASE CIRCLE)	WHAT HELPS ME (PLEASE DO THIS)
LIGHT (Photophobia)	MILD / MODERATE / SEVERE	<input type="checkbox"/> Dim the lights in my room. <input type="checkbox"/> Turn off overhead fluorescent lights. <input type="checkbox"/> Close the blinds/curtains. <input type="checkbox"/> Allow me to wear sunglasses/tinted glasses.
SOUND (Hyperacusis)	MILD / MODERATE / SEVERE	<input type="checkbox"/> Speak quietly and calmly. <input type="checkbox"/> Close my door to block out corridor noise. <input type="checkbox"/> Avoid sudden or loud noises (e.g., dropping items, loud alarms). <input type="checkbox"/> Allow me to use noise-cancelling headphones or earplugs.
SMELL	MILD / MODERATE / SEVERE	<input type="checkbox"/> Please avoid using scented products (perfume, aftershave, strong deodorant, hand lotion) near me. <input type="checkbox"/> Please use fragrance-free cleaning products in my room where possible.
TOUCH	MILD / MODERATE / SEVERE	<input type="checkbox"/> My skin can be very sensitive or painful to the touch. <input type="checkbox"/> Please tell me before you are going to touch me. <input type="checkbox"/> Please use gentle movements during examinations or personal care.
TEMPERATURE	MILD / MODERATE / SEVERE	<input type="checkbox"/> I have poor temperature regulation. <input type="checkbox"/> I am often very cold, even in a warm room. Please provide extra blankets. <input type="checkbox"/> I am very sensitive to heat. Please provide a fan or help me stay cool.

SECTION 7: Other Key Contacts and Documentation:

Key Contacts

GP Name
GP Practice
Contact Number:
Specialist Clinician / Service:
Contact Number:
Other (e.g. District Nurse, Social Worker)

Location of Other Important Documents

<input type="checkbox"/> Advance Directive / Advance Decision to Refuse Treatment Location:
<input type="checkbox"/> Advance Statement of Wishes Location:
<input type="checkbox"/> Lasting Power of Attorney (Health and Welfare) Location:
<input type="checkbox"/> List of Current Medications and Supplements Location:

SECTION 8: CRITICAL DO'S AND DON'T'S FOR SAFE CARE

Area of Care	PLEASE DO	PLEASE DON'T (this can cause harm)
Exertion & Activity	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Cluster essential care; allow short rest periods in between and longer, undisturbed rest periods afterwards. <input checked="" type="checkbox"/> Ask the patient/carer what they can manage <i>before</i> you act. <input checked="" type="checkbox"/> Support them to lie in a comfortable position as needed. 	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Encourage the patient to "push through" fatigue or pain. <input checked="" type="checkbox"/> Expect the patient to sit in a chair for long periods. <input checked="" type="checkbox"/> Perform non-essential checks or procedures that disturb rest.
Sensory Environment	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Dim lights, close the door, and speak in a quiet voice. <input checked="" type="checkbox"/> Ask about and minimise noise from monitors and equipment where possible. 	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Leave bright fluorescent lights on. <input checked="" type="checkbox"/> Have loud conversations in or near the room. <input checked="" type="checkbox"/> Wear strong perfumes or scented products.
Communication	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Provide information in writing. <input checked="" type="checkbox"/> Allow extra time for responses. <input checked="" type="checkbox"/> Involve the designated advocate as requested. 	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Rush the patient for answers. <input checked="" type="checkbox"/> Rely solely on verbal communication for important information. <input checked="" type="checkbox"/> Assume the patient will remember previous conversations.
Medication	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Consider starting any new medication at a low dose <input checked="" type="checkbox"/> Consult a pharmacist regarding sensitivities. 	<ul style="list-style-type: none"> <input checked="" type="checkbox"/> Stop existing medications or supplements abruptly. <input checked="" type="checkbox"/> Administer a standard starting dose of a new medication without careful consideration.