# Proposal for the Inclusion of Severe Myalgic Encephalomyelitis (ME) in the ALS Law (summary). CONFESQ.

## 1. Introduction

The National Coalition of Fibromyalgia, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Multiple Chemical Sensitivity, and Electrohypersensitivity (CONFESQ) is a coalition of 26 member organizations across 14 autonomous communities in Spain. It represents over 21,000 affected individuals, advocating for the recognition, rights, and quality of life of patients suffering from these debilitating conditions.

This proposal has been developed in collaboration with the Catalan Association of Fibromyalgia and Chronic Fatigue Syndrome (ACAF) and the Platform of Families Affected by FM-SFC-SQM, which contributed their expertise to emphasize the urgent need for the inclusion of Severe ME in Law 3/2024.

## 2. Reasons for the Inclusion of Severe ME in Law 3/2024

### 2.1 Compliance with the Established Criteria

a) Irreversible Condition with Severe Reduction in Quality of Life and Life Expectancy

Myalgic Encephalomyelitis (ME/CFS) is a multisystemic, chronic, and disabling disease that affects the immune, neurological, cardiovascular, endocrine, and gastrointestinal systems.

- Scientific studies show that patients with Severe ME have a 15-year reduction in life expectancy.

- There is an increased risk of cardiovascular diseases, cancer, and suicide, largely due to prolonged suffering and lack of treatment.

b) No Effective Treatments Available

- There is no cure for ME/CFS, and there are no disease-modifying drugs to alter its chronic and irreversible progression.

- Current therapies focus solely on symptom management and often do not provide substantial relief.

c) High Complexity of Social and Healthcare Needs

- Severe ME patients require a multidisciplinary approach, including medical care, social support, and home adaptations.

- The disease causes total dependence on caregivers, significantly impacting families.

d) Rapid Progression in Severe Cases Requires Administrative Recognition

Severe ME has been defined by Dr. José Alegre, Spain's leading expert on the disease, as follows:

- Mild ME: Limited mobility but can still work or attend school with difficulty.

- Moderate ME: Cannot work or attend school; extreme cognitive and physical fatigue.

- Severe ME: Housebound with only 5% to 15% of normal functionality. Hypersensitive to stimuli.

- Very Severe ME: Bedridden with less than 5% functionality.

2.2 Scientific Evidence Supporting Inclusion

Prevalence

- ME/CFS affects 0.3% - 0.5% of the population, translating to 120,000 - 200,000 cases in Spain.

- 75% of cases are women, reflecting a gender disparity in diagnosis and care.

Socio Economic Impact

- In the United States, the economic burden of ME/CFS ranges between $18 and $51 billion annually.

- The lack of official data in Spain suggests a significant economic impact, affecting healthcare systems and families.

Recognition by International Authorities

- The UK's National Institute for Health and Care Excellence (NICE) and the European Network on ME/CFS (EUROMENE) recognize ME as a severe multisystemic disease requiring urgent healthcare policies.

- The US National Institutes of Health (NIH) classify ME as a severe, chronic, complex, and systemic disease with neurological, immunological, and autonomic dysfunction.

3. Real-Life Cases of Patients with Severe ME

Case 1: 31-Year-Old Woman - 76% Disability

- Previously independent and working full-time.

- Developed Severe ME after a viral infection; now completely bedridden.

- Suffers from severe orthostatic intolerance, cognitive dysfunction, and hypersensitivity to stimuli.

- Requires home-based IV fluids due to life-threatening autonomic dysfunction.

Case 2: 45-Year-Old Man - 81% Disability & Total Dependency

- Developed Severe ME with Postural Tachycardia Syndrome (POTS) and Mast Cell Activation Syndrome (MCAS).

- Requires assisted ventilation due to sleep apnea and autonomic dysfunction.

- Diagnosed with very severe cognitive and physical disability, leaving him bedridden and 100% dependent on caregivers.

Case 3: 52-Year-Old Woman - Deceased in 2024

- Spent the last 7 years of her life bedridden.

- Experienced severe chronic pain, extreme sensory hypersensitivity, and life-threatening intolerance to movement, noise, and light.

- Denied palliative care, despite severe symptoms.

- Passed away due to lack of proper medical care, highlighting the urgent need for legal recognition of Severe ME.

4. Conclusion: Why Severe ME Must Be Included in the ALS Law

Severe ME Meets All the Criteria for Legal Recognition:

✔ Irreversible and life-threatening condition

✔ No effective treatments available

✔ Total dependency on caregivers

✔ Severe socioeconomic impact on families

✔ Urgent need for policy intervention

Benefits of Inclusion in the ALS Law:

- Access to essential healthcare and home-based care
- Official disability and dependency recognition
- Facilitates research funding and healthcare training
- Ensures social and economic support for families

Final Appeal to Policymakers

We urge the immediate inclusion of Severe Myalgic Encephalomyelitis (ME/CFS) in the ELA Law to provide dignified healthcare, financial aid, and legal protection to patients suffering from one of the most disabling and neglected conditions in Europe.

For further information, this is the link to our web: CONFESQ contributions