# The Challenges People with ME Face When Applying for Benefits

People living with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) continue to face major obstacles when applying for benefits. For those who are severely affected — often housebound or bedbound — these challenges are even greater. The benefits system is not designed for people with complex, fluctuating, and invisible illnesses, leaving many struggling to access the support they urgently need.

## 1. Lack of Understanding of ME/CFS

ME remains poorly understood within the benefits assessment process. The condition does not always produce clear clinical evidence, and symptoms such as post-exertional malaise, extreme fatigue, and cognitive dysfunction are often underestimated. As a result, many applicants are wrongly deemed “fit for work” or awarded insufficient support.

## 2. Physically and Mentally Demanding Application Processes

Completing detailed forms for PIP, ESA, or Universal Credit can be overwhelming for those with severe ME. The effort required to describe symptoms and gather evidence can cause significant deterioration in health. Even the process of reading, writing, or communicating with the DWP can be beyond the capacity of some members.

## 3. Assessments that Do Not Reflect Fluctuating Conditions

Face-to-face and telephone assessments are particularly unsuitable for people with ME. The system tends to assess an individual based on how they appear on a single day, failing to account for the severe and unpredictable variation in symptoms. Many people are left worse off after being forced to attend assessments that trigger relapses lasting weeks or months.

## 4. Difficulty Obtaining Appropriate Medical Evidence

Although awareness of ME/CFS is improving, some healthcare professionals remain unsure how to describe its disabling effects in DWP terms. Medical reports often fail to capture the real impact on daily living or the need for rest, assistance, and adaptations.

### 5. Stress and Administrative Barriers

The stress and complexity of applying for benefits can be overwhelming. Long waits for decisions, repeated reassessments, and the need to appeal incorrect outcomes can all worsen symptoms. Some people are unable to begin or complete the process without dedicated advocacy or support.

### 6. The Need for Informed Support and Advocacy

Access to benefits advice from people who understand ME is essential. Specialist advocates can help ensure that forms accurately reflect the impact of the illness, that communication with the DWP is manageable, and that claimants receive fair and lawful decisions. Support from family, carers, and ME organisations can make a crucial difference.

### Moving Forward

The 25% ME Group continues to raise awareness of the barriers faced by people with severe ME and to campaign for fairer treatment within the welfare system. We believe no one should be left without essential financial support simply because the system fails to recognise the realities of this illness.

### How You Can Get Involved

If you are currently applying for benefits or supporting someone who is, the 25% ME Group is here to help.

### Get in touch

We can provide information, guidance and signposting to reliable benefits advice for people with severe ME and their carers.

### Gathering evidence for benefits claims

1. Understand What “Good” Evidence Looks Like

Medical evidence should:

Describe how your condition affects your daily life and function, not just list diagnoses.

Be recent (ideally within the last year) and from a reliable professional.

Match the benefit criteria (e.g., PIP daily living and mobility descriptors).

## 2. Who Can Provide Evidence

You can collect letters or reports from:

GPs or consultants (neurology, immunology, rheumatology, etc.)

Occupational therapists (on energy management, function, aids/adaptations)

Physiotherapists (on mobility limits, post-exertional malaise)

Psychologists or counsellors (on emotional impact and coping)

Carers, family members, or support workers (as “informal evidence”)

## 3. How to Request Evidence

Write a short, clear request letter or email (you can include a simple form for them to fill in).

Mention what benefit you’re applying for and that you need information about how your condition affects your daily life.

Provide specific examples of difficulties (e.g., preparing food, washing, walking distances, managing fatigue).

Let them know you don’t need a full medical history, just how M.E. limits you now.

“I’m applying for Personal Independence Payment (PIP) and need a short letter describing how M.E. affects my daily living and mobility. In particular, could you explain how fatigue, pain, or cognitive issues affect my ability to carry out tasks safely and repeatedly?”

## 4. Make It Easy for Busy Professionals

Provide a summary sheet of your main symptoms and limits — they can copy or refer to it.

Offer to collect the letter by email or post (to save them time).

Be patient and follow up politely if needed.

## 5. Keep Your Own Records

Keep a symptom diary or short log (e.g., 1–2 weeks) showing how your symptoms fluctuate.

Note “post-exertional malaise” patterns — e.g., if doing a task one day causes worsening fatigue for several days.

Save copies of clinic letters, medication lists, care plans, and test results.

## 6. Use Supporting Statements

If medical evidence is limited, you can add:

A personal statement detailing how your condition affects daily tasks.

A carer or family statement confirming what they observe.
These help illustrate real-life impact in plain, believable language.