#NOT JUST FATIGUE

Invisible Illness Report:
The Economic Impact of ME/CFS in 2025

A first-of-its-kind report with new data on the economic and social impacts of a widespread chronic illness

EXECUTIVE SUMMARY

A public health and economic crisis is hiding in plain sight. Affecting millions of Americans, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a debilitating, chronic neuroinflammatory / neuroimmune illness, often triggered by an infection.

This first-of-its-kind survey reveals a public health and economic crisis hiding in plain sight. Based on newly collected data from individuals with ME/CFS, this report presents unprecedented insights into the economic burden of this debilitating condition. Beyond the physical symptoms, this report reveals the staggering economic impact on those living with the condition. Based on a comprehensive survey of people with ME/CFS, **94% of respondents experienced professional disruption due to their illness,** with an **average income reduction of 42.8%**. These costs and impacts extend beyond lost wages and compound over time, depleting savings, increasing medical costs, diminishing the ability to work, and relying on unpaid caregiving from family and friends.

ME/CFS is becoming one of the defining public health equity issues of our time. Despite affecting more Americans than multiple sclerosis and Parkinson's disease combined, ME/CFS receives only 11% of comparable research funding. The lack of clinical recognition, FDA-approved treatments, and research funding for ME/CFS has led to devastating personal and societal losses. This report calls for urgent policy changes to address these economic challenges and improve support systems for people with ME/CFS.

Economic Toll at a Glance:
- 94% of respondents experienced some change in their professional life due to ME/CFS
- 43% average income lost, with only 57% of pre-illness income maintained
- $4,439 in annual out-of-pocket medical costs
- 62% rely on unpaid caregiving from family or friends
- 22% depleted retirement savings
- Only 27% were approved for disability benefits within 6 months

This professionally conducted survey by Talker Research, using ESOMAR-compliant methodology, captures the experiences of individuals diagnosed with ME/CFS across diverse demographics, providing unprecedented insights into their economic challenges.

ABOUT ME/CFS

ME/CFS is a complex, serious, and chronic condition that often occurs following an infection. It is characterized by post-exertional malaise, which is when even small amounts of physical, mental, or emotional activity cause a severe and prolonged worsening of symptoms, including fatigue and brain fog.

One of the greatest challenges people with ME/CFS face is obtaining an accurate diagnosis. Despite affecting up to 9 million Americans, many spend years navigating the healthcare system, seeing multiple specialists, and enduring the attitude that their symptoms are "just fatigue."

The reality is far more severe. ME/CFS can be profoundly disabling, preventing individuals from maintaining employment, participating in social activities, and, in some cases, even performing basic self-care. The severity ranges from mild to very severe, with approximately 25% of people with ME/CFS left housebound or bedbound at some point in their illness.

Most concerning is that there are no FDA-approved treatments specifically for ME/CFS, and research funding is only a fraction of what is allocated to other conditions with similar disease burden. Given that ME/CFS affects three times more women than men, its lack of research funding reflects a broader pattern in how the medical system overlooks women's pain and chronic conditions. This report highlights how this medical dismissal translates directly into economic hardship for people living with ME/CFS.

WORKPLACE DISRUPTION AND ECONOMIC IMPACT

"I had to go back to work and I remember sitting reading legal documents and appraisals, and, uh, and I would read a paragraph three times and I had no idea what I was reading....I used to work for a major Wall Street firm." -Andy, person with ME/CFS

Our survey reveals a stark picture of professional disruption among those with ME/CFS:
- 94% of respondents reported some change in their professional life due to ME/CFS
- Only 3% of people with ME/CFS reported no change to their employment status
- 52% reduced their working hours to part-time or freelance work
- 20% were on temporary medical leave or unemployed due to illness
- 22% permanently left the workforce due to ME/CFS
    - This is even more common for women, with 27% leaving the workforce entirely, compared to 19% of men

These findings highlight how ME/CFS forces many talented professionals to scale back their careers or leave the workforce entirely, resulting in substantial lost productivity and economic activity at both individual and societal levels.

FINANCIAL BURDEN AND HEALTH CARE COSTS

"The general public should care about this disease because people are dying, it is costing the economy billions of dollars, it is ruining lives, and they could get it next." -Terri, person with ME/CFS

The financial impact is equally severe:

- Respondents earned an average of only 57.2% of their pre-illness income
    - Women with ME/CFS retain significantly less of their pre-illness income (49.1% on average) compared to men (63.2%)
- Only 8% maintained 91-100% of their pre-ME/CFS income
- 22% earned less than 30% of their pre-illness income
- 5% reported earning no income at all

"The financial impact of this illness is devastating. It cleans out your savings. It bankrupts families. People lose their jobs, their homes, and can't get treatment. You can't work to pay for medical expenses." -Heidi, person with ME/CFS

The economic impact of ME/CFS extends well beyond lost wages. Survey respondents reported:

- An average annual out-of-pocket medical spending of $4,439 for ME/CFS-related care
- 55% had to reduce household spending
- 42% increased reliance on others for financial support
- 36% depleted savings and retirement funds
- 33% accumulated debt due to illness

Many people with ME/CFS face a cruel paradox: as their income decreases, their medical expenses increase.

This financial strain has long-term consequences, with **22% reporting altered retirement planning**, **effectively compromising their financial security** for decades to come.

NAVIGATING SUPPORT SYSTEMS

"The doctor had no idea what was wrong with me…he's not giving you anything useful. Nothing except a big bill." -Howard, person with ME/CFS

Our findings reveal significant challenges in accessing support systems designed to help those with disabilities:

- 30% of respondents rely on disability benefits as their primary source of income
- Only 27% were approved for disability benefits within 6 months
- 16% were denied disability benefits entirely
    - Women are nearly 4 times more likely to be denied disability benefits (27% denied vs. 7% of men)
- 18% heard the process was too difficult and didn't apply
- 9% lacked the energy to complete the application process due to their illness

Those who did apply for disability benefits faced numerous obstacles:

- 46% reported difficulties with the application process (paperwork, wait times)

- 39% encountered medical documentation issues (including doctors unfamiliar with ME/CFS)
- 39% faced financial barriers (legal costs, appeal expenses)
  - Men reported higher rates of financial barriers (47% vs. 29%) and documentation issues (45% vs. 32%)
- 37% weren't taken seriously by evaluators
  - Women are significantly more likely to report "not being taken seriously by evaluators**"** (44% vs. 31% of men)
- 31% were denied despite clear impairment

"If you come into a doctor's office and say 'I have chronic fatigue syndrome,' your doctor is not going to take you very seriously. They're going to think you're one of those whiney women or whiney people that can't get it together and want to complain." - Dr. David Tuller, Journalist & Public Health Researcher at UC Berkeley

Perhaps most strikingly, **62% of respondents rely on unpaid caregiving from family and friends**, **creating a shadow economy of unpaid labo**r and additional economic impact that extends beyond the patient themselves.

CONCLUSION AND POLICY RECOMMENDATIONS

ME/CFS is #NotJustFatigue – it's a complex medical condition with profound economic consequences for those affected. Our findings demonstrate that the impact extends far beyond health to affect employment, income, savings, and long-term financial security.

As ME/CFS Awareness Month highlights these challenges, we call on policymakers, healthcare systems, and employers to recognize the economic burden of this condition and implement solutions that provide meaningful support to those affected.

The survey data summarized in this report illuminates the need for urgent policy changes to address these economic challenges and improve support systems for people with ME/CFS:

1. With respondents reporting an average of $4,439 in annual out-of-pocket medical expenses, it's no surprise that 28% of survey participants identified **universal healthcare coverage** as their top policy priority.
2. Given that only 27% of respondents were approved for disability benefits within 6 months, **streamlining the application process** (supported by 23% of respondents) emerged as a critical priority.
3. With 94% of respondents experiencing some change in their professional life due to ME/CFS, **increased research funding for treatments** (prioritized by 20% of respondents) could develop therapies that help people with ME/CFS maintain or return to work.
4. With respondents spending an average of $4,439 annually on out-of-pocket medical care, **tax credits** for these expenses (supported by 14% of respondents) would provide financial relief for the 55% who have had to reduce household spending and the 33% who have accumulated debt due to their illness.
5. For the respondents who have managed to stay in the workforce despite their illness, **required workplace accommodations** (identified by 11% of respondents as a priority) could help maintain employment with appropriate support.

In particular, we advocate for increased ME/CFS research funding within the RECOVER Long COVID Initiative and urge Congress to fund the ME/CFS Research Roadmap. Only through coordinated action can we address the hidden economic crisis facing people with ME/CFS and build a more supportive, understanding society for individuals living with this debilitating condition.

"These are not aspirational ideals, they are foundational to preventing further economic fallout. Without action, more people - especially women - will be pushed out of the workforce or into caregiving roles with no compensation or recognition, causing tremendous economic strain." - Elizabeth Ansell, person with ME/CFS and founder of leading advocacy group #NotJustFatigue

SURVEY METHODOLOGY

This survey was conducted in April 2025 with a robust, diverse group of individuals with confirmed Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) diagnoses. The research captures valuable insights from a population that is traditionally difficult to study due to diagnostic challenges and limited recognition among healthcare providers. The clear patterns emerging across respondents suggest these findings have broader applicability to the ME/CFS community as a whole, providing valuable insights into the economic challenges faced by those living with this condition.

The survey population represented a diverse cross-section of people with ME/CFS across key demographics:

- **Gender:** 58% male, 41% female, 1% other
- **Age:** 20% Gen Z (1997-2007), 48% Millennials (1981-1996), 24% Gen X (1965-1980), 6% Baby Boomers (1946-1964), 2% Silent Generation (1926-1945)
- **Region:** 17% Northeast, 29% Southeast, 23% Southwest, 17% Midwest, 14% West

The survey was conducted by Talker Research, whose team members belong to the Market Research Society (MRS) and the European Society for Opinion and Marketing Research (ESOMAR), ensuring the questions were fair, unbiased, and not leading. All survey methodology adhered to professional market research standards, with appropriate screening, routing, and response options to maximize data validity.

#NotJustFatigue is a non-profit sharing educational information to inform people about Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (aka ME/CFS), a chronic condition that often occurs following an infection where small amounts of physical, mental, or emotional activity cause severe symptoms, including fatigue and brain fog.

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www.notjustfatigue.org