ACTION FOR M.E.

REPORT

The Cost of Neglect: Evidence from the 2026 Big Survey

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wellcome



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appg All-Party Parliamentary Group on Myalgic Encephalomyelitis (ME)

This report reveals a profound injustice: hundreds of thousands of people with ME are living with one of the most disabling long-term health conditions in the country while being denied the understanding, care and support that should be their right. We are all poorer for this. We cannot continue to look away.

Tessa Munt MP
Chair of the All-Party
Parliamentary Group on ME

Cover image: Lea Aring, German Association for ME/CFS.

Executive Summary

When four in five people with ME do not feel supported by the NHS and three quarters have lost trust in public institutions, we are not looking at isolated service failures. We are looking at a systemic failure that demands a national response.

The voices in this report tell a stark story: people with ME are being abandoned by the systems we all expect to support us when we become seriously ill. This abandonment benefits no one and we are all paying the price. It compounds the impact of illness on individuals, places additional pressures on families, restricts participation in communities and wider society, and imposes substantial economic costs.

A hidden crisis affecting 1.35 million people

Myalgic encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS) or ME/CFS, is one of the most disabling long-term health conditions in the UK. Together, ME and ME-like Long Covid are estimated to affect 1.35 million people nationwide.

Action for ME's 2026 Big Survey provides one of the most comprehensive pictures ever assembled of what it means to live with ME in the UK today. Conducted between October 2025 and January 2026, the survey heard from 5,424 adults, children and young people, and parents or carers. Respondents contributed nearly 750,000 words of testimony, creating a powerful evidence base that reveals not only the devastating impact of ME, but the profound consequences of years of systemic neglect.

Lives constrained by illness

The 2026 Big Survey reveals an illness that reaches into almost every aspect of life. The vast majority of adults had reduced or stopped social contact, hobbies and household tasks, while many had lost independence and relationships. Among children and young people, isolation and shrinking friendship circles were widespread, and more than one-quarter were too ill to access education. For those living with severe and very severe ME, everyday tasks such as eating, washing, communicating, sitting upright or leaving bed can become difficult or impossible.

Yet despite the life-altering nature of the condition, many of these experiences have changed little over more than a decade. The findings suggest that while understanding of ME may have advanced, the everyday reality for many people has not.

The human and economic costs are immense

ME is pushing people out of the workforce on a striking scale. Less than two in five working-age respondents were in any paid employment, a rate substantially lower than those reported among people with other disabling illnesses. This is not because people with ME are unwilling to work – far from it. Respondents described fighting to remain in employment as their health deteriorated: reducing their hours, changing roles and accepting lower pay, until they became too ill to continue.

These losses are not only personal; they are economic. Our model estimates that reduced labour market participation associated with ME and ME-like symptoms costs the UK economy £19.66 billion every year, equivalent to approximately 0.68% of UK GDP. This figure captures only one aspect of the overall burden; it excludes healthcare and social care costs, disability benefits, and the impact on informal carers. The true cost is therefore likely to be substantially higher.

An NHS that is failing those who need it most

The scale of these human and economic costs makes effective healthcare all the more important. While there is currently no cure for ME, good care should support people to maintain the best health and quality of life possible. Yet six in seven respondents are living with a profoundly disabling illness without any regular NHS care or monitoring. Access to specialist support remains a postcode lottery, with services unavailable in many areas and often inaccessible to those too ill to travel.

A troubling paradox runs through the findings: as ME becomes more severe, appropriate care becomes harder to access and experiences of healthcare worsen. Three times as many adults with very severe ME as those with mild ME described an experience of NHS healthcare as ‘traumatic’ or ‘traumatising’. Consequently, most respondents with severe and very severe ME now avoid NHS healthcare where possible, often because previous experiences have caused harm or deterioration.

Unmet social care needs are causing preventable harm

For many people, the absence of ongoing NHS care is compounded by inadequate social care. More than two-thirds of adults who needed social care were going without some or all of the support they required, with consequences for their ability to wash, eat adequately and manage their homes. Crucially, unmet social care needs could contribute to further deterioration in health, increasing the very need for care that was already going unmet.

Parents, partners and relatives are filling critical gaps in care, often alongside work,

childcare and health challenges of their own. In doing so, they absorb needs that remain unmet by formal services, masking the true scale of the social care deficit.

From abandonment to action

Across thousands of survey responses, one word emerged again and again, unprompted: "Abandoned." Abandoned by healthcare services. Abandoned by social care services. Abandoned by institutions that should protect and support people when they are most vulnerable.

This abandonment is not an inevitable consequence of ME. It is the result of policy choices, service gaps and longstanding failures to recognise and respond to the realities of the condition.

Action for ME is calling for urgent action to:

1. End the postcode lottery in ME healthcare.
2. Improve understanding of and attitudes towards ME across the NHS, social care and education sectors through mandatory, role-appropriate ME training.
3. Deliver regular reviews and personalised care plans, as outlined in the NICE guideline.
4. Ensure social care reform meets the needs of people with ME.
5. Deliver flexible and personalised education for children and young people with ME.
6. Make sustained, coordinated investment in ME research a national priority.

The foundations for change already exist, including the NICE guideline and the Final Delivery Plan on ME/CFS. What is needed now is implementation.

The question is no longer whether people with ME are being failed; the evidence is overwhelming. The question is whether policymakers, health leaders and government will act with the urgency that this crisis demands.

1. About the Big Survey

Action for ME's Big Survey is a major UK-wide study of people living with myalgic encephalomyelitis (ME). Conducted approximately every five years, it provides a state of the nation assessment of the impact of ME on people, families and communities, while tracking change over time. The findings provide an evidence base that underpins all aspects of the charity's work (see Box 1).

The 2026 Big Survey was conducted as part of a formal collaboration between Action for ME and Durham University's Institute for Medical Humanities (see Box 2), which has been supported by the Wellcome-funded Discovery Research Platform for Medical Humanities. Working in partnership with Action for ME, Dr Katharine Cheston led the design, delivery, analysis and reporting of the 2026 Big Survey. This collaboration has united the expertise of a national charity and a leading research institution to generate new evidence about the realities of living with ME in the UK.

Ethical approval for the secondary analysis of survey data and Dr Cheston's role in the project was granted by Durham University's Department of Sociology ethics committee in summer 2025.

Box 1: About Action for ME

Action for ME is the only charity in the UK providing support, including healthcare, to people of all ages affected by ME. We take a holistic approach so we can make an impact on multiple fronts – from amplifying the voices of people affected by ME in Government and leading on breakthrough research to create change for the future, to providing "lifeline" information, support and unique healthcare services to improve lives now.

Guided by our values of collaboration, empathy and equity, we put the experiences and needs of people with ME at the heart of everything we do. We're committed to challenging inequalities and ensuring everyone affected by ME has a voice and access to the support they need.

Find out more **www.actionforme.org.uk**

2. How the survey was conducted

People with lived experience of ME and ME-like Long Covid were involved throughout the design and development of the survey. This included engagement with a Patient and Public Involvement (PPI) group, whose expertise and feedback shaped the survey questions and dissemination strategy. Additional feedback was sought from members of the ME and Long Covid communities before the survey was finalised.

The Big Survey was open between October 2025 and January 2026. It comprised two separate questionnaires: a comprehensive survey for adults and a shorter survey for children and young people, which also contained an additional set of questions for parents and guardians. Participants could complete the survey online or by filling out a paper copy. To maximise accessibility, telephone support was offered to those most severely affected by ME.

Survey responses were anonymised before analysis. Free-text responses were analysed using an inductive qualitative content analysis approach, allowing recurring themes to emerge from participants' accounts rather than being defined in advance (Elo & Kyngäs, 2008). Percentages were calculated based on the number of respondents who answered each question, unless not answering the question was itself a valid response, in which case percentages were based on the full survey sample. The majority of questions had a response rate greater than 90%.

Box 2: About the Institute for Medical Humanities, Durham University

The Institute for Medical Humanities at Durham University conducts research into 'hidden experiences' and investigates experiences of health and illness which are marginalised, difficult, unspeakable, unacknowledged or invisible. It aims to transform knowledge within and beyond the critical medical humanities, improve health policy and practice, and benefit the lives of communities and individuals.

Find out more: **www.durham.ac.uk/imh**

3. Who took part

A total of 5,424 people participated in the 2026 Big Survey, providing a substantial body of evidence about the current experiences and needs of people living with ME in the UK. The vast majority of participants (5,182) were adults. 132 children and young people, and 110 of their parents or guardians, completed the shorter version of the questionnaire.

Alongside their survey responses, participants contributed almost 750,000 words of written testimony, describing in their own words the realities of living with ME and its impact on their lives. These accounts reveal the human impact behind the statistics and are reflected throughout this report.

3.1: How the sample compares with the wider population

The geographical distribution of adult respondents was similar to that of the UK population. Most lived in England (82.6%), followed by Scotland (11.1%), Wales (4.7%) and Northern Ireland (1.6%), broadly aligning with Office for National Statistics population estimates (ONS, 2026).

The adult sample was concentrated in middle age, with almost half (49.5%) aged 46-65. The median age of adult respondents was 51. Among children and young people, three-quarters of the sample (75.3%) were aged between 14-17, with the rest aged between 10-13.

Action for ME estimate that there are up to 1.35 million people in the UK living with ME or ME-like symptoms (Action for ME, 2025). This figure combines the most recent estimate that 404,000 people live with ME in the UK (Samms & Ponting, 2025), with research suggesting that around half of the 1.9 million people in the UK living with Long Covid (ONS, 2023) experience ME-like symptoms (Jason & Dorri, 2023; Davis et al, 2023). This potentially large post-Covid population was less prominent in the Big Survey sample, with only 17.2% of adults (and 34.4% of children and young people) associating the onset of their illness with Covid-19.

Reflecting the recognised female predominance in ME (Lim et al, 2020), 85.1% of the adult sample identified as women, 12.2% as men and 2.1% as non-binary. This female-to-male ratio is higher than that observed in NHS hospital data (Samms & Ponting, 2025),

but comparable to that reported in other large-scale surveys of the UK ME population (Bretherick et al., 2023).

The majority (97.0%) of the adult sample identified as White, 1.7% as of mixed or multiple ethnic groups, 0.7% as Asian, 0.4% as of another ethnic group, and 0.2% as Black. This should be considered in the context of recognised inequalities in receiving a diagnosis of ME, with substantially lower diagnosis rates among other-than-white ethnic groups (Samms & Ponting, 2025; Bayliss et al., 2014).

More than half (55.2%) of adult respondents described themselves as moderately affected (see Box 3); just over one-quarter (26.3%) were mildly affected. The remaining 18.4% of the adult sample were severely (16.9%) or very severely (1.5%) affected. The National Institute for Health and Care Excellence estimate that 25% of people with ME are severely or very severely affected (NICE, 2021). The slight underrepresentation of people with severe and very severe ME may reflect the considerable challenges they face in taking part in a survey of this kind.

The adult sample reflected the prolonged duration of ME, with research indicating that full recovery is unusual (Ghali et al., 2022; Kielland & Liu, 2025). Just over half (53.5%) had been ill for at least 10 years, including almost one in six (15.8%) who had been ill for at least 30 years.

Box 3: ME Severity

Studies have found that people with ME experience poorer quality of life and greater levels of disability than those with other chronic conditions (Komaroff et al, 1996; Hvidberg et al, 2015). Severe and very severe ME involve profound suffering, and even 'mild' presentation is life-changing, as illustrated by the descriptions below (adapted from NICE, 2021).

Mild
People with mild ME care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education (often with reduced hours) but to do this they have stopped or significantly reduced leisure and social pursuits.

Moderate
People with moderate ME have reduced mobility and are restricted in all activities of daily living. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours.

Severe
People with severe ME are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They may depend on a wheelchair for mobility, are often unable to leave the house, and may spend most of their time in bed.

Very severe
People with very severe ME are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli.

4. ME continues to devastate lives

The landscape around ME has changed considerably since the last Big Survey in 2019. The Covid-19 pandemic and emergence of Long Covid have brought renewed attention to post-viral illness; the DecodeME study has identified eight genetic signals associated with ME, providing important new insights into its biological basis (Genetics Delivery Team et al, 2025); and in 2025 the UK Government published its Final Delivery Plan on ME/CFS, setting out actions intended to drive change to improve care and support for people with ME (DHSC, DfE & DWP, 2025). Yet the findings of the 2026 Big Survey suggest that these developments have not yet translated into meaningful improvements in the lives of many people living with ME.

4.1: ME restricts every area of daily life

Everyday activities that most people take for granted were restricted for the vast majority of respondents. More than 9 in 10 adult respondents had stopped or reduced social contact (93.3%), sports and hobbies (92.6%) and household tasks (92.3%), while 89.3% said that having ME had affected their emotional wellbeing.

These restrictions also affected respondents' relationships with others and their independence. Three-quarters (76.1%) were less able to provide emotional or practical support to others, while almost one third (30.3%) had stopped or reduced caring roles. More than half had reduced or lost their ability to drive (54.1%) or to leave home independently (50.8%). One in four (24.6%) said their ME had affected their decision about whether to have children, showing how the illness can shape major life choices as well as the routines of everyday life.

9 in 10

respondents have stopped or reduced household tasks, social contact, sports and hobbies



Half

have reduced or lost their capacity to drive and to leave their home independently

4 in 5

82.9% respondents with very severe ME require full time care



9 in 10

96.1% respondents with very severe ME have to spend all day in bed



1 in 2

respondents with very severe ME



And 1 in 4

respondents with severe ME



struggle to eat enough to maintain their weight

For those with severe and very severe ME, the impact on everyday functioning is profound. More than half (55.3%) of respondents with severe ME had to spend all day in bed, rising to almost all (96.1%) of those with very severe ME. Among respondents with very severe ME, more than four in five (82.9%) required full-time care, and the majority often or always could not speak (77.6%) or tolerate light or sound (94.7%). Difficulties maintaining adequate nutrition were also widespread among those most severely affected. More than half (53.9%) of respondents with very severe ME, and one in four (25.5%) with severe ME, often or always struggled to eat enough to maintain their weight. These findings are particularly concerning given the risk of life-threatening malnutrition associated with very severe ME, highlighted in a 2024 Prevention of Future Deaths report (Archer, 2024).

Behind these figures are accounts of lives increasingly constrained by illness:

> *"I can't remember what 'normal' life is like. […] I can't remember what it's like to be able to just have a shower when you want one. I can't remember when I didn't have to plan activities to be able to carry out a simple task like speaking on the phone. I can't remember what a refreshing night's sleep is."*

Comparison with previous Big Surveys, in 2014 and 2019, reveals a strikingly persistent picture. While differences between the survey samples mean that direct comparisons should be made with caution, there is little evidence of meaningful improvement in the impacts of ME since 2014. Many of the most commonly reported impacts – including reductions in household tasks, social contact, hobbies and caring roles – have remained at similar levels, while some impacts were reported more frequently in 2026.

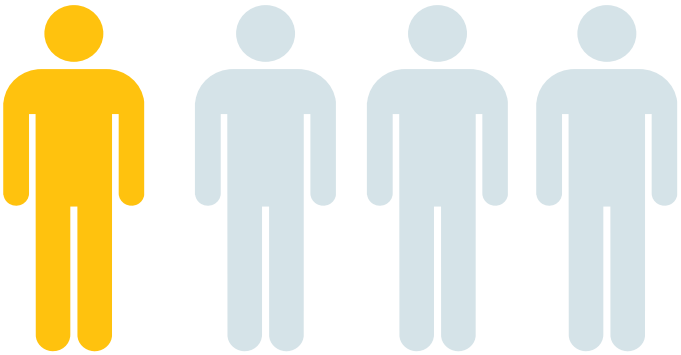
4.2: Childhood and adolescence interrupted

When ME begins in childhood or adolescence, these restrictions interrupt education, friendships and the ordinary experiences through which young people grow up. The impacts may extend far beyond childhood, shaping (and potentially limiting) future opportunities and life trajectories.

Almost one-third (31.0%) of children and young people surveyed were attending school or college on a reduced timetable and fewer than one in ten (9.5%) were attending full-time. Others were accessing education through alternative arrangements, including home-schooling (11.9%), online learning (17.5%) and, for a small minority, an AV1 robot (1.6%). However, more than one-quarter (28.6%) of children and young people were too ill to access any education at all. This figure is virtually unchanged from children and young people's responses to the 2019 Big Survey, in which 30.0% of respondents were too ill to access education. This persistence indicates that severe educational disruption remains a significant issue for children and young people with ME.

More than 1 in 4

children and young people are too ill to access education



Box 4: In their own words

The symptoms of ME include, but are not limited to, post-exertional malaise (PEM, a worsening of symptoms after physical or mental exertion), debilitating fatigue that is not relieved by sleep, cognitive difficulties, and flu-like malaise (NICE, 2021). In their own words, Big Survey respondents described the severity and wide-ranging impacts of ME symptoms:

A relentless form of exhaustion that people cannot imagine unless they've experienced it. It's not just being tired, it's like every scintilla of energy has been sucked out of your body and mind. You literally feel as if you are dying.

I haven't been downstairs for years and spend 23 hours a day in bed. My muscles are so weak that I sometimes cannot chew my meals and I can't lift my arms for more than a few seconds at any time.

My body is in constant pain and I feel like I'm walking in cement with heavy limbs.

My brain doesn't feel mine anymore and I'm very frustrated that I can't remember simple things. I feel like I have flu most of the time and lots of headaches too.

My body aches. I have to spend 95% of my day in bed. Eating is tiring, I have to take breaks. I struggle to hold my head up. Overhead lights hurt my eyes and the sound of my family's voice hurts my ears.

7 in 10

now have lower self-confidence



4 in 5

83.7% reported that their friendship circle had reduced due to their ME



Almost all

97.7% children and young people have had to reduce participation in sports and hobbies

The impacts on children and young people extend far beyond the classroom. Almost all (97.7%) had reduced their participation in sports and hobbies, while more than four in five (83.7%) had seen their friendship circle shrink. Eight in ten (81.4%) often felt excluded, and over two-thirds (70.5%) reported lower self-confidence because of their ME. These figures have remained stable across the 2019 and 2026 Big Surveys, with differences of less than eight percentage points.

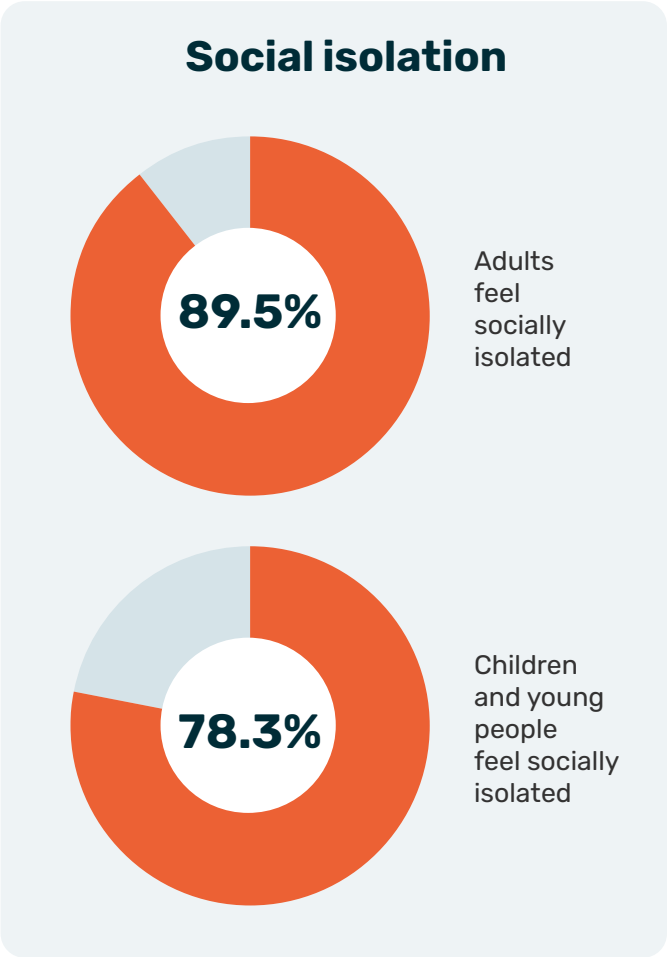
The result is a profound and persistent interruption to childhood and adolescence, with many missing out on experiences and opportunities that their peers take for granted.

Children and young people described these losses starkly, in their own words:

> **“I feel like I have missed my whole teenage years, friendships, social life, opportunities, and this will affect my whole life going forward. It’s hard not to be angry and also mourn the life I should be living.”**

> **“ME has robbed me of my childhood.”**

4.3: ME leaves people isolated and disconnected



Social isolation is one of the most widespread impacts of ME. Nine in ten (89.5%) adult respondents and more than three-quarters (78.3%) of children and young people reported feeling socially isolated because of their ME. Among those most severely affected, social isolation was almost universal: 98% of adults and 100% of children and young people with severe or very severe ME reported feeling socially isolated.

One adult respondent captured the painful reality of wanting social connection while being too ill to sustain it:

> *"I am so lonely that I literally ache with the pain of isolation. And yet I am too ill to speak with people."*

Yet the Big Survey findings indicate that social isolation is not only a consequence of the physical symptoms imposed by ME. The misunderstanding and stigma surrounding ME are seen to deepen disconnection. More than half (55.3%) of adults had lost friendships or relationships because of other people's attitudes towards ME, while only one in twenty (5.5%) felt that others understood what ME meant when they disclosed their condition. More than two-thirds (67.9%) also worried about being judged if they had to tell a stranger they had ME.

Stigma and misunderstanding also contributed to isolation among children and young people, as this respondent expresses:

> *"I have lost every single friend I had as they believed I was faking it. This has caused isolation and mental health difficulties."*

5. Failure to act is a burden we can no longer afford

Evidence from the Big Survey indicates that ME is associated with substantial labour force losses, representing significant economic burden for the UK.

5.1: A workforce lost to illness

The majority of adult respondents were not in paid work: two in five (41.0%) reported that they could not work because their ME was too severe, while almost one-quarter (22.3%) had taken early retirement because of ill health and 4.6% were retired for reasons unrelated to ill health. Only one in twelve (8.3%) were working full-time. A further 11.1% were working 20-34 hours per week and 12.6% were working 1-19 hours per week.

The scale of the impact of ME on employment becomes even clearer when the analysis is restricted to respondents of working age. Among Big Survey respondents aged 18 to 64, three in five (63.0%) were not working, either because their ME was too severe or because they had retired early due to ill health. Just over one quarter (27.4%) were working part-time and less than 1 in 10 (9.6%) were working full-time. Overall, less than two in five (37.0%) working-age respondents were doing any paid work.

Previous research has recorded similarly low employment among working-aged people with ME. One study found that employment among working-age people with ME fell from 89% before the onset of ME to 35% after becoming ill, which was significantly lower than the employment rate of 60% among working-age participants with multiple sclerosis (Kingdon et al, 2018). Recent data indicates that 53% of disabled working-age adults in the UK were in employment in April-June 2026 (ONS, 2026). These comparisons suggest that



1 in 12

Only **8.3%** adults surveyed were working full-time



2 in 5

41% respondents could not do any paid work because their ME was too severe

the impact of ME on employment is particularly severe, with employment rates lower even than those reported among disabled people generally and among people with multiple sclerosis.

5.2: Staying in work becomes increasingly difficult

The findings also show a clear relationship between illness duration and employment. Among adult respondents, full-time employment declined steadily with longer illness duration, from 13% of those in their first year of illness to 4% of those who had been ill for 30-39 years. Part-time employment initially rose from 25% in the first year to 31% among those ill for 1-5 years, potentially reflecting a shift from full-time to reduced working hours, before declining progressively to 13% among those ill for 30–39 years. This pattern is consistent with previous research showing a longer median duration of illness among patients who had ceased working, compared with those who were currently employed (Collin et al, 2011).

Respondents' accounts indicate the considerable efforts that many people with ME make to remain in paid employment. Rather than making an immediate decision to leave work, respondents described a progressive narrowing of their working lives: reducing hours, moving into more flexible or less demanding roles, accepting lower pay, before finally having to leave employment altogether.

> **"I have gone from a well paid full-time professional role to a lower paid full-time role to a part-time lower paid role to even fewer hours in that role."**

The impact can subsequently spread across a household as partners or relatives reduce their own employment to provide care.

> **"I lost a career and went from a teaching wage to minimum wage, then I lost work altogether, then my partner had to reduce his work so that he could care for my needs."**

These accounts show people trying to remain economically active, often at considerable personal cost, until their health no longer allows them to do so.

This trajectory is particularly concerning in the absence of a curative treatment for ME. Current clinical guidance focuses on diagnosis, care, support, energy management and symptom management; it does not identify a treatment that cures ME (NICE, 2021). Without interventions capable of substantially improving health and functional capacity, the movement from full-time work to ultimate labour market exit remains difficult to halt or reverse.

5.3: Reduced labour-force participation costs the UK an estimated £19.66 billon each year

The employment impacts identified in the Big Survey represent not only a loss of income for individuals and families, but also a substantial reduction in productive capacity across the UK economy. To estimate the scale of this impact, we developed a model of labour force losses associated with ME and Long Covid with ME-like symptoms using a human capital approach, a standard economic method that values lost productivity using earnings as a proxy for economic output (Pike & Grosse, 2018).

Action for ME estimates that approximately 1.35 million people in the UK are living with either ME or Long Covid with ME-like symptoms (Action for ME, 2025). Contextual analysis of the adult Big Survey sample (described in section 3.1) supports cautious extrapolation to this wider population, although differences in its composition – particularly the lower representation of people whose illness followed Covid-19 – mean that the resulting estimates should be regarded as indicative rather than definitive.

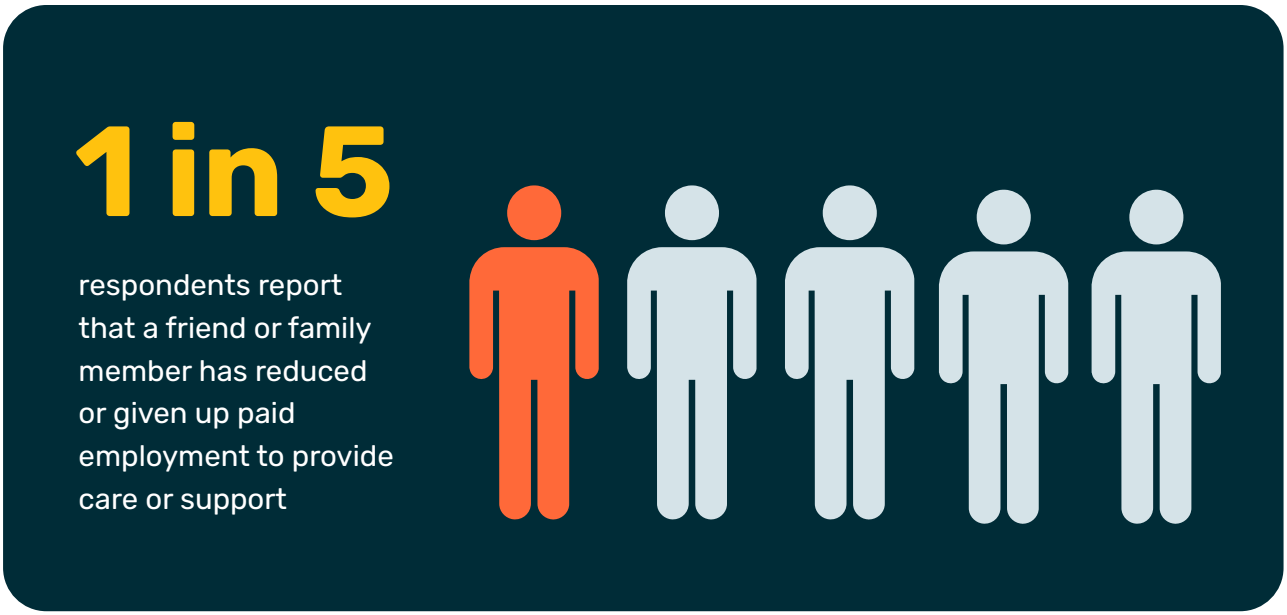
Extrapolating the age profile of Big Survey respondents (86% of whom were of working age) suggests that approximately 1.16 million people with ME and ME-like Long Covid in the UK are of working age. Among working-age Big Survey respondents, only 9.6% were employed full-time and 27.4% part-time, while 63.0% were not working because their illness was too severe or because they had retired early due to ill health. By comparison, 56.1% of working-age adults are employed full-time, 19.0% work part-time and 24.9% are not in employment (House of Commons Library, 2026).

The findings therefore indicate a substantial shift away from full-time employment and towards economic inactivity among people living with ME and ME-like Long Covid. Relative to national employment patterns, this equates to an estimated reduction of approximately 540,000 full-time workers across the affected population. Applying Office for National Statistics median earnings data (ONS, 2025) suggests that this shortfall represents around £21.1 billion in lost annual labour output. This loss is slightly offset by

the higher proportion of people with ME who work part-time compared with the general population. When the economic contribution of these additional part-time workers is taken into account, the net annual loss to the UK economy from reduced labour market participation due to ME and ME-like symptoms is estimated at £19.66 billion, equivalent to approximately 0.68% of UK GDP.

5.4: The wider economic burden is greater still

This is a conservative estimate. Rather than assuming that everyone affected by ME would otherwise be employed full-time, it compares employment outcomes reported in the Big Survey against observed UK labour market participation rates and recognises the economic contribution of those who remain in part-time work despite significant illness-related limitations. Moreover, it does not account for presenteeism (reduced productivity among those who remain in work), nor does it consider that people affected by ME may earn less than the national average (for example, due to moving into lower-paid employment to remain in work, or due to the impact of ME on educational attainment). The impact of the latter may be significant, considering that over two-thirds of adult respondents (69.7%) reported that having ME had affected their career choices or development.



Notably, the estimate does not include the impact of informal caring on labour market participation. One in five adult respondents (20.1%) reported that a friend or family member had reduced or given up paid employment to provide care or support, indicating that the labour force losses associated with ME are likely to extend far beyond those directly affected by the illness.

This model captures only the effects of ME on national labour force participation and

excludes a range of additional costs borne by individuals, families, public services and the wider economy. Most notably, it does not account for the direct costs of healthcare provision, social care, and disability benefits. Consequently, the estimated £19.66 billion annual loss should be understood not as the total economic cost of ME, but as a conservative measure of one element of a much wider societal and economic burden. Emerging international evidence suggests that these wider costs may be substantial. In Germany, an updated economic analysis estimated that Long Covid and ME generated combined annual costs of approximately €64.4 billion in 2025, equivalent to 1.44% of German GDP (Daniell et al, 2026).

Photo Credit: Lea Aring, German Association for ME/CFS.



Reduced labour-force participation due to ME costs the UK an estimated £19.66 billon each year, equivalent to approximately 0.68% of UK GDP

6. We are failing people with the greatest need

80.3% of adult respondents did not feel supported by the NHS, rising to 85.5% among those with very severe ME. Across the findings, a consistent pattern emerges: as ME becomes more severe, NHS care becomes less accessible and experiences of care become poorer.

6.1: Absent or inaccessible NHS services

Current clinical guidance for England and Wales (NICE, 2021) describes ME 'specialist teams' as multidisciplinary services staffed by healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME.

For many respondents, however, no such service was available. Two in five adult respondents (40.7%) reported having no NHS specialist ME service in their area, with stark inequalities between the four nations. While this affected one-third (32.8%) of respondents in England, it affected the majority in Wales (62.1%) and Scotland (69.5%), and more than four in five (85.2%) in Northern Ireland.

This indicates that, in practice, access to specialist ME care remains a postcode lottery across the UK.

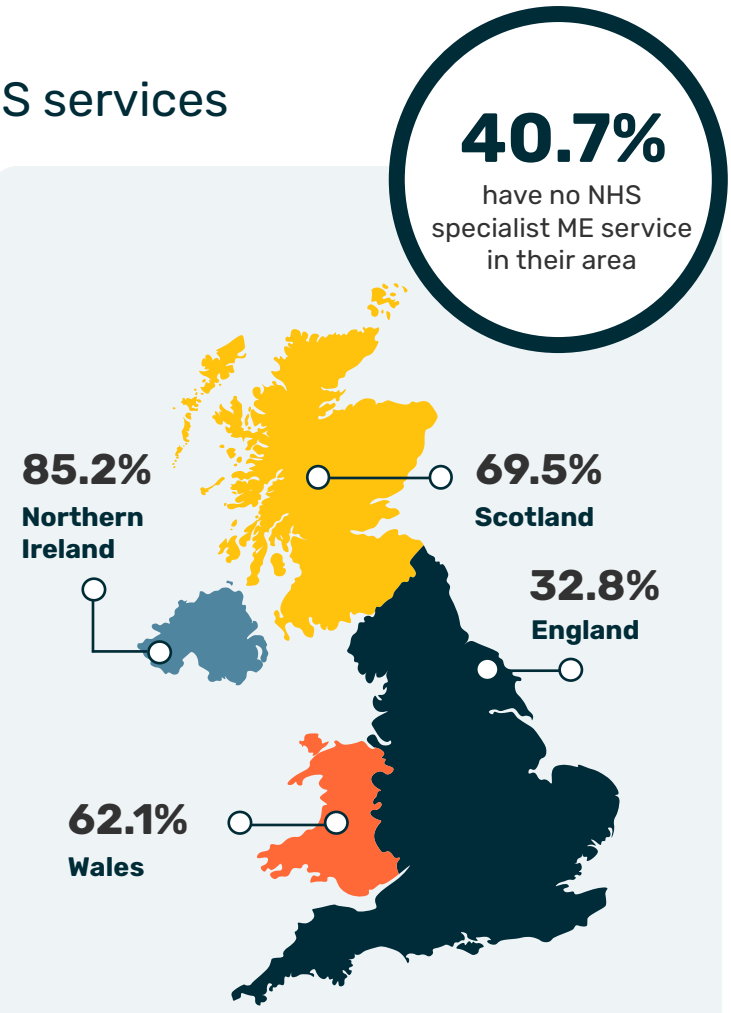


Fig 1: % Respondents with no specialist ME service in their area by nation.



3 in 5

respondents with **severe ME** are too ill to access NHS services for ME



4 in 5

respondents with **very severe ME** are too ill to access NHS services for ME

Where such services do exist, they are frequently inaccessible to those most in need of them. One in six respondents with severe or very severe ME (16.6%) reported that their local specialist service does not or did not accept referrals from patients at these levels of severity. Even where services accepted referrals from people with severe or very severe ME, this did not necessarily translate into meaningful access. Many were too ill to attend in person, while alternative forms of access, such as home visits or virtual appointments, were not available. As a result, three in five respondents with severe ME (60.1%) and more than four in five with very severe ME (83.8%) – in other words, the majority of respondents most severely affected by ME – reported being "too ill" to access NHS services for their condition.

Among those who are able to access a specialist team, most discover that this support is time-limited. Only around one in sixteen adults (6.2%) received regular monitoring or review from an NHS specialist ME team, and those receiving this ongoing care had typically been ill for substantially less time: a median of four years, compared with ten years across the adult sample as a whole. This pattern was reflected in respondents' accounts, analysis of which revealed a common theme: specialist services offered only a limited number of appointments, after which respondents were discharged despite remaining unwell or, in some cases, having deteriorated.

As one respondent put it:

> **"My NHS ME clinic can only offer 6 appointments with a specialist consultant before discharging me. Having such limited support when this condition is untreatable and will likely last the rest of my life is frightening and frustrating."**

6.2: Most receive no ongoing care or follow-up

For most respondents, the lack or loss of specialist care was not replaced by regular monitoring in primary care. NICE recommends that adults with ME should be offered 'a review of their care and support plan in primary care at least once a year', with more frequent reviews completed as needed, depending on the severity and complexity of symptoms (NICE, 2021).

However, Big Survey findings suggest routine follow-up is a rarity for adults with ME. Only one in seventeen adult respondents (5.9%) reported receiving regular monitoring or review from their GP, while six in seven (85.1%) received no ongoing support or follow-up care for their ME from either their GP or specialist team. As one adult respondent summarised:

> **"I have been left in the medical desert to fend for myself and just get on with it."**

Regular monitoring and review in primary care increased with illness severity, from 3% of respondents with mild ME to 18% of those with very severe ME. However, even among those with the greatest care needs, ongoing support remained the exception: 70% of respondents with very severe ME and 83% of those with severe ME reported receiving no ongoing support or follow-up care at all, from either primary or secondary care.

6.3: Experiences of NHS care worsen as illness becomes more severe

Adult respondents' experiences of NHS healthcare varied considerably. Around half had experienced being believed (53.2%) or treated with respect (50.8%) by an NHS healthcare professional. At the same time, negative experiences were widespread: six in ten (59.4%) had left an NHS appointment feeling upset because of the way they were treated about their ME, and over one-third (36.1%) described an experience of NHS

6 in 7

85.1% respondents receive no ongoing support or follow-up care for their ME



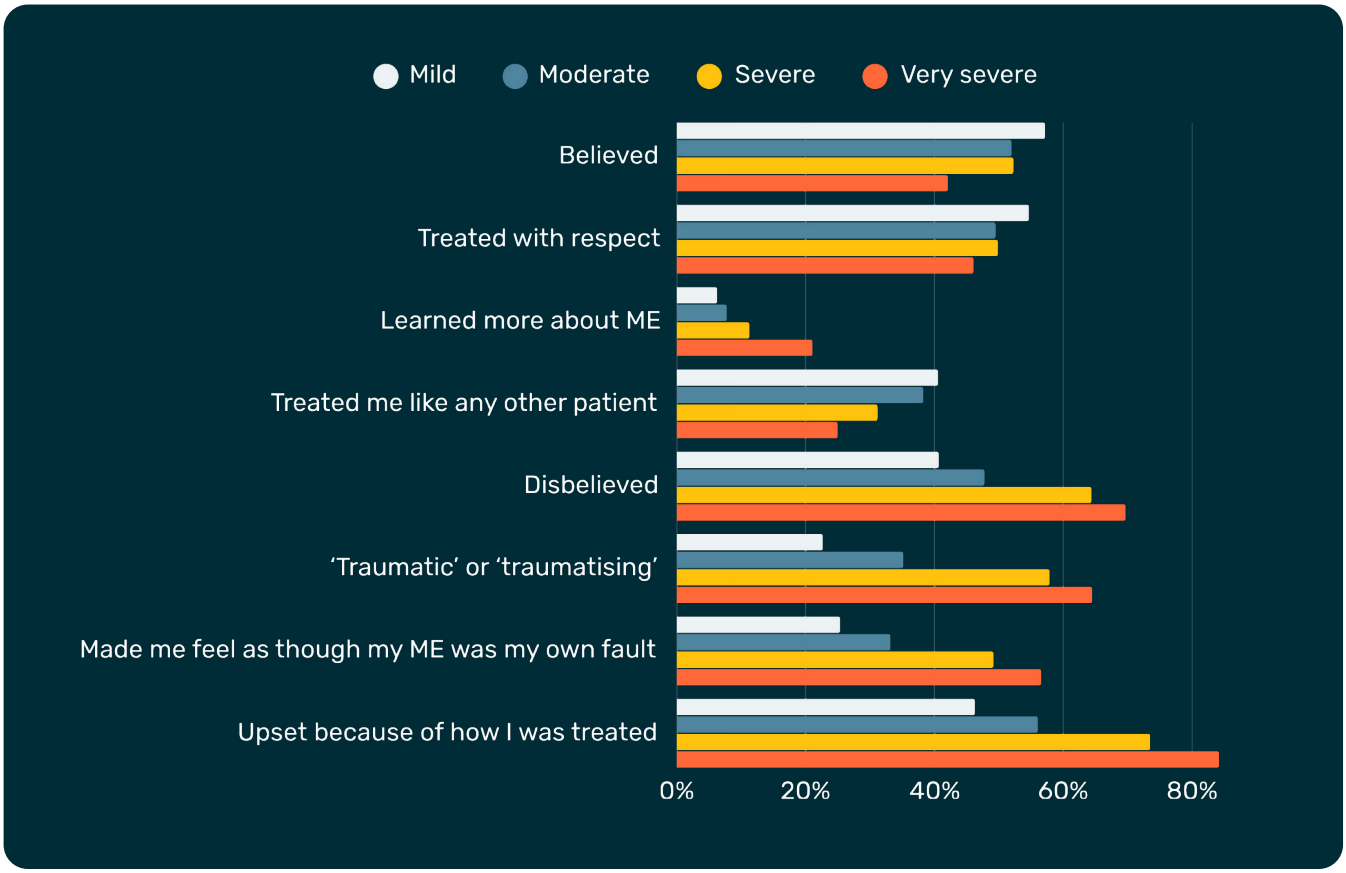
healthcare related to their ME as ‘traumatic’ or ‘traumatising’.

A clear relationship emerged between illness severity and respondents’ experiences of NHS care. As severity increased, respondents were more likely to report negative experiences and less likely to report positive experiences. As one respondent observed:

> **“Paradoxically, as my condition deteriorated from moderate to severe ME, my treatment by the NHS has worsened.”**

This pattern was evident across the wider sample. Only two in five respondents with very severe ME (42.1%) reported being believed by an NHS healthcare professional, compared with almost three in five (57.2%) of those with mild ME. More than half of respondents with very severe ME (56.6%) reported that an NHS healthcare professional had made them feel as though their ME was their own fault, more than twice the proportion among those with mild ME (25.4%). Almost two-thirds (64.5%) described an experience of NHS healthcare related to their ME as ‘traumatic’ or ‘traumatising’, nearly three times the proportion among those with mild ME (22.7%).

Poor experiences of NHS care are not confined to the past. In the year before completing the survey, one-third of adult respondents (34.3%) reported a negative interaction with an NHS healthcare professional. The findings therefore suggest that negative experiences of NHS care remain a common and current reality for people with ME.



	Mild	Moderate	Severe	Very severe
An NHS healthcare professional has believed what I have told them about my ME	57.2%	52.0%	52.3%	42.1%
I have been treated with respect by an NHS healthcare professional	54.7%	49.5%	49.9%	46.1%
An NHS healthcare professional has learned more about ME so they can support me better	6.3%	7.8%	11.3%	21.1%
An NHS healthcare professional has treated me just like any other patient	40.6%	38.3%	31.2%	25.0%
I have been disbelieved by an NHS healthcare professional about my ME	40.7%	47.8%	64.4%	69.7%
I have had an experience of NHS healthcare, related to my ME, that I would describe as 'traumatic' or 'traumatising'	22.7%	35.2%	57.9%	64.5%
An NHS healthcare professional made me feel as though my ME was my own fault	25.4%	33.2%	49.2%	56.6%
I have felt upset after an NHS appointment because of the way I was treated about my ME	46.3%	56.1%	73.5%	84.2%

6.4: Safety concerns drive avoidance of healthcare

As a result of their past experiences, most adult respondents (78.0%) had changed their approach to the NHS. Half (49.8%) reported that they now avoid seeking NHS healthcare, where possible; one in twenty (5.7%) have stopped seeking NHS healthcare completely.

Avoidance of healthcare increased substantially with illness severity: one-third (38.7%) of respondents with mild ME avoided seeking NHS care where possible, rising to almost two-thirds of those with severe (65.3%) and very severe (65.8%) ME. Among those with very severe ME, 15.8% had stopped seeking NHS healthcare completely, more than three times the proportion among those with mild ME (4.3%).

Analysis of free-text responses indicates that this avoidance represents a considered assessment of risk, rather than a general reluctance to seek help. Respondents described weighing the potential benefits of accessing healthcare against previous experiences of disbelief, inappropriate treatment, and subsequent deterioration in their health. For some, concerns about the consequences of seeking care were sufficiently significant that they delayed accessing NHS services even when becoming critically unwell. As one respondent living with very severe ME explained:

> *"We delayed seeking medical attention for over a week while I was becoming critically unwell from severe dehydration and malnutrition because the last time we were sent in through A&E and to a ward I was discharged the next day, not listened to, and given treatments that ended up causing further decline. Getting healthcare shouldn't be terrifying, but it is."*

These findings raise a fundamental patient-safety concern: some respondents face an impossible choice between the risks of going without necessary healthcare and the risks of accessing care that has previously made them more unwell.

1 in 2

respondents now avoid seeking NHS healthcare where possible as a result of past experiences



Around 1 in 6

respondents with very severe ME have stopped seeking NHS healthcare completely



7. People are being denied independence and dignity

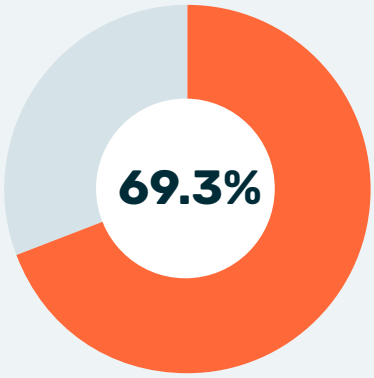
Big Survey findings reveal substantial levels of unmet social care need among people with ME, with consequences for independence, dignity and health. In the absence of adequate formal support, families were often left to fill the gaps.

7.1: Too many people are living with unmet care needs

Among adult respondents with social care needs, more than two-thirds (69.3%) reported that these needs were not being met.

For some, this was because support was too expensive: almost one-quarter of respondents with unmet care needs (23.0%) said they could not afford to pay for the care they needed and that their local council would not provide it. Mirroring the pattern seen in healthcare, previous negative experiences were also a barrier, with more than one-quarter of respondents with unmet care needs (26.6%) saying that an earlier attempt to seek support from their local council had put them off seeking further help.

Unmet needs



Respondents with social care needs say that these needs are not being met

Even where care was available, it was not always delivered in a way that people with ME could safely access. Analysis of free-text responses identified a recurring mismatch between existing models of social care and the needs of people with severe and very severe ME. Respondents described needing practical support while simultaneously struggling with the sensory, cognitive and physical demands of having another person in their home. A lack of understanding of ME could compound these difficulties: more than one in ten respondents with unmet care needs (13.4%) said they could not find a carer or personal assistant who understood the condition.

One respondent captured this tension particularly clearly:

"Care is a double-edged sword for people with ME. It's obviously much needed, but often simply being in the presence and company of other people is draining and can exacerbate symptoms. Communicating needs, explaining everything and answering questions, directing someone, engaging in pleasantries, the noise/movement of them/odours they bring into your vicinity, can all offset the benefits of their help. Care companies lack the type and flexibility of care they can provide, that best suits and meets the needs of ME patients with complex needs."

7.2: Unmet care needs compromise health, nutrition and basic living

The consequences of unmet social care needs extended into the most basic aspects of daily life. More than half of respondents with unmet care needs (52.7%) reported that they struggled to maintain a clean and comfortable living environment as a result, while more than two in five (46.7%) could not maintain their personal care to the standard they wanted. Respondents described being unable to wash regularly or manage essential household tasks, potentially undermining their dignity and compounding social isolation:

> **"I feel ashamed and become even more socially isolated because I am too embarrassed for people to visit me at home."**

Unmet care needs also had direct consequences for respondents' ability to eat enough and maintain a good diet. Half (50.1%) reported difficulties preparing nutritious food, while one in eleven (8.9%) could not eat enough to maintain their weight. Free-text responses described missing meals, relying on convenient but less nutritious food, or being unable to eat until a family member was available to help. For some, simply preparing food consumed so much of their limited energy that they were unable to eat regularly:

"I am unable to have lunch because getting up to get myself breakfast leaves me too exhausted."

Unmet care needs could create a damaging cycle: respondents had to expend their limited energy meeting basic needs, but doing so could worsen their ME and further reduce their ability to care for themselves. More than half (55%) reported that their ME symptoms worsened because they did not have the care they needed.

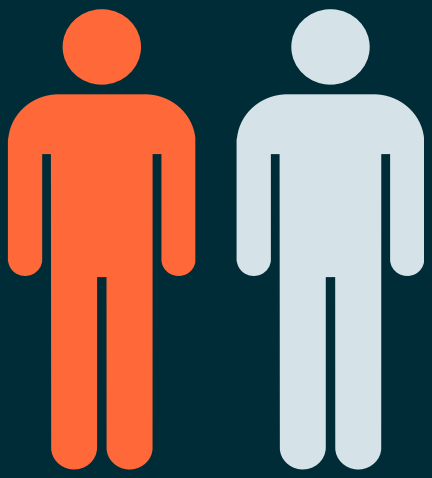
As a result of unmet care needs

1 in 2

are unable to maintain a clean and comfortable living environment

struggle to manage their personal care to the standard they would want

struggle to prepare nutritious food



Where formal care was absent or insufficient, the responsibility for meeting essential care needs often fell to families. Respondents described partners, parents and other relatives stepping in to provide essential care, frequently while working, caring for children or managing health problems of their own. Yet this was not necessarily a sustainable solution. Some respondents depended on ageing parents and faced an uncertain future:

> *"Currently my parents are my carers but they're elderly and can struggle. I'm terrified about what it means for me when they're no longer able to provide the care that I need."*



1 in 11

cannot eat enough to maintain their weight

8. Conclusion: Debilitating illness compounded by institutional failure

The 2026 Big Survey reveals the profound and enduring impacts of ME. The illness significantly restricts independence, education and the ability to work; for those most severely affected, even the most basic activities of daily living can become impossible.

But the findings also indicate that this burden of suffering is not created by illness alone. Respondents described being unable to access specialist healthcare, receiving no ongoing medical support and living with unmet social care needs. Paradoxically, those with the greatest need are often the least well served; as ME becomes more severe, appropriate care becomes harder to access and experiences of healthcare become poorer.

Taken together, these findings point to a wider pattern of institutional failure, with the systems intended to provide care and support repeatedly falling short of the needs of people with ME. This is reflected in a substantial loss of trust: three in four adult respondents (76.4%) reported that their experiences of ME had reduced, or caused them to lose, trust in institutions such as the NHS and Department for Work and Pensions.

Big Survey respondents frequently summarised these experiences in one word: abandoned. This word was not used anywhere in the survey questions but emerged repeatedly and unprompted in written accounts. Alongside descriptions of being “abandoned”, respondents also wrote of being “left to rot” and having “nowhere to turn for help”. Across these accounts was a recurring sense that the societal “safety net” they had previously expected would be there in times of serious illness did not materialise.

The consequences of this abandonment extend far beyond people with ME. Families are left to fill gaps in care, communities lose the contributions of people whose lives are constrained by illness, and the UK economy loses billions of pounds each year through reduced labour-market participation alone.

This abandonment benefits no one, and it is not an inevitable consequence of ME. Instead, it reflects longstanding policy choices, inadequate provision and insufficient investment that have left too many people without the care and support they need and deserve. Addressing these failures requires more than statements of intent: it requires measurable improvements in healthcare, social care, education and wider support, alongside sustained, significant investment in research to improve the understanding, diagnosis and treatment of ME.

3 in 4 respondents have lost trust in institutions including the NHS and DWP



Photo Credit: Reinhard Balzer, German Association for ME/CFS.

9. From evidence to action: Policy recommendations

The Government's Final Delivery Plan on ME is failing to deliver.

The 2026 Big Survey provides a substantial evidence base for action. Despite a comprehensive programme of work, culminating in the Final Delivery Plan on ME/CFS (DHSC, DfE & DWP, 2025), nothing has changed; in fact, children and adults with ME have told us that things have got worse.

The measure of progress must now be whether people with ME experience meaningful change in their everyday lives. Long-term systemic reform remains essential, but people cannot wait for it. **Action is needed immediately to address the systemic failures identified by the 2026 Big Survey.**

Within two years, every person with ME should be able to expect three fundamental improvements: access to an appropriate NHS pathway regardless of where they live; regular review and support for their condition; and services that understand the nature and severity of ME. Underpinning this is the need for sustained investment to accelerate breakthroughs in the scientific knowledge of ME that will lead to diagnostics and treatments. Progress towards these goals should be transparently reported each year so that people with ME, policymakers and healthcare leaders can hold systems accountable for delivery.

These recommendations apply to the UK Government and those of Wales, Scotland and Northern Ireland where responsibilities are devolved. The terminology used in the recommendations should be adapted, where appropriate, to reflect devolved responsibilities. We will produce separate reports, in due course, for the devolved nations.

1. End the postcode lottery in ME healthcare

1.1 Improve coding of ME, data collection and accountability

Three-quarters (76.4%) of adult respondents reported reduced or lost trust in institutions

such as the NHS and Department for Work and Pensions.

Rebuilding that trust requires greater transparency about whether services are meeting people's needs. Without reliable data on diagnoses, illness severity, access to services and outcomes, it is difficult to identify inequalities or measure the impact of policy changes.

Two-year deliverables

By March 2027:

- National guidance issued on consistent recording of ME diagnoses and severity.
- ME included within NHS population health datasets and dashboards.

By March 2028:

- Publication of the first annual ME Statistics Report covering: incidence, service provision, waiting times, annual reviews, demographic inequalities, severe and very severe ME prevalence.
- Every Integrated Care Board (ICB) publishes an annual statement on ME services and progress.

Success measure: Reliable national data available for the first time to inform service planning, commissioning and accountability. Baseline data has already been obtained and can be used to measure success.

1.2 Establish nationally consistent minimum standards for specialist ME services

Two in five adult respondents (40.7%) reported having no NHS specialist ME service in their area, rising to 85.2% in Northern Ireland. Even where services exist, many people with severe and very severe ME are too unwell to attend them.

NICE (2021) already recommends a coordinated, multidisciplinary approach to ME care, while the Government's Final Delivery Plan on ME/CFS committed to developing a template service specification for mild and moderate ME and exploring a specialised service for people with very severe ME (DHSC, DfE & DWP, 2025). Government and NHS bodies must now ensure these commitments translate into accessible, consistent specialist care across the country, including home-based provision for people with severe and very severe ME, with clear responsibilities for addressing gaps in provision.

Two-year deliverables

By March 2027:

- Publish and implement the template service specification for mild, moderate and severe ME in England, with equivalent frameworks across the devolved nations. The Delivery Plan committed to publication by December 2025; an October 2026 update

- indicates the specification has been developed but not published. Publication must now be accompanied by a clear implementation plan, with responsibility for delivery and monitoring clearly defined.
- Progress the development of a nationally commissioned specialist service for very severe ME, including convening the clinical committee before April 2027.
- Map all existing ME specialist services and publish a national gap analysis.
- Appoint a national ME Clinical Lead to oversee improvements in healthcare and implementation of the Final Delivery Plan.

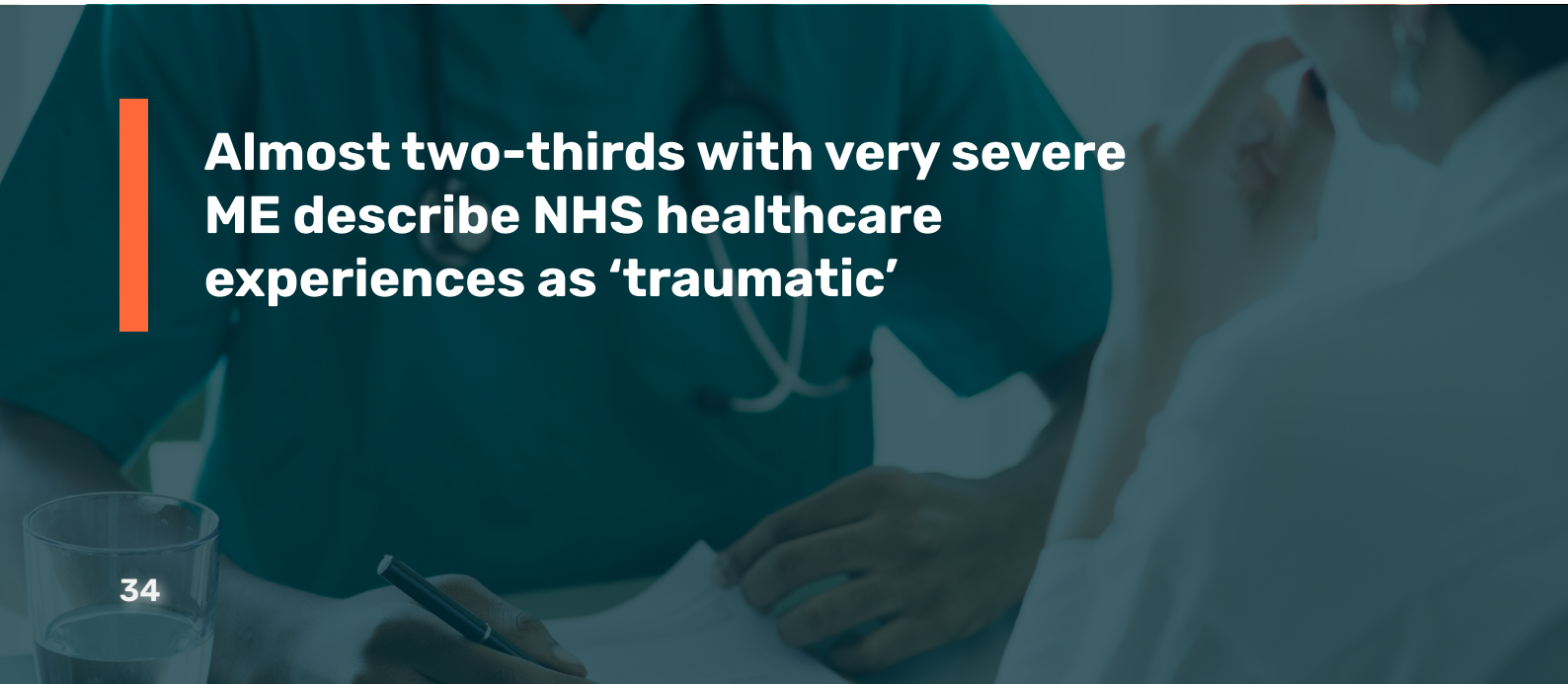
By March 2028:

- Every ICB identifies a named ME clinical lead.
- 100% of ICBs have a commissioned referral pathway for ME.
- All specialist services offer remote consultations.
- All specialist services have a mechanism for home-based assessment and support for people with severe and very severe ME.
- Annual publication of ME waiting times and service coverage.

Success measure: No area of England lacks access to a specialist ME pathway for all levels of severity.

2. Improve understanding of ME across the NHS, social care and education sectors through mandatory, role-appropriate ME training

Four in five adult respondents (80.3%) did not feel supported by the NHS, while almost two-thirds (64.5%) of those with very severe ME described an NHS healthcare experience as “traumatic” or “traumatising”.



Almost two-thirds with very severe ME describe NHS healthcare experiences as ‘traumatic’

Although the Final Delivery Plan on ME/CFS (DHSC, DfE & DWP, 2025) includes commitments to improve professional education and promote NHS e-learning resources, the availability of training does not guarantee that healthcare professionals complete it or apply it in practice.

Two-year deliverables

By March 2027:

- Widescale promotion of NHS England e-learning 'An Introduction to ME/CFS' and 'Supporting People with Severe ME/CFS' to healthcare professionals, special educational needs and disability co-ordinators, adult and children's social workers.

By March 2028:

- The two e-learning modules become mandatory for healthcare professionals, special educational needs and disability co-ordinators, adult and children's social workers.
- 20,000 full completion of e-learning modules (up from current figure of 650).

Success measure: Year-on-year improvement in uptake of e-learning modules.

3. Deliver regular reviews and personalised care plans, as outlined in the NICE guideline

NICE recommends that adults with ME receive a review of their care and support plan at least annually, and children and young people at least every six months. Yet six in seven adult respondents (85.1%) reported receiving no ongoing support or follow-up for their ME from either their GP or a specialist team.

Two-year deliverables

By March 2027:

- Develop a standardised ME review template for primary care.
- Provide guidance of how to record reviews.
- Introduce a personalised care plan template aligned with NICE guidance.

By March 2028:

- 75% of patients on GP ME registers offered an annual review.
- 75% of people with ME have a documented care plan.
- Clear escalation pathways available for deterioration and crisis situations.

Success measure: Annual increase in people receiving regular reviews and care plans in line with NICE guidance.

4. Ensure social care reform meets the needs of people with ME

More than two-thirds (69.3%) of adults with social care needs reported that these needs were unmet. Among those with unmet needs, 55% said their ME symptoms had worsened as a result, while half struggled to prepare nutritious food.

The Burnham Government's proposals for a National Care Service present an opportunity to address these failures. While the initial commitment to free personal care focuses on older people (DHSC, 2026), reform must also consider working-age disabled people whose independence and health depend on appropriate care. This should include access to timely assessments, flexible home-based support, greater understanding of severe ME among care professionals, and recognition of the growing burden placed on unpaid family carers.

Two-year deliverables

By March 2027:

- National guidance issued to local authorities on assessing people with ME, including fluctuating symptoms and post-exertional malaise.
- ME incorporated into social worker training resources.

By March 2028:

- Every local authority has access to at least one practitioner with specialist knowledge of ME.
- Assessment processes include home-based and remote options.
- Local authorities publish data on waiting times for care assessments involving long-term neurological conditions including ME.

Success measure: Reduction in reported unmet care needs among people with ME.

5. Deliver flexible and personalised education for children and young people with ME

More than one-quarter (28.6%) of children and young people surveyed were too ill to access any education – a proportion that has remained largely unchanged since the 2019 Big Survey.



Local authorities in England already have duties to arrange suitable education for children unable to attend school because of illness (DfE, 2023). However, the findings point to a significant gap between these responsibilities and the experiences of children with ME.

Improving provision would support the Government's wider focus on preventing young people from becoming disconnected from education, training and employment. This must be achieved through education adapted to children's health and capabilities, rather than pressure to attend school when doing so could worsen their condition. The Government's proposed SEND reforms provide an opportunity to strengthen delivery (DfE, 2026a). The Department for Education should ensure that Individual Support Plans recognise the specific needs of children with ME, including flexible timetables, home-based or remote learning where appropriate, and access to specialist advice through the proposed Experts at Hand programme (DfE, 2026b). These arrangements must complement existing duties under Section 19 of the Education Act 1996, ensuring that children unable to attend school because of illness can access suitable education regardless of whether they have an Education, Health and Care Plan.

Two-year deliverables

By September 2027:

- Department for Education publishes ME-specific guidance for schools and local authorities.
- National attendance guidance updated to explicitly reference ME and other fluctuating conditions.

By September 2028:

- Every local authority has a named lead responsible for supporting pupils with long-term health conditions.
- All children with ME absent for more than 15 school days receive an assessment for alternative provision.
- Schools have access to model individual support plans for pupils with ME.

Success measure: Reduction in the number of children with ME missing education without suitable alternative provision.

6. Make sustained, coordinated investment in ME research a national priority

More than half (53.5%) of adult respondents had been ill for at least ten years. With no curative treatment currently available, the long-term impacts of ME on health, independence and employment remain difficult to address.

Recent scientific developments, including DecodeME, provide an important foundation for further progress. The challenge is now to bring existing research assets – from patient cohorts and datasets to biomarkers, therapeutic candidates and clinical trial capability – together within a coordinated translational programme. Current funding mechanisms tend to support individual stages of this pathway rather than connecting them around a shared mission. Without sustained funding and coordination, promising discoveries risk failing to progress into diagnostics and treatments that improve the lives of people with ME.

This is also an opportunity for the Government to translate its wider ambitions for research and innovation into action. Dedicated investment in ME would strengthen UK research capacity while creating a model for accelerating progress in other complex chronic illnesses that contribute substantially to NHS demand, economic inactivity and declining population health. The benefits could therefore extend beyond ME, demonstrating how coordinated investment can translate scientific discovery into better health while advancing the Government's ambitions for regional research investment, commercialisation and economic growth set out in the NHS Ten Year Health Plan (DHSC, 2025) and Life Sciences Sector Plan (DBT, 2025).

Two-year deliverables

By March 2027:

- Government and research funders publish a UK ME Biomedical Research Roadmap which directly responds to the 10+ Priorities identified through the Priority Setting

- Partnership and builds on the investment in the PRIME Strategic Partnership, DecodeME and Sequence ME & Long Covid (Action for ME, 2025).

By March 2028:

- Commit at least £25 million in dedicated biomedical ME research funding a year for 5 years.

Success measures: Increase in funded biomedical projects, researchers entering the field and active clinical studies, including studies accessible to people with severe and very severe ME.

Sustained, coordinated investment in ME research is a national priority



Photo Credit: Lea Aring, German Association for ME/CFS.

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