

## **Cystic Fibrosis Trust**

### **Support in crisis: the unseen costs of cystic fibrosis**

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## **Introduction**

People living with cystic fibrosis (CF) are facing further significant financial challenges due to the ongoing cost of living crisis. In addition to the typical expenses related to their condition such as, medical equipment, heating, and special dietary needs, the burden has intensified. This report presents new analysis drawn from a multitude of sources. This includes testimony from people with CF, academic research from the University of Bristol and our own surveys of the CF community. It reveals the pressing challenges confronting those with CF and their families and the urgent need for innovative, systemic solutions.

Our 'Your life and CF' 2023 survey<sup>1</sup> revealed:

**Financial struggles:** A staggering 72% of people with CF or caring for a child with CF report feeling financially disadvantaged compared to their peers

**Difficult choices:** 1 in 3 respondents had to make tough decisions, having to choose between everyday essentials in the past year

**Missed hospital appointments:** Shockingly, 1 in 5 people missed a crucial hospital appointment in the last year due to financial constraints, a rate significantly higher than the national average

**Widespread concern:** 9 in 10 people with CF are deeply worried about their financial future

Through our support services, we've heard firsthand accounts from those who are increasingly struggling to manage on their own - directly grappling with the increased cost of living, housing insecurity, and inadequate sporadic access to essential care. Rita and Asra's story below is a poignant example of a family who, after being let down by government and local council support systems, relied on the Trust for support. Whilst Rita and Asra's names have been changed to protect their anonymity, tragically their experiences are far from unique.

*Rita first contacted our Helpline for support when her daughter, Asra, who has CF, was three years old. Rita said: "I lived in a house with 15 other people and there were sewage, flies, maggots, fleas, and dead rats constantly in our living environment. Asra developed a skin condition due to the excess humidity and dampness in the room and a very dry cough... she was also always vomiting from tummy bugs she would pick up."*

*The Trust provided a package of support including an emergency grant, help in applying to be rehoused, and emotional support. Rita was unable to access a social worker through Asra's CF team, which prevented her from getting the help they needed. Later Rita told us she had suffered a mental health crisis and that she had been thinking of taking her own life - "When the landlord found out I was pregnant, he served me with a notice... he kept turning off the heating and hot water despite knowing I have a child with CF."*

*Cystic Fibrosis Trust intervened further when the council offered them alternative accommodation which was dirty and unsuitable. Rita was finally given a flat which was clean and suitable almost a year after she first contacted Cystic Fibrosis Trust.*

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<sup>1</sup> Your life and CF 2023. Available at: <https://www.cysticfibrosis.org.uk/sites/default/files/2023-06/Your%20Life%20and%20CF%20Report%202023.pdf>

This distressing reality unfolds daily among people with CF who turn to us for support. In the past year alone, our Helpline has experienced an unprecedented surge in inquiries, with a majority centring around financial distress. Additionally, we've observed a surge in more intricate challenges such as, family breakdowns, instances of domestic abuse, and concerns for the well-being of children, all exacerbated by the ongoing financial strain on households. Housing, too, has emerged as an obstacle for some with heartbreaking accounts of people with CF enduring living conditions marred by dampness, mould, and vermin infestations. Addressing these complex issues demands time, effort, and resources — no small feat for anyone, let alone those simultaneously grappling with the pressing concern of putting food on the table.

**Despite people with CF facing challenges like those in Rita and Asra's story, recent analysis by Cystic Fibrosis Trust shows that not all people with CF can access necessary support services like social workers and psychologists when they need them.**

Research from the University of Bristol<sup>2</sup> unequivocally demonstrates that living with cystic fibrosis comes with a heavy financial toll – with the financial cost of living with CF hitting nearly £7000 a year. The relentless surge in the cost of living in recent years has pushed many people with CF to the brink, making it increasingly difficult for them to cover the essentials required for their well-being. For those with limited incomes, this struggle has escalated to a point where daily existence is precarious. Going without heating, proper nutrition, and even basic toiletries can inflict profound and enduring physical and mental damage to their health. Regrettably, previous government interventions have fallen short of adequately safeguarding the health of those who are most vulnerable in the face of this cost-of-living crisis. The social security system continues to prove inadequate in meeting the unique needs of those with complex, fluctuating and life-long conditions like cystic fibrosis. We are now confronted with the very real prospect that health inequalities within the CF community will widen as adults and children from low-income households may find themselves unable to afford the most fundamental necessities crucial for maintaining their health.

**It is imperative that the government addresses our concerns and takes action to alleviate the everyday challenges faced by people with CF.**

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<sup>2</sup> Evans, J., Davies, S. and Cross, K. (2023). *The impact that CF can have on individual and family finances The Financial Costs of Cystic Fibrosis*. [online] Available at: <https://www.cysticfibrosis.org.uk/sites/default/files/2023-01/CFT%20final%20report.pdf>

## **The Road ahead: The government action needed to support the CF community**

**Equal access for all – a CF specialist when needed:** Everyone with CF should be able to access to a CF social worker and CF clinical psychologist when needed, extending beyond the confines of annual reviews. Our staffing report<sup>3</sup> brings to light a stark reality: only 33% of responding adult centres and 32% of responding paediatric centres had a CF social worker on their MDT. 28%<sup>4</sup> of children with cystic fibrosis or their families reported being unable to access a social worker.

**Fixing the gap - training and keeping CF specialists:** The government must swiftly implement a workforce strategy to tackle the recruitment and retention issues plaguing specialist CF teams. Consultations with CF psychologists and social workers have revealed a clear absence of a targeted strategy to attract professionals to specialised healthcare settings. This gap is especially pronounced for social workers, who lack a clear recruitment, training, and management structure tailored for specialised healthcare settings.

**Empower health - enhanced social prescribing for CF:** The government should introduce an enhanced social prescribing system — a vital component of Universal Personalised Care. Social prescribing fosters connections between individuals and activities, groups, and services in their community to address the practical, social, and emotional needs influencing their health and well-being. Cystic Fibrosis Trust proposes an innovative form of enhanced social prescribing that targets the root causes of challenges faced by individuals with long-term conditions. This would empower doctors to prescribe support beyond medical or physical care. For example financial support for energy bills, essential domestic appliances to ensure people can live in warm and healthy homes, or transport and exercise options that promote healthier, more active lifestyles.

**Protecting the vulnerable - a new guarantee on benefits:** The government must take immediate action to safeguard benefit uprating like they have pensions. Currently, benefits increase every April based on the previous September's CPI inflation figure. However, this can result in real costs outpacing the rate at which benefits are increased. To protect vulnerable individuals, such as those with CF, a new guarantee on benefit uprating must be implemented that sees more timely and accurate increases to the vital support people receive. Similar mechanisms are already in place for state pensions, which have risen by 14% in real terms since 2010, in stark contrast to working-age benefits, which have fallen by 9% during the same period.<sup>5</sup>

**Free prescriptions for all - ending the cost burden of CF meds:** No one should bear the financial burden of prescription charges for life-changing medicines that can help them live healthier and longer lives. Everyone with CF should be granted free prescriptions, regardless of where they live in the UK. The government must revisit the prescription charge exemption list for those residing in England, recognising the substantial financial challenges faced by people living with long-term conditions like CF.

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<sup>3</sup> Witt, J., Lewis, S. and Clarke, S. (2022). *UK Cystic Fibrosis Service Resourcing 2020 to 2022 Based on findings from the annual Cystic Fibrosis Trust staffing tool*. [online] Available at:

[https://www.cysticfibrosis.org.uk/sites/default/files/2023-03/CF\\_Staffing\\_Report\\_UK\\_2023\\_FINAL.pdf](https://www.cysticfibrosis.org.uk/sites/default/files/2023-03/CF_Staffing_Report_UK_2023_FINAL.pdf)

<sup>4</sup> Witt, J. and Lewis, S. (2023). *UK Patient Reported Experience Measures survey (PREMs), Paediatric Report 2023*

<sup>5</sup> McRae, I. (2023). *State pension rise due to triple lock will be 'wholly unfair' on benefits claimants*. [online] The Big Issue. Available at: <https://www.bigissue.com/news/social-justice/state-pension-rise-triple-lock-unfair-benefits-analysis/>

## **The impact of the cost-of-living crisis**

The crippling cost of living crisis which has gripped the UK over the past two years, has inflicted profound hardships across the country. It's important to underscore that those individuals living with disabilities, such as those with cystic fibrosis, have borne an especially heavy burden. CF comes with unavoidable costs that accumulate throughout the year and despite the ability to claim health-related benefits, many people with long-term conditions find themselves shouldering additional expenses and, in some cases, plunging into poverty.

Research conducted by the University of Bristol reveals a stark reality.<sup>6</sup> Parents of children with CF face additional monthly costs of £362 and a reduction in income amounting to £609 per month. These immutable costs place an enormous strain on families, translating to an average annual financial hit of nearly £7000 — an insurmountable sum for many. Predictably, families affected by CF are more likely to grapple with financial difficulties compared to the general UK population. 24% of adults with CF and a staggering 35% of parents caring for children with CF describe meeting their monthly bills as a 'constant struggle' in contrast to 17% of households across the UK.

Research underscores the extraordinary efforts people with CF invest in maintaining their health. However, the relentless rise in the cost of living and many people's income failing to keep pace makes this increasingly challenging. More substantial support is urgently required.

## **Bridging gaps in our communities**

Cystic Fibrosis Trust plays a pivotal role in bridging critical gaps in care.<sup>7</sup> We offer guidance, grants, and various forms of support to those let down by the lack of available provisions. Our grant programme encompasses a wide range of essential support, from refrigeration units to store temperature-sensitive medications, to washing machines that enable frequent laundering due to salt-induced sweat, to gym memberships promoting exercise that significantly enhances CF health.

Over the past two years, our Helpline has witnessed an unprecedented surge. The primary concern cited is the financial struggle faced by people with CF, coupled with a growing number grappling with housing issues like mould and damp. Both of which pose serious health risks to those with the condition.

In this report, we can confirm that Cystic Fibrosis Trust emergency grants saw an 11% increase in recipients in 2022/23. Shockingly, when surveyed, 81% of grant recipients admitted to consuming smaller meals or skipping them altogether due to financial constraints, and 8% even endured entire days without sustenance. Despite our efforts to fill these voids, Cystic Fibrosis Trust faces unprecedented demands on our services. A staggering 85% of those who accessed emergency grants confessed that without this assistance, they would have struggled to purchase sufficient food this winter, and a startling 91% admitted to facing challenges in adequately heating their homes.

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<sup>6</sup> Evans, J., Davies, S. and Cross, K. (2023). *The impact that CF can have on individual and family finances The Financial Costs of Cystic Fibrosis*. [online] Available at: <https://www.cysticfibrosis.org.uk/sites/default/files/2023-01/CFT%20final%20report.pdf>

<sup>7</sup> Cystic Fibrosis Trust Grants (2023) Grants. [online] Available at: <https://www.cysticfibrosis.org.uk/the-work-we-do/support-available/financial-support/grants>

Our 'Your life and CF' 2023 survey<sup>8</sup>, which garnered participation from roughly 10% of the CF population exposed distressing realities:

- 72% felt financially disadvantaged compared to their peers due to their own, or their child's CF
- 1 in 3 respondents had to make difficult choices, prioritising one essential over another in the past year
- 1 in 5 missed vital hospital appointments in the last year due to financial constraints — a rate substantially higher than the national average
- a staggering 9 out of 10 harbour deep concerns about their future.

Cold and damp housing elevates the risk of falling ill, particularly during the winter season. Many people with CF now face harrowing dilemmas, with the 2023 'Your life and CF' survey showing 30% of respondents admitting to choosing between fundamental needs, such as heating their homes and putting food on the table. It is imperative for people with cystic fibrosis to remain warm for their lung health and maintain high-calorie diets to support their weight due to poor digestive function. Rising fuel bills have a particularly devastating impact on those with long-term health conditions like cystic fibrosis, as they require a warm home to stay well.

**Emergency measures over the past two years have failed to provide adequate support to people with CF. Fuel bills have soared across the board, and despite recent indications that energy markets are stabilising<sup>9</sup>, these bills remain higher than they were two years ago.<sup>10</sup> The immediate and targeted intervention we call for in this report is essential to alleviate the mounting financial hardships faced by people with cystic fibrosis.**

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### **The lifesaving role of CF specialists**

To maintain physical and mental well-being, people with CF rely on a dedicated team of multidisciplinary specialists. As outlined in NHS England's guidance on CF care for both adults and children, CF centres are required to include a multidisciplinary team (MDT) comprising specialists well-versed in the complexities of CF, including social workers and psychologists.

CF social workers possess comprehensive knowledge of all significant welfare and benefit changes. They understand and apply current legislation to support patients effectively. They have a profound understanding of chronic illness and its day-to-day and long-term impact on people with CF and their families. Social workers also play a pivotal role in facilitating patient access to social and housing services and serve as advocates, ensuring suitable support arrangements are in place on behalf of their patients.

However, as highlighted in Rita and Arsa's story, regrettably not everybody with CF can access the specialised social support they need when they need it. The Trust's recent Paediatric

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<sup>8</sup> Earlam, K and Kind, B (2023) Your life and CF 2023. Available at: <https://www.cysticfibrosis.org.uk/sites/default/files/2023-06/Your%20Life%20and%20CF%20Report%202023.pdf>

<sup>9</sup> Ofgem. (2023). Energy prices to fall again this winter. [online] Available at: <https://www.ofgem.gov.uk/publications/energy-prices-fall-again-winter>

<sup>10</sup> Energy bills drop slightly for winter but will remain high. (2023). BBC News. [online] 24 Aug. Available at: <https://www.bbc.co.uk/news/business-66607005>

Patient-Reported Experience Measures survey (PREMs)<sup>11</sup>, which records the experiences of paediatric CF patients, uncovered a concerning statistic: 28% of respondents had been unable to see a CF social worker when they needed one in the past year.

Survey responses have indicated that limited access to CF clinical psychologists and social workers can lead to anxiety and exacerbate mental health issues. It can also raise concerns that families may be missing out on vital benefits and support. One respondent expressed, "I believe we may have missed out on support and benefits, due to not having access to a CF social worker."

The Trust's staffing data reveal that not all CF centres have a specialist social worker or psychologist. In its March 2023 staffing report<sup>12</sup>, the Trust assessed CF centre staffing levels in October 2022. Worryingly, the report found that only 1 in 3 participating CF centres reported having a CF social worker as part of their MDT, a decrease from around 1 in 2 in the previous year's report.

**We urge the government to ensure that people with CF can access specialised psychosocial support through their CF centre and to address recruitment and retention challenges facing specialist service MDTs. The welfare of the CF community demands nothing less.**

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<sup>11</sup> Witt, J. and Lewis, S. (2023). UK Patient Reported Experience Measures survey (PREMs), Paediatric Report 2023 [https://www.cysticfibrosis.org.uk/sites/default/files/2023-09/PREMs\\_Paediatric\\_Report\\_2023.pdf](https://www.cysticfibrosis.org.uk/sites/default/files/2023-09/PREMs_Paediatric_Report_2023.pdf)

<sup>12</sup> Witt, J., Lewis, S & Clarke, S. (2023). UK Cystic Fibrosis Service Resourcing 2020 to 2022 [https://www.cysticfibrosis.org.uk/sites/default/files/2023-03/CF\\_Staffing\\_Report\\_UK\\_2023\\_FINAL.pdf](https://www.cysticfibrosis.org.uk/sites/default/files/2023-03/CF_Staffing_Report_UK_2023_FINAL.pdf)