



# Your life and CF 2023

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**Uniting for a life** *unlimited*

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## Contents

Executive summary	3
Background to our research	4
Key findings	5
Our asks	7
The detail	9
Reform PIP	11
What is the monetary cost of CF?	12
Mental health and wellbeing	13
Cystic Fibrosis Trust intervention	14
Full findings and demographics	16
Summary	20
We're here to help	21

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### Acknowledgements

We would like to thank the CF community who took the time to share their story with us; without you this report would not have been possible. Thanks to you, we're able to use our findings to continue to lobby the Government and campaign for long lasting and meaningful change. A huge thank you to the CF community for your ongoing continued support, and to anyone who has generously donated to Cystic Fibrosis Trust.

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# Executive summary

In spring 2023, the Trust launched a UK-wide survey to gather crucial data and first-hand accounts on life with cystic fibrosis (CF), focusing on the additional financial burdens associated with the condition.

Our 2022 Cost of CF report exposed the devastating consequences of the national cost of living crisis that was just beginning. Fast forward a year, and the UK has witnessed record-breaking inflation and skyrocketing costs of food and other essential items. While energy bills are now stabilising (in part due to additional government support provided following campaigning by many organisations, including Cystic Fibrosis Trust), they are still significantly higher than before the cost of living crisis. This leaves many facing an impossible choice between heating their homes and putting food on the table – all while managing a life-limiting genetic condition without a cure.

Living with CF comes with significant and never-ending costs. Recent research from the University of Bristol, supported by Cystic Fibrosis Trust, showed that the average family incurs over £6,500 in combined additional costs and lost income as a result of the condition. For many people living with CF and their families, the cost of living crisis has had a profound and devastating impact.

Our new report reveals 9 out of 10 individuals affected by CF worry about the cost of living, with 1 in 3 resorting to borrowing money for basic essentials. 7% have sought help from food banks, over twice the general population figure. In the past year, we've seen more people turning to us for assistance in bridging financial gaps caused by circumstances beyond their control. And we're seeing more complex issues, including family breakdown, domestic abuse, and concerns for the welfare of children, as the financial strain on households has continued to bite. Housing has been a challenge for some, and we've heard shocking stories of people with CF living with damp, mould and vermin problems.

There are solutions to the significant challenges faced by those with long-term conditions like CF – from changes to the benefits system to implementing a social security tariff. It is shocking that despite years of campaigning, many people with CF still must bear the cost of prescription charges for life-sustaining treatments. Governments across the UK must act swiftly to ensure that the health of people with CF is not put further at risk.

I would like to thank the CF community for their ongoing support and especially for taking the time to respond to the survey. We couldn't do what we do without you.

We also want your feedback on the work we do, including this report. Please get in touch with us on social media or by emailing [publicaffairsinbox@cysticfibrosis.org.uk](mailto:publicaffairsinbox@cysticfibrosis.org.uk) to let us know your comments and questions.

## David Ramsden

Chief Executive of Cystic Fibrosis Trust



# Background to our research

There are over 10,900 living with cystic fibrosis in the UK. In order to stay well, people with cystic fibrosis face a significant treatment burden: take up to 70 tablets every day, follow a special high-calorie diet, daily exercise and respiratory physiotherapy, and monthly health checks at their local CF centre. This is alongside any hospital admissions due to health deterioration. Failure to maintain this daily routine can lead to serious health declines. Keeping up this routine heavily relies on having sufficient income to meet the accompanying costs.

Between March and April 2023, Cystic Fibrosis Trust ran our annual 'Your life and CF' survey, asking our community about their life with CF and the additional cost of living with a lifelong condition. The cost of living crisis is in its second year, and although inflation is showing signs of slowing, a year of inflation at record levels has eroded the purchasing power of everyone in the UK. This has been particularly felt by people with long-term conditions like the CF community, who have additional immutable costs. Our community are facing financial worries like never before. Our follow-up report shows that people with CF and their families continue to experience the same worries, with 87% still worried about the cost of living.

Members of our community took the opportunity to share their experiences and their personal stories with us, and we would like to thank all who participated for their time and energy into supporting our work.

Please note that the contents of this report could be distressing for some readers.

We offer practical support and information for people living with CF and their families through our free Helpline. You can contact us on **helpline@cysticfibrosis.org.uk** or **0300 373 1000**. More detail can be found at the end of this report.



Over **10,900** people  
living with cystic fibrosis  
in the UK

## Key findings

72%

felt they have less money compared to those around them, due to either their own or their child's CF.



85%

had been stressed, anxious or worried about money, with 1 in 3 worrying about money every day.



1 in 3

respondents had to prioritise one essential over another in the last 12 months.



1 in 5

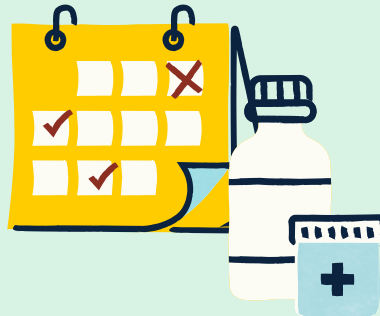
people missed a hospital appointment due to the cost in the last 12 months.

(Nationally, roughly 1 in 15 hospital appointments are missed.)



# 77%

of respondents felt their CF or caring responsibilities have an impact on their employment opportunities.



# 1 in 5

ran out of food before they had money to buy more in the last 12 months.



# 1 in 3

borrowed money for basic essentials, such as food, clothing, heating, and internet.



# 9 out of 10

respondents were worried about their future, with 1 in 3 worrying about it every day.



# Our asks

The rising and sustained cost of living in addition to the financial burden of living with a lifelong condition is a constant worry for the majority (87%) of people living with cystic fibrosis. The compounding factors of surging inflation, rising interest rates and rising taxes affect everyone across the UK, but present an enhanced challenge for people with CF to maintain physical health and mental wellbeing.

In April 2022 the then-Chancellor announced a suite of support measures designed to lessen the impact of the rising cost of living. The Trust responded to these measures, outlining they were short-term and lacked immediacy in their implementation with some not being implemented until January 2023. In re-running this survey in 2023, we are able to see that many in our community are still worried about the cost of living, and even more feel like they have less money than those around them.

Once again, the winter months presented further challenges for people with cystic fibrosis. We will continue to call on the Government to monitor the situation and implement the additional measures that are needed after last year's emergency measures failed to adequately support our community.

The April budget brought with it the Health and Disability white paper. This long-awaited Government follow up to the 2021 green paper scrapped the Work Capability Assessment (which historically had given people with CF a fair award), forcing people with CF into the Personal Independence Payment (PIP) pipeline, which often doesn't deliver the right award the first time, pushing people into appeals and arbitration to get what they are entitled to in arrears.

The Chancellor also announced that for a full year, the fuel duty rate will not change. The temporary 5p reduction from last year will remain in effect, and duty will not rise in line with inflation. This offers some protection for people with CF who often have to rely on their own vehicle or their family and friends for lifts to essential hospital appointments.

Below are a suite of policy asks that, if implemented, would create lasting and meaningful change for the CF community.

■ **No one should pay for medicines**

Everyone with CF should have access to free prescriptions regardless of where they live in the UK. The UK Government must review the prescription charge exemption list for those in England and acknowledge the financial challenges faced by people with long-term conditions like CF.

■ **Fair benefits system**

The PIP system repeatedly fails people with CF. There are too few occasions where the right PIP assessment decision is made the first time. Assessments are often conducted by people with little to no experience with CF.

■ **Affordable travel**

Those with a lifelong medical condition need access to free hospital parking. Implementing a hospital travel card system for people with CF would provide subsidised access to green (through the use of electric vehicles), clean, and quick direct access to hospitals on an ad-hoc basis.

■ **Affordable energy**

Those in greatest need, including those with CF, need warm homes to stay healthy. By introducing a social tariff for gas and electricity it would ensure our community don't have to rely on future governments for temporary cost of living support.

■ **Support at work**

SSP represents a safety net for those with long-term conditions. However, it is in dire need of reform. In its current state, it risks plunging those who rely on it into debt and poverty.



# The detail

## Prescription charges

CF is one of the few life-threatening, chronic conditions where people are still required to pay for prescriptions, incurring a lifelong financial burden. Under the current system, many people with CF will continue to incur an ongoing cost for their daily treatments through prescription charges, or will have to pay the £111.60 for a yearly prescription prepayment certificate (PPC).

When the exemption list was produced in 1968, children with CF weren't expected to live to be adults – so CF wasn't included. There are now more adults than children living with the condition. The list is outdated and unfair, with a recent survey by the Trust showing that 95% agreed that prescriptions should be free for people with CF. It is vital that everyone with CF should have access to free prescriptions regardless of where they live in the UK. The Government should review the prescription charge exemption list and include everyone with cystic fibrosis, acknowledging the financial challenges faced by people with long-term conditions like CF.

## Access to free hospital parking and a hospital travel card

CF can require constant and consistent medical interventions. Access to the specialist CF multidisciplinary team (MDT) is essential to staying well. Our survey showed that 1 in 5 people with CF said they had missed a hospital appointment due to the associated costs of attending, in the last 12 months. This figure has risen to 1 in 3 over a lifetime. Our calls around transport and hospital access are twofold. Firstly, those with a chronic medical condition should have access to free hospital parking. Secondly, we are asking for a hospital travel card system to be implemented for people with CF. This card would provide subsidised access to green (through the use of electric vehicles), sanitary, and quick access to hospitals on an ad-hoc basis.

## Statutory Sick Pay (SSP)

23% of respondents with CF in employment said they have had to rely on SSP while sick at some point. Cystic Fibrosis Trust believes that SSP is in need of reform. We recommend two key changes in order to make SSP fit for purpose. Firstly, the Government must address the woeful level of SSP, which currently stands at £109.40 per week. This is simply not enough to cover the cost of living. With the cost of living increasing by the month, SSP needs to be re-evaluated to be in line with a living wage.

The current 28-week cap on SSP is arbitrary and unnecessary, if an individual can provide a professional sick note there should be no reason to cut off SSP after an amount of time. The Government should offer support to businesses to provide sick pay in the rare cases where this is required beyond 28 weeks.

## Allowances and benefits

Households of people with CF typically have higher energy needs, because of the requirement to keep warm to prevent infection and having to power medical equipment. We are proposing an energy social tariff for those in greatest need, including those with CF. This would mean those with CF don't have to rely on future governments implementing various temporary cost of living measurements. Furthermore, it would be cheaper than the Energy Price Guarantee as it would be targeted. While energy prices are coming down, the July 2023 energy price cap is forecast to be 58% more than its winter 2021/22 level – or in monetary terms, over £700 a year more.

All people with cystic fibrosis should have access to a CF social worker, to help them navigate the complex social security systems and provide employment support. This will ensure our community receive what they are entitled to and can maximise their income to weather the cost of living increases. The rising cost of living on top of the additional financial burdens associated with a long-term progressive condition like CF can lead to anxiety and other mental health conditions. Early intervention from psychologists can help alleviate mental health issues, this is why we are also calling for bespoke funding for access to psychologists and social workers for people with CF.

We call for the Government to make a meaningful increase to the warm home discount allowances, to match the soaring costs of energy bills. Additionally, we call on the Government to reverse eligibility changes to the scheme which mean those who receive non-means-tested benefits such as DLA, PIP, or Attendance Allowance – are no longer eligible. People who are in receipt of disability benefits have faced huge rises in costs.

## Conclusion

From our survey results it is clear that there are multiple areas in which our community need help. Cystic Fibrosis Trust suggests using the existing infrastructure around PIP to make additional awards for those with long-term conditions, these individual payments would be made around the following areas:

- **Food:** It is essential that everyone with CF has access to a high-calorie, nutrient-dense diet. An additional payment on top of current PIP levels would allow those with a long-term condition to ensure they are not worrying about choosing between heating and eating.
- **Energy:** People with CF face higher energy bills as they have to incur additional energy use in order to stay well. This can be due to keeping their homes warm to stave off lung infections, running additional washing machine cycles to wash clothes which need to be washed more frequently, and needing an additional fridge to store sterile medications.
- **Medical devices:** Some people with cystic fibrosis have to run additional medical devices to ensure they stay well. This can include running ventilators and other medical devices, additional white goods, or running computers to allow for virtual appointments.
- **Fuel bills:** Although they are increasing for everyone, this has a particularly devastating effect on those with long-term health conditions like CF. Cold homes can lead to being very unwell. We are calling on the Government to zero-rate energy bills, which means customers will not pay VAT. This measure will offer meaningful reductions to all of our community, at a point where 30% of our respondents said they were currently choosing between essentials like heating their homes and putting food on the table.

"I rely on family generosity, but I could probably scrape by without it."

Person with cystic fibrosis

"I sell my things to make extra money."

Person with cystic fibrosis

"I would like not to have to worry about money, I am forever trying to think of ways to make money whilst juggling my child, part time work, nursery costs, family life, dog... My health ends up as an afterthought. I'd like to be able to have time to myself, to work on my health and wellbeing."

Person with cystic fibrosis

"I've not been able to go on holiday, my child who has CF has never been on holiday. We never get to go on days out due to having a very unreliable car."

Person with cystic fibrosis

# Reform PIP

## Make PIP fairer – right decision first time

Cystic Fibrosis Trust are seeing claimants with CF in despair when they receive their PIP decision. Our aim is that they get the right decision the first time. Some do, but many do not, and the consequences are devastating, particularly to those on a low income. People use their child's DLA or PIP to pay for food to maintain weight, extra water and fuel costs caused by having CF, exercise classes and enrolment in sports clubs, and worryingly, to make ends meet and help with travel to hospital appointments. If you take DLA/PIP away, there are four weeks to adjust to this change. A small grant can help, but very often a family will lose their carer's benefits and additional elements paid in their Universal Credit or Tax Credits. Sometimes, a parent who is a carer will be forced to go to work.

After reaching out to us, our Welfare and Rights Advisor will help with their reconsideration and appeal. Most incorrect PIP decisions are made following a report from an Assessment Provider. Many people with CF are bewildered at the report, and the conclusions formed show little understanding of the preventative nature and burden of treatments, the issues around maintaining a good weight and co-morbidities such as CF diabetes (CFD), and the impact of having a lifelong condition on their mental health. All of the cases we have taken to appeal have resulted in a decision being overturned, sometimes after 10-18 months of waiting. In this time, the lack of finances means that health may have deteriorated. The pressure and stress of fighting an unnecessary appeal is a shadow over their lives. With a life-shortening condition, many do not have this time to spare.

We therefore ask for the Government to:

1. end repeat assessments for those whose health is unlikely to improve
2. reduce reviews by increasing the award length for all those with CF
3. make the claims and review forms and processes claimant-friendly so that they are clear on what sort of evidence they can provide themselves that will help decision-makers
4. commit to fairer decision-making based on gathering evidence from the CF teams
5. ensure that where the assessments are passed to an AP for another form of assessment, this is with someone with appropriate expertise
6. strive to get the decision right the first time, thus reducing the cost to the public for appeals, and the unnecessary stress and reduction in income for many months!
7. pay a reduced rate of DLA/PIP during the appeal, (that will not need to be paid back, if appeal lost)<sup>1</sup>
8. reduce backlogs and waiting times for appeals.

If the current system of Personal Independence Payment decisions were better assessed and made correctly the first time, it would be simpler, more cost-effective, and work better for both the applicant and the Government.

<sup>1</sup> Supported by a parliamentary advisory committee

# What is the monetary cost of CF?

In January 2023, the Trust joined forces with the University of Bristol to release a groundbreaking research paper examining the staggering financial toll of living with cystic fibrosis.

The study uncovered a shocking truth: the average cost of living with CF surpasses £6,500 annually. This figure takes into account the additional expenses incurred and the potential loss of earnings due to unpredictable health conditions.

Through surveys, focus groups, and in-depth interviews, the University of Bristol boldly declared that a typical CF family faces a monthly loss of £564 (£6,768 per year) due to the condition. Shockingly, parents of children with CF reported even higher financial impacts than adults with CF themselves.

Adults with CF typically bear an extra burden of £209 per month in additional costs, while parents of children with CF endure an astounding £291 more per month. These expenses encompass various aspects such as transportation to medical appointments, medical treatments, dietary requirements, and escalated energy bills.

The research also exposed a troubling reality: CF families are more likely to grapple with financial hardship compared to the general UK population. A staggering quarter (24%) of adults with CF and over a third (35%) of parents with CF report constant struggles to meet their monthly bills. This starkly contrasts with the 17% of the overall UK households facing similar challenges.

Furthermore, individuals with CF face disproportionate financial obstacles when it comes to accessing insurance, benefits, coping with prescription charges, and finding suitable accommodation. These issues hit CF patients harder than the general UK population, exacerbating their financial burdens.

The findings of this research underscore the urgent need for action to alleviate the financial strain faced by those living with CF and to address the systemic challenges they encounter.

**"I try and get a job, my daughter gets sick and ends up in hospital for two weeks so I end up getting sacked. Also, it's hard to find a job that earns less than the carer's allowance limit – even at 16 hours you are still overpaid."**

Parent of a child with cystic fibrosis

**"CF entirely changed my and my husband's careers – we lived and worked in Africa and South Asia. We have changed career direction but also compromised on jobs so as to have jobs flexible enough to let us do evening treatments, regular hospital visits etc."**

Person with cystic fibrosis

**"My job earnings aren't enough to cover my bills, loans and living expenses alone so my benefit helps to stop me getting into debt."**

Person with cystic fibrosis

# Mental health and wellbeing

Living with a long-term physical condition doubles the likelihood of experiencing poor mental health compared to those without such conditions.

In August 2020, the introduction of Kaftrio to UK patients marked a groundbreaking improvement in quality of life for many in our community. The expanded license for its use, covering more genotypes and younger age groups, is set to benefit an estimated 90% of people with CF at some point in their lives.

Access to Kaftrio has brought numerous reported benefits to the CF community, including enhanced physical health and wellbeing, significant improvements in lung function, reduced coughing, fewer flare-ups, and a lighter treatment burden due to improved health stability. Kaftrio has truly opened doors for many, providing increased opportunities in education, employment, and starting families.

However, for some, the prospect of a different future can trigger anxiety and worry. Our community continues to express the need for managing CF-related complications and ensuring CF services adapt to support the evolving needs of individuals living with CF.

The rising cost of living has also demonstrably affected the mental health of people with CF. 2023 data shows that individuals with CF rated their average happiness levels as 5.9 out of 10 versus a national rating for the same question of 7.5 out of 10. In 2016, individuals with CF rated their average happiness levels at 7.36 out of 10.

Similarly, when asked to rate their anxiety levels on the same scale, the average response was 4.6, compared to the general population's response of 3.12.

These results highlight that our community experiences lower levels of happiness and higher levels of anxiety compared to the average person in the UK. We acknowledge the historical and emerging challenges that lie ahead. The prospect of a markedly different future can trigger anxiety and worry for some individuals with CF. It is crucial to address CF-related complications and ensure that CF services adapt to provide the necessary support for the evolving needs of our community.

The historic difficulties of CF can leave some with past gaps in education and employment, which have been caused by living with a life-limiting condition. Some parents expressed concern about their children's future: "She missed so much school and qualifications. What kind of job can she do now?".

Despite access to modulators improving health for many, CF remains a challenging condition to live with. We also know that not everyone can benefit from Orkambi, Symkevi and Kaftrio, which is why we continue to invest in cutting-edge CF research for effective treatments for all.

**"I didn't know how to cope with the fact that I had got such a life changing drug... I've got such an opportunity."**

Person with cystic fibrosis

**"I kind of reflected back on life... oh God, if I'd have known that I had this future, then I would have probably chosen to do things a lot differently."**

Person with cystic fibrosis

# Cystic Fibrosis Trust intervention

Our research has shown that life with cystic fibrosis is expensive, and the rising cost of living over recent years has made it harder for everyone with CF to afford the things they need to stay as well as possible. For many people and families affected by CF on low incomes, this is becoming impossible, and they are facing a daily struggle to afford basic essentials. Going without heating, food and basic toiletries can all have a serious, long-lasting impact on CF health. So far, government interventions have not gone far enough to protect the health of those most vulnerable to the cost of living crisis, and the welfare system continues to fail to meet the needs of people with a complex and fluctuating conditions like cystic fibrosis.

We now face a very real danger that health inequalities in cystic fibrosis will widen, and adults and children with CF from low-income households will be unable to afford the very basics needed to support good CF health.

We see this every day in the people who come to us for support. In the past year, we've received more Helpline enquiries than ever before, and many of those have related to financial worries. We've seen more complex issues, including family breakdown, domestic abuse, and concerns for the welfare of children, as the financial strain on households has continued to bite. Housing has been a challenge for some, and we've heard shocking stories of people with CF living with damp, mould and vermin problems. These complicated issues take time, energy and resources to sort out – this is challenging for anyone, but it's even harder if, at the same time, you're trying to work out how you'll afford to put food on the table.

Delia\*, a CF social worker, told the Trust: "I'm getting requests for emergency and cost of living grants nearly every day. People are reporting they are really struggling with cost of food, heating and electrical costs."

This winter we provided an extra 342 grants to help those most affected by rising costs to afford food and basic essentials.

Imogen\* is one year old and has CF. She spent the first 3 months of her life in hospital, and her mum, who is a young single parent on a low income, is still struggling to cope with the impact of this on the family's finances. They missed some rent payments when Imogen was in hospital because of the cost of being with her every day. The family were facing really tough decisions about how to spend their money and Imogen had recently missed a clinic appointment because they couldn't afford to travel to the hospital.

Families like Imogen's are facing impossible decisions and it's important that we share their stories. We asked people who received these grants to tell us about their experiences. Over 100 people responded, and their feedback paints a clear picture of what rising living costs mean for people on low incomes.

Almost everyone told us they'd eaten smaller meals to save money, 10% of people told us they'd been hungry but not eaten, and a shocking 8% of people told us they had gone without food for a whole day because they couldn't afford food.

38% of people said they had gone without basic toiletries or hygiene products, and almost two-thirds told us they had missed clinic appointments because they couldn't afford to go. Overall 78% of people on low incomes said that in the last year, they've struggled to afford the basics they need to stay well with CF.

\*names have been changed

"My baby is only 6 weeks old but I am panicking about returning to work when she is around 1 as other people won't be able to give her the care I can, such as physio and medication."

Parent of a child with cystic fibrosis

"It's hard to find a job that fits your needs when you have cystic fibrosis and other related conditions. Particularly if you've had a bad night with stomach issues and you can't go to work the next day. It's so hard to find a balance of eating the foods I need to stay well which also won't affect my stomach and cause me to lose weight."

Person with cystic fibrosis

"Live without fear. CF is scary enough at times but constantly worrying about being able to afford food and other essentials is horrific."

Person with cystic fibrosis



Sam\*, an adult with CF, explained what this means for him:

"I never thought I'd be this financially fragile in 2023, but here I am. Last week I had pasta and rice as my dinner for three nights until I could borrow money. I find myself losing weight I've spent years putting on."

The benefits system is supposed to be a safety net for those finding it hard to manage. PIP and DLA are there to cover the additional costs of having a disability or long-term health condition. But in many cases, the system is making things worse. The stress of coping with a PIP reassessment, or explaining every detail of the care needs of a child with CF for a DLA claim, can take its toll on physical and mental health, and build on the pressure households are under. Delays in the system, the complexity of Universal Credit, and poor decision-making (72% of PIP applications are won on appeal) leave people affected by cystic fibrosis without the money they need to look after their health. This can push more people into poverty and can have a long-term impact on their CF health.

Jackson\* is five years old, and has CF. He lives with his grandmother in an isolated rural area, in a house that has coal-fired heating. The family had been moved onto Universal Credit and were in the five-week wait for their first payment. Their CF social worker was concerned about the weather turning colder and felt Jackson could be at increased risk of infection if the house was cold, and was worried he would go without adequate food until the Universal Credit payments started. We provided an emergency grant of £150 to ensure there was coal and suitable food in the house, protecting Jackson's health and reducing stress and worry for his grandmother.

David\* contacted the Helpline as rising energy and food costs were causing him a lot of anxiety. He shared that he has an oxygen concentrator he has to use most of the time, and needs a fan on throughout the night. He also has to buy other non-prescription items. He said he's done what he can to reduce his food bill already, without compromising his dietary needs. He lives in a rural area, so has bulk LPG gas for his heating system. His combi boiler is old, so he fears it breaking down. When we worked with David to check his benefits, we found he could potentially claim an additional £283 per month, which he currently wasn't receiving, which would make a significant contribution to his household income.

Everyone with cystic fibrosis deserves the opportunity to have the best possible health. We don't want people to just survive; we want people affected by cystic fibrosis to have every opportunity to live a long and fulfilling life, but it is clear that, particularly for households on low incomes, just being able to afford the basics is becoming an increasing challenge. People with CF are dealing with a benefits system that feels like it is stacked against them, as well as barriers to work and education which affect their ability to build a secure financial future, and increasing challenges in being able to access the very basics – a safe, warm, dry home, enough food to meet their needs, and the ability to get to their vital medical appointments.

We see a very real risk that some people with CF will have their health, and even their life expectancy, irreparably damaged by poverty, and while we can and do step in to provide support, we need policymakers to pay attention to our asks and make real changes to ensure everyone affected by CF has the resources they need to live well.

\*names have been changed

# Full findings and demographics

## Who took the survey

900 respondents took the survey from across all four nations.

- 79% were from England
- 9% from Scotland
- 6% from Wales
- 5% from Northern Ireland
- <1% From other Nations<sup>2</sup>

Of these respondents 411 had cystic fibrosis, and 489 were parents, partners or carers.

- 22% of respondents were male
- 76% of respondents were female
- <1% of respondents were non-binary
- <1% of respondents chose not to say

76% of people with cystic fibrosis and their families who took the survey indicated that they or the person they support had access to CFTR modulators.

## Cost of living worries

A worryingly large number of people affected by CF indicated that they had money concerns, both generally and directly because of their or the persons they care for cystic fibrosis.

87% respondents indicated that they were worried about the cost of living.

7 out of every 10 respondents felt like they had less money than their peers due to cystic fibrosis.

1 in 4 respondents worried about money every single day

Once again, the percentage of people in our community was 87%, worryingly high. Even more concerning was the number of people anxious every single day about the cost of living.

This year the number of respondents who felt like they had less money than their peers increased from 6 in every 10 to 7 in every 10, this 10% increase demonstrates as the cost of living crisis continues it further exacerbates the financial divide between those living with long term conditions and those who do not.

## “We spend more on”

We asked respondents to tell us what they felt like they spent more money on, in comparison to those around them without cystic fibrosis. Alongside the below figures we received 73 written answers which highlighted specific additional costs of living with cystic fibrosis. Some of these responses are highlighted throughout this report.

75% of respondents spent more on food than their peers.

70% of respondents spent more on heating than their peers.

55% of respondents spent more on travel than their peers.

50% of respondents spent more on energy than their peers.

4 out of every 10 respondents spent more on insurance than their peers.

4 out of every 10 respondents spent more on exercise provisions than their peers.

1 in 4 respondents spent more on clothing than their peers.

1 in 5 respondents spent more on private therapies than their peers.

1 in 10 respondents indicated they spent more on home adaptations and financial products than their peers.

<sup>2</sup> Other nations include the IoM, IoW, Jersey Island and ex-pats.



## Income, benefits and employment

We asked questions around work, access to welfare and what income was spent on.

### Benefits

94% of respondents with CF indicated that they were in receipt of disability benefits.<sup>3</sup>

Only 56% of families and carers indicated they were in receipt of benefits.

### How benefits were spent

We asked families and people with CF what they spent their benefits on. Some spread their benefits across multiple outgoings. Respondents were asked to choose from a list of options including food, energy and prescription charges. Disability benefits are designed to meet the cost of disability, but an increasingly worrying number of recipients are spending all of their benefits on the bare essentials to live.

Cystic Fibrosis Trust has seen the financial burden the cost of living crisis has caused first-hand, with the number of emergency grants the charity has awarded rising by 11%, and grants for winter hardship or cost of living rising by 37%. In total, the charity has awarded over £310,000 to help support people with cystic fibrosis, and their families, and the helpline has answered 4,799 enquiries, more than ever before.

### People with CF

- 86% spent part of their benefits on food.
- 79% spent part of their benefits on household bills.
- 74% spent part of their benefits on transport.
- 71% spent part of their benefits on essential household items.
- 52% spent part of their benefits on household maintenance.
- 42% spent part of their benefits on exercise.
- 29% spent part of their benefits on prescription charges.

### Families and carers of people with CF

- 79% spent part of their benefits on food.
- 78% spent part of their benefits on household bills.
- 69% spent part of their benefits on transport.
- 64% spent part of their benefits on essential household items.
- 47% spent part of their benefits on exercise provisions.
- 41% spent part of their benefits on household maintenance.

It is particularly concerning that 29% are using their disability benefits to pay for prescriptions that are essential to live with the condition. It doesn't make sense for benefits to be used to purchase essential, life-saving medicines. It is vital that everyone with CF should have access to free prescriptions.

<sup>3</sup> <https://www.litrg.org.uk/tax-guides/tax-credits-and-benefits/state-benefits>

# Employment

## People with CF

79% of people with CF felt like their condition had an impact on their employment.

79% of parents, carers and spouses felt their caring responsibilities had an effect on their employment.

18% of people with CF had to rely on statutory sick pay (SSP) in the last 12 months.

1 in 2 people with CF did not have a pension, significantly higher than the general population.

Both people with CF and those who care for them are less likely to be employed and less likely to be in full time work when compared to the general population.

In full-time work	37%
In part-time work	26%
Working on a zero-hour contract	3%
Not in employment	12%
In full-time education	5%
In part time education	3%
Homemaker	7%
Voluntary work	3%
Unable to work	21%
Prefer not to say	0%
Other (please specify)	7%

The other responses were made up of people indicating retirement or self employment.

Parents, spouses and carers indicated that they were:

In full-time work	34%
In part-time work	34%
Working on a zero-hour contract	3%
Not in employment	10%
In full-time education	1%
In part time education	3%
Homemaker	14%
Voluntary work	4%
Unable to work	3%
Prefer not to say	3%
Other (please specify)	10%

The other responses were made up of people indicating retirement, self employment or maternity leave.

## Travel and food

### Hospital travel

3 in 4 of respondents travelled to hospital in their own car.

1 in 4 of respondents travelled to hospital on public transport.

1 in 5 of respondents relied on lifts from family.

Note: respondents could select more than one transport option.

In the last 12 months, 1 in 5 people with cystic fibrosis had missed a hospital appointment due to the cost associated with attending. (Nationally, roughly 1 in 15 hospital appointments are missed.)

### Holidays

1 in 2 people with cystic fibrosis and their families/carers had decided not to travel due to the cost of travel insurance.

### Food and other essentials

1 in 3 of respondents indicated that they have had to prioritise one essential over another, such as choosing heating over eating or prescription charges over internet access.

1 in 3 had borrowed money for basic essentials in the last 12 months.

1 in 5 respondents indicated that they had run out of food before they had enough money to buy more in the last 12 months.

7% had accessed food banks. (Within the national population this figure is only 3%.)

## Money and debt

1 in 3 respondents had to borrow money to buy essentials or cover bills.

13% of respondents had required a loan to pay off another bill or loan.

"I would like to be able to live comfortably in a home that isn't a threat to my health, I'd like to find a job and find something fulfilling to do but instead I'm trapped in this poverty circle and I don't have any way of getting out that won't make my financial situation worse for an extended period."

Person with cystic fibrosis

"I haven't been able to go on holiday or go for a meal out in years."

Person with cystic fibrosis

# Summary

This report demonstrates the hard reality in which people with CF find themselves. 9 out of 10 are worried about the cost of living, with 1 in 4 worrying every single day, while 1 in 3 are choosing between essentials like heating and eating. This is having a direct effect on their short and long term health. We now know that if you are living with CF you are twice as likely to have accessed a food bank in the last 12 months and you are more than twice as likely to have missed an essential hospital appointment.

The Government has rightly acted and implemented cost of living measures, but for those living with long-term conditions these are not enough to stop them sinking further into poverty.

We call on the Government to do more to help our community in the here and now, and to implement the policy asks that we have outlined within this report. The Trust is worried that without long-term commitments to lessening the cost of living for those most vulnerable, even more people will fall into poverty and destitution.

The Trust would like to thank all those who took the time to share their experiences with us. Without your time and support this report would not have been possible.

Cystic Fibrosis Trust is planning to re-run this survey in spring 2024, using 2022 and 2023 data as benchmarks, to establish and monitor trends and focus our policy work based on what you tell us.

"We just want to have peace of mind that we can afford things and not panic that the future is uncertain for us. Even being able to spend the night in without using time to sell things online or search for cheaper deals for bills. We are currently selling our home and moving in with family to save money to buy a family home that is big enough for us as it's not possible to do this at the moment."

Person with cystic fibrosis

# We're here to help

If you're concerned about any topics raised in this report or need advice, please contact our free Helpline at [helpline@cysticfibrosis.org.uk](mailto:helpline@cysticfibrosis.org.uk) or call **0300 373 1000** to speak to one of our friendly advisors. You can also message us on WhatsApp on **07361 582053**.

If you or someone you support with CF are struggling to afford basic essentials to stay well, please contact our Helpline and we'll look at how we can help. You can also find lots of information on financial support available to you on our website.

Your CF team can also support you, and it's important that you let them know if you're finding it hard to afford the things you need to stay well.

## Benefits advice

It is very difficult to give general benefits advice, as your entitlement depends on many things, like who you live with, if you have a partner in employment, your savings situation, and your National Insurance record.

Another major factor is whether you have a good relationship with your employer, and if you are entitled to any contractual sick pay. Your employer can also get support.

Sometimes there are difficult decisions to make, and while we don't always have the answers, we can support you and make sure you are well-informed to make your own decisions weighing up practical arrangements, finances and risks to health.

## Grants

We provide a range of welfare grants to help in times of financial need. These include grants for emergencies, transplant assessments, health and wellbeing, holidays and breaks, home care, education, prescription prepayment certificates (PPC) and funerals.

## Prescription charges

Many people with cystic fibrosis still have to pay for their prescriptions. Find out everything you need to know about prescription charges and CF, including whether you could be exempt and how you can apply for a prescription prepayment certificate (PPC) on our website.

## Work Forwards

Work Forwards is our programme of free tailored careers information, advice, and guidance for people with CF and their loved ones. Through Work Forwards, we offer tailored one-to-one support from employment experts to help identify your career goals and find fulfilling employment, support with employment rights, and group sessions to learn key employability skills.

## Income maximisation

Our Income Maximisation Service can support you to access our benefits advice, as well as check you are getting all the financial assistance you are entitled to, and help you to make the most out of your money.

Cystic Fibrosis Trust is the charity uniting people to stop cystic fibrosis. Our community will improve care, speak out, support each other and fund vital research as we race towards effective treatments for all.

We won't stop until everyone can live without the limits of cystic fibrosis.

**[cysticfibrosis.org.uk](https://cysticfibrosis.org.uk)**

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