



The cost of cystic fibrosis 2022

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Uniting for a life *unlimited*

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Acknowledgements

We would like to extend our gratitude to everyone in the UK cystic fibrosis community who took the time to share their experiences with us. Thanks to you, we can work together to lobby for long-lasting and meaningful change, and ensure that everybody with CF can live a life without limits.

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Foreword

In spring 2022, the Trust launched a UK-wide survey to collect data and testimony on the cost of living with cystic fibrosis. Over 1,100 of you shared your experiences – and we couldn't be more grateful for your support.

We know that living with cystic fibrosis presents unique challenges: 69% of our respondents felt like they had less money than their peers because of CF. The impact of shielding and lockdowns as a result of the COVID-19 pandemic, and the rising cost of living have added an even further financial burden for many people.

Through our survey, people with CF, as well as parents, partners and carers, have told their story of the cost of living with cystic fibrosis, giving powerful insights into the financial consequences of living with a long-term condition and how this affects their physical and mental health and wellbeing. We will use this information, and their emotional and candid testimony, to inform governments across the UK of the need to make meaningful and lasting change.

The results from the survey paint a shocking picture, with one in three CF families revealing they had run out of food before they could afford to buy more, and one in three people with CF missing hospital appointments due to the cost. Without long-term government intervention, the winter months will present further financial difficulties.

In this report, we recommend policies that we believe will help address the issues our community have identified and ensure people with cystic fibrosis can truly live a life unlimited by their condition.

Thank you again for your support. If you'd like to share your views please get in touch with us on social media or by emailing costofcf@cysticfibrosis.org.uk

David Ramsden

Chief Executive of Cystic Fibrosis Trust



Key findings

87%

are worried about the cost of living



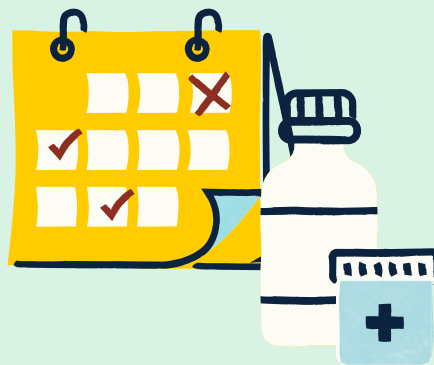
69%

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



80%

felt their CF or caring responsibilities had an impact on their employment



1 in 3

people had missed a hospital appointment due to the cost



1 in 3

had run out of food before they had enough money to buy more



1 in 3

had to prioritise one basic essential over another



In brief:

What we are calling for

We are calling for:

- The UK Government to guarantee that uprating of benefits will reflect current inflation, rather than the previous year's September consumer price index (CPI)
- The UK Government to end unnecessary benefit reassessments and introduce a minimum PIP award length (2+ years) for people living with a lifelong condition like cystic fibrosis
- NHS hospitals to ensure people with chronic medical conditions have access to free hospital parking, and for the governments in England, Wales, Scotland and Northern Ireland to fund a hospital travel card scheme which would provide subsidised travel for those living with a lifelong condition
- The Secretary of State for Health and Social Care to ensure everybody with CF has access to free prescriptions regardless of where they live in the UK, and to order a review the prescription charge exemption list
- The UK Government should end VAT on energy bills – reducing the burden on people with long-term health conditions like cystic fibrosis, who require a warm home to stay well
- The UK Government to pause the universal benefits migration process until it can guarantee that a person's benefits will not be stopped until they have established a claim to Universal Credit
- The NHS to ensure all people with cystic fibrosis have access to a CF social worker, to help them navigate the complex social security systems, rising cost of living and provide employment support
- The UK Government to make a meaningful increase to the Warm Home Discount Scheme allowances
- The UK Government to reform Statutory Sick Pay (SSP) and end the 28-week cap on SSP
- The UK Government to use the existing infrastructure around Personal Independence Payment (PIP) to make additional awards for those with long-term conditions so they can afford food, energy and essential equipment.

Background

There are currently over 10,800 people living with cystic fibrosis in the UK. To maintain their health, people with CF have a significant treatment burden. This can include:

- taking up to 70 pills every day
- following a special high-calorie diet
- daily exercise and respiratory physiotherapy
- monthly health checks at their local CF centre, alongside any hospital admissions.

This routine comes with costs attached, and often relies on an individual or family having sufficient income to cover it.

Between March and April 2022, the Trust ran an online cost of cystic fibrosis survey. We asked people with CF, and their families and carers, about the cost of living and their experience of managing the condition.

This is the first year the Trust has run the cost of CF survey. With the cost of living increasing and our community facing financial worries like never before, we feel it's the right time to set a benchmark of how our community experience the cost of CF.

The survey collected data on a broad range of topics, including:

- demographics
- income, benefits, and employment
- housing, travel, and food
- money and debt.

We invited our community to tell their story of living day-to-day with cystic fibrosis and 1,151 shared their experiences with us.

Cystic Fibrosis Trust would like to thank all those who took part.

Please note that the contents of this report could be distressing for some readers. If you would like help or support please contact our helpline on **0300 373 1000** or email us helpline@cysticfibrosis.org.uk



Over **10,800** people
living with cystic fibrosis
in the UK

What we found out

Who took the survey?

1,151 people took the survey from across all four nations. Of these people, 45% had cystic fibrosis, and 55% were parents, partners or carers.

- 63% were women
- 35% were men
- <1% were non-binary
- 1% indicated they didn't want to say

78% of people indicated that they, or the person they support, had access to CFTR modulators, also known as precision medicines and modulator therapies, which work to tackle the underlying cause of cystic fibrosis.

Cost of living worries

8 in 10 (87%) people were worried about money.

7 in 10 (70%) people felt like they had less money than their peers because of cystic fibrosis.

4 in 5 (85%) people said they were worried about money, with 1 in 3 (33%) saying they worried about money every single day.

“We spend more on...”

We asked what people with CF felt like they spent more on in comparison to those around them. Alongside the 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.

4 in 5 (82%) spent more on food than their peers.

3 in 5 (63%) spent more on travel than their peers.

2 in 3 (66%) spent more on heating than their peers.

1 in 3 (36%) spent more on holidays than their peers.

1 in 2 (51%) spent more on energy than their peers.

4 in 10 (46%) spent more on insurance than their peers.

1 in 4 (26%) spent more on household equipment than their peers.

1 in 4 (27%) spent more on clothing than their peers.

4 in 10 (47%) spent more on exercise provisions than their peers.

1 in 10 (15%) spent more on home adaptations and financial products.

“It was always a struggle to work full-time and maintain my health so I opted to work part-time. This meant I couldn't manage as well as my peers who were able to progress in their careers, have children and work. I could only work to pay my living costs then spend rest of time on my CF care. It became exhausting. I gave up working temporarily in 2018 as I became very poorly.”

Person with cystic fibrosis

“I live a frugal life so that I am able to meet the essential needs of the household. Bills and rent are prioritised over everything else. I buy clothes when mine are worn out. Everything is practical and bought to last and work hard. Nothing is pretty or 'just because'. I have two pairs of shoes – walking shoes and a pair of trainers.”

Person with cystic fibrosis

Income, benefits and employment

We asked people about their employment, income, access to benefits and expenditure.

Benefits

7 in 10 (73%) people with CF said they were receiving benefits.

Only 4 in 10 (44%) families and carers said they were receiving benefits.

9 in 10 (94%) people with cystic fibrosis received sickness or disability benefits.

How benefits were spent

We asked families and people with CF what they spent their benefits on.

	People with CF	Families and carers of people with CF
Spent part of their benefits on food	80%	78%
Spent part of their benefits on household bills	79%	68%
Spent part of their benefits on transport	72%	56%
Spent part of their benefits on essential household items	66%	60%
Spent part of their benefits on exercise provisions	45%	51%
Spent part of their benefits on household maintenance	45%	36%
Spent part of their benefits on prescription charges	25%	13%

It is particularly concerning that 25% of people with CF use their benefits to pay for prescriptions that are essential to live with the condition. It is vital that everyone with CF should have access to free prescriptions.

Employment

We asked families and people with CF how they would describe their employment status:

	People with CF	Parents, spouses, and carers
In full-time work	33%	37%
In part-time work	29%	28%
Working on a zero-hour contract	2%	3%
Not in employment	11%	9%
In full-time education	3%	<1%
In part-time education	<1%	2%
Homemaker	6%	15%
Voluntary work	2%	2%
Unable to work	21%	4%
Prefer not to say	%	1%
Other (please specify)	8%	12%

The effects of the COVID-19 pandemic on employment

We asked if people's employment status had changed from before the pandemic. Most of the changes were marginal (<1%), with the exception of parents, carers, and spouses, who experienced a 4% drop-in full-time employment between 2019 and 2022. Free text answers indicated that in most cases this was a knock-on effect of shielding, and carers pursuing alternative forms of employment to protect those with CF from COVID-19.

8 in 10 (82%) people with CF felt like their condition had an impact on their employment.

7 in 10 (77%) parents, carers and spouses felt their caring responsibilities had an effect on their employment.

4 in 10 (44%) people with CF had to rely on Statutory Sick Pay (SSP) at some point.

"I can't look after my health enough while working. I can't afford not to work. So I work and put my health second."

Person with cystic fibrosis

"We both decided to work part-time when my son was diagnosed so that one of us was always home with him and not relying on someone else to take on his needs. We wanted to spend as much time with him as we could."

Parent of a child with cystic fibrosis

"I feel so overwhelmed with trying to keep myself healthy. I feel unable to work."

Person with cystic fibrosis

Travel and food

Hospital travel¹

7 in 10 (77%) travelled to hospital in their own car.

2 in 10 (23%) travelled to hospital on public transport.

2 in 10 (21%) relied on lifts from family.

1 in 3 (34%) people with cystic fibrosis had missed a hospital appointment due to the cost (nationally, roughly 1 in 10 hospital appointments are missed).

Holidays

1 in 2 (56%) 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 (35%) people had run out of food before they had enough money to buy more.

4 in 10 (40%) people have had to borrow money for basic essentials like food, clothing, heating and internet.

1 in 3 (34%) said they have had to prioritise one essential over another, such as choosing heating over eating, or prescriptions charges over internet access.

Money and debt

4 in 10 (41%) people had to borrow money to buy basic essentials or cover basic bills.

3 in 10 (31%) required a loan to pay off another bill or loan.

“The cost of a hospital stay can be immense – travel costs, parking, additional food and drink, refreshments for you and other family members, books and magazines, time off work, loss of benefits.”

Parent of a child with cystic fibrosis

“I try to just use my benefits for CF-related issues like transport to hospital, a bit toward gas/electric for the extra flushing of taps, cleaning and sterilising products, sports physio classes, replacing water bottles, toothbrushes and everything else that is around water regularly.”

Parent of a child with cystic fibrosis

“Hospital appointments, blood tests, or general testing. Leaves me anxious. I don’t want to lose my job because I’m not able to work. Or because I’m always absent. I don’t want to miss the tests or appointments.”

Person with cystic fibrosis

¹ Respondents could select more than one transport option.

In detail:

What we are calling for

Many people with CF are increasingly worried about the rising cost of living and the financial burden of living with a lifelong condition. Rising costs affect everyone in the country, but present an even greater challenge for those with a long-term condition like CF to maintain physical health and mental wellbeing.

In May 2022, the Chancellor announced new measures to support people with the increased cost of living. Although we welcome this intervention, we are concerned that some of the proposed measures will not be implemented until January 2023, well after the start of the winter months. In addition, they do not address the full scale of financial challenge people with CF are facing.

Our top five priorities

We are calling on the Government to make five key changes that we believe will create lasting and meaningful change for our community:

Benefits linked to inflation, not CPI

Linked benefits and tax credits rose by only 3.1% in April 2022, in line with the Consumer Price Index (CPI) rate of inflation in September 2021. This falls short of the current rate of CPI, which is at the highest it has been since 1992. This means those who rely on welfare will experience a 7% pay cut. The UK Government must guarantee that the uprating of benefits will be based on current inflation.

An end to unnecessary benefit reassessments

We are calling for the UK Government to bring:

- an end to unnecessary benefit reassessments for people with long-term health conditions
- a minimum PIP award length (2+ years) for those with a lifelong condition that does not have a cure, like CF.

There is already a requirement for claimants to report any change in health to the Department for Work and Pensions (DWP). In a situation where somebody has a progressive, lifelong condition, there is unlikely to be an improvement, while the threat of constant reassessment can cause anxiety, and is costly and unnecessary.

Additionally, we are asking for the DWP to commit to paper-based assessments using evidence from specialist clinicians for people listed for transplant.

Subsidised travel

We are calling on NHS hospitals to provide access to free hospital parking for people with chronic medical conditions.

We are also recommending that governments across the UK implement a hospital travel card scheme, which would provide subsidised quick, hygienic, and environmentally friendly travel.

"I am currently administering IV antibiotics at home to my child. Three times a day for two hours each session, starting at 6am, finishing at 12am. For two weeks. It is impossible to be in employment with this level of caring responsibility – employers can't cope with sporadic, unplanned and unpredictable need for lengthy periods of absence. I had to give up a highly paid job to fulfil my caring responsibilities."

Parent of a child with cystic fibrosis

Free prescriptions for everyone with CF

We believe it is vital that everyone with CF should have access to free prescriptions regardless of where they live in the UK. We are calling on the Secretary of State for Health and Social Care to review the prescription charge exemption list and acknowledge the financial challenges faced by people with long-term conditions like CF.

No more VAT on energy bills

Fuel bills are increasing for everyone, but this has a particularly devastating effect on those with long-term health conditions like cystic fibrosis, who require a warm home to stay well. We are calling on the UK Government to end VAT for energy bills. This measure will offer meaningful reductions to our community at a point where 30% of people said they were currently choosing between essentials like heating their homes and putting food on the table.

“Home insulation is too expensive and heating the home during the day is too expensive, so I go without heat during the day and frequently in the evening too. At most, I use the heating for one or two hours every 24 hours, which is not good for my health. My chest is getting worse.”

Person with cystic fibrosis

We're also calling for

An end to Universal Credit migration

We are asking the UK Government to halt the process of Universal Credit migration unless it can guarantee that nobody's benefits are stopped until they have established a Universal Credit claim. The DWP must prioritise safety by providing proactive support that allows those who face challenges to get the support they need and avoid penalising people based on arbitrary deadlines.

Access to a social worker for everyone with CF

Everyone 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 burden 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 psychological and social professionals for people with CF.

A meaningful increase to the Warm Home Discount Scheme

The planned £10 increase of the Warm Home Discount Scheme (from £140 to £150) is not going to go far enough, when the UK's energy price cap has risen by 54%. The Trust welcomes plans to expand the scheme to more households. We call for the Government to make a meaningful increase to the Warm Home Discount Scheme allowances, to match the soaring costs of energy bills.

SSP reform

44% people with cystic fibrosis said they rely on SSP while sick. We believe that SSP is in need of reform. We recommend two key changes in order to make it fit for purpose.

Firstly, the Government must address the woeful level of SSP, which is currently £99.35 per week. This is simply not enough to cover the cost of living, and it should be revaluated to be in line with a living wage.

Secondly, we are calling for an end to the arbitrary and unnecessary 28-week cap on SSP. If an individual can provide a professional sick note, there should be no reason to cut off SSP after a set amount of time. The Government should offer support to businesses to provide SSP in the rare cases when it is required beyond 28 weeks.

Additional awards for long-term conditions

It is clear there are a number of areas in which our community need help. We suggest using the existing infrastructure around PIP to make additional awards for those with long-term conditions, and these individual payments would be made around:

- **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 don't have to choose between heating and eating.
- **Energy.** People with CF use extra energy to stay well. For example, they may keep their homes warm to stave off lung infections, do extra loads of laundry, power an additional fridge to store sterile medications, or run essential medical devices such as ventilators.
- **Essential equipment.** People with CF may incur additional costs in procuring essential equipment, such as an additional fridge to store sterile medications or a computer to allow for virtual appointments, as well as the associated energy costs.

"I am always having to juggle my working hours because of appointments and hospital stays. I always run out of holidays and end up trying to work my time back or usually end up taking unpaid parental leave."

Parent of a child with cystic fibrosis

"When my child is in hospital, I have to take unpaid leave from work if I want to be with him."

Parent of child with cystic fibrosis

Summary

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

As the results of the Cost of CF survey 2022 show, cystic fibrosis brings significant financial challenges as well as the physical and mental health impacts of living with a life-limiting genetic condition. We call on governments across the UK and the NHS at national and local level to take urgent action and do more to help people with cystic fibrosis who are struggling now, and are likely to face further difficulties as bills continue to rise.

Where you can find support

If you're struggling to afford basic essentials, visit cysticfibrosis.org.uk/financialsupport or contact our Helpline at helpline@cysticfibrosis.org.uk or on **0300 373 1000**.

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 with your CF.

Grants

We provide a range of welfare grants to help in times of financial need, from emergencies and transplants assessments to holidays and breaks. Find out more at cysticfibrosis.org.uk/grants

Benefits advice

We understand it can be complicated to negotiate the benefits system, as entitlements depend on many different things. Cystic Fibrosis Trust can support you through the process, including applying for benefits like Personal Independent Payment, Disability Living Allowance and Universal Credit. Find out more about the benefits support we can provide at cysticfibrosis.org.uk/benefits

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 at cysticfibrosis.org.uk/prescriptioncharges

Income maximisation

Our Income Maximisation Service can support you to access our benefits advice, check you are getting all the financial assistance you are entitled to, and help you to make the most out of your money. Find out more at cysticfibrosis.org.uk/incomemaximisation

If you're concerned about any topics raised in this report or need advice, please contact our Helpline.

Our friendly Helpline team are here if you need us – whether you're looking for information, support, or just someone to talk to. You can get in touch on 0300 373 1000 or helpline@cysticfibrosis.org.uk. The Helpline is open Monday to Friday, 9am to 5pm.

Cystic Fibrosis Trust

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

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