Cystic Fibrosis Trust

Since 1964 | We won't stop until CF does

# Your life and CF

## 2024 report

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June 2024

Uniting for a life unlimited

# Your life and CF

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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

2024 marked 60 years of the Trust. For six decades we've worked together, sharing moments of frustration, despair and hope, overcoming challenges, and celebrating breakthroughs. Always learning and moving forward, with the valuable support and insights from the CF community.

Our annual UK-wide survey opened in February 2024 to gather crucial data and first-hand accounts on life with cystic fibrosis (CF). This is the third year we have conducted this data gathering exercise, building on the foundations laid out in previous years, allowing us to better focus our questions and gather new insights, including what our community hopes are for the future.

This year we have launched new surveys to two youth cohorts, to ensure the younger members of our community have their voices heard. The stories and testimony that they have provided shines a light on their lives and the future of CF. Additionally, the report demonstrates the hope our younger community has for the future.

Previous Your Life and CF reports exposed the devastating consequences of the national cost of living crisis that was only just beginning. Fast forward a year, and the UK has witnessed double-digit inflation and skyrocketing costs of food and other essential items. While many bills and inflation have now stabilised, they are still significantly higher than before the 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.

Our new report reveals 9 out of 10 people affected by CF worry about the future, with 1 in 5 going without food, yet only 4% seeking help from food banks. 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 energy tariff. It is shocking that despite decades of campaigning, many people with CF in England 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 to let us know your comments and questions.

We won't stop until CF does.

**David Ramsden**
Chief Executive of Cystic Fibrosis Trust

# Background to our research

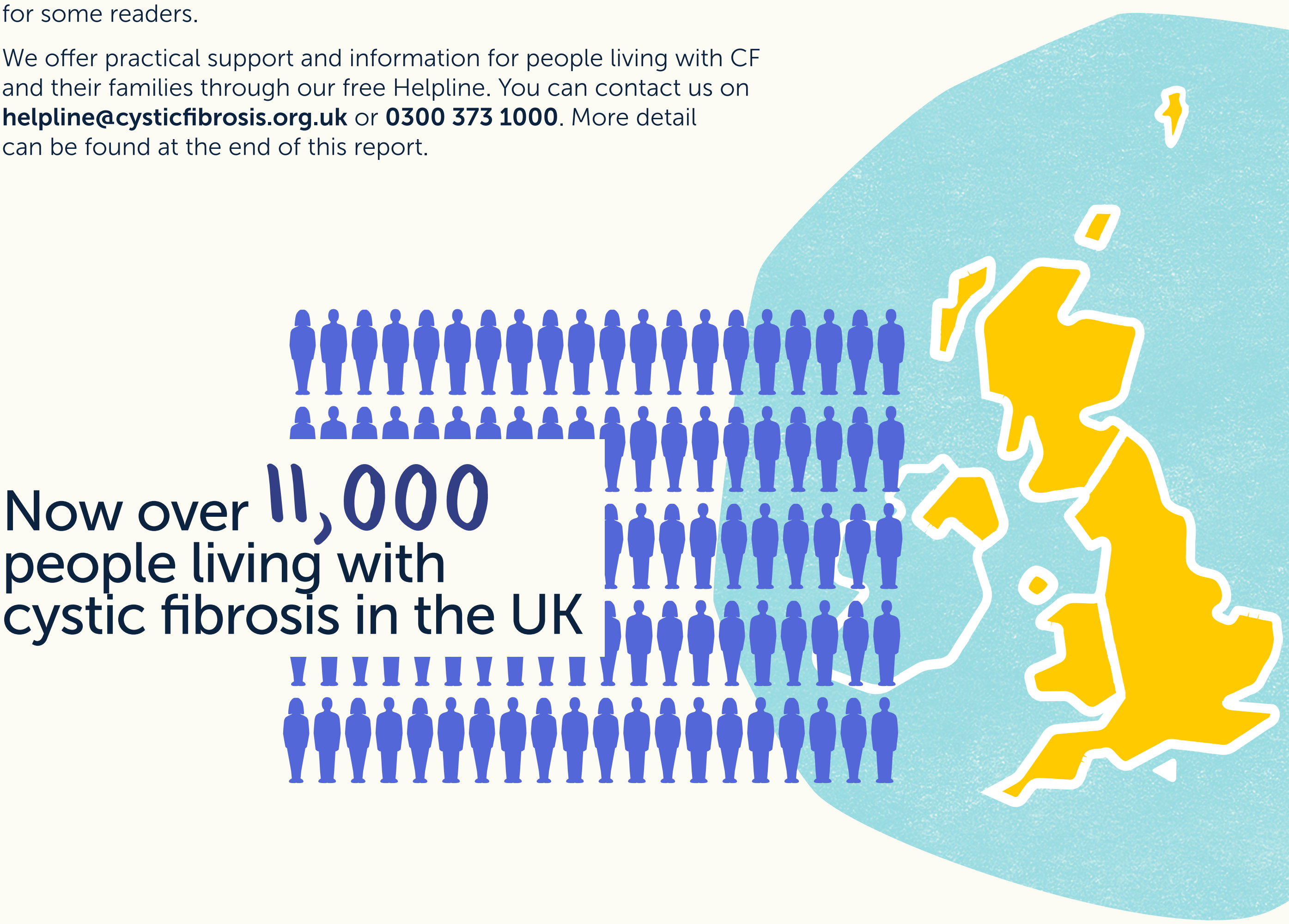
There are over 11,000 living with cystic fibrosis in the UK. In order to stay well, people with cystic fibrosis face a significant treatment burden: some people have to take over 100 tablets every day, follow a special high-calorie diet, daily exercise and respiratory physiotherapy, and monthly health 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 February and March 2024, Cystic Fibrosis Trust ran our annual 'Your life and CF' survey, asking our community about a range of topics relating to their life with CF and the additional cost of living with a life-long condition. Over the past three years we have demonstrated that the cost of living with CF has additional immutable costs. Although the UK cost of living crisis has eased and inflation has slowed, costs remain high, and the ever-present additional costs of living with cystic fibrosis means day to day living can present difficult financial choices.

For the third year, 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.

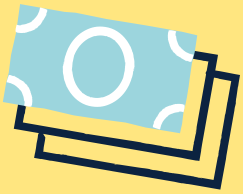
Please note that the contents of this report could be distressing for some readers.

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.



# Key findings

From people with CF



**37%**

were not making provisions for their retirement

**79%**

said in the last 12 months their physical health had prevented them living life to the fullest

**11%**

identified as unable to work

**42%**

said the burden of monitoring their health was high or very high

**20%**

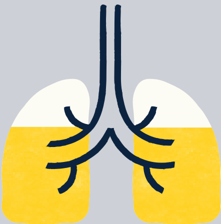
had missed a hospital appointment because of the cost

**39%**

were worried about air pollution affecting their CF

**39%**

find it harder to breathe/ cough more when they have been in polluted areas



**31%**

worried about their physical health every day, with a further 34% worrying sometimes

## From both parents/carers and people with CF

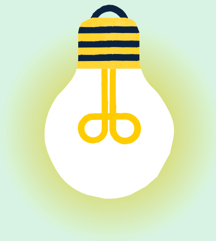
**69%**

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

**31%**

were paying for prescriptions

**39%**



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

**84%**

were worried about the cost of living

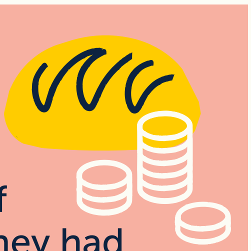
**23%**

were reliant on public transport to get to hospital appointments

**90%**

were worried about the future, 43% were worried every day

**21%**



had run out of food before they had money to buy more in the last 12 months, and 4% had used a foodbank

**77%**

were worried about their mental health with 31% worrying everyday

# Our asks

- **Equal access for all**
  Everyone with CF should be able to access a CF social worker and CF clinical psychologist when needed.

- **Training and keeping CF specialists**
  The Government must swiftly implement a workforce strategy to tackle the recruitment and retention issues plaguing specialist CF teams.

- **Enhanced social prescribing**
  The Government should introduce an enhanced social prescribing system — a vital component of Universal Personalised Care.

- **A new guarantee on benefits**
  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.

- **Free prescriptions for all**
  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.

- **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.

- **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.

- **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.

- **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.

# Our asks in 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 £114.50 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 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 a CF specialist when needed

The responses throughout the survey made it clear that access to mental health support is increasingly needed. Those who have benefited from Kaftrio find themselves navigating life with a new lens and in some cases facing new worries.

It is essential that everyone with CF should be able to access a CF social worker and CF clinical psychologist when needed, extending beyond the confines of annual reviews. Our survey showed that 1 in 3 people with CF worried about their mental health on a daily basis. Our staffing report brings to light a stark reality: only 33% of responding adult centres and 32% of responding paediatric centres have a CF social worker on their MDT. 28% of children with cystic fibrosis or their families reported being unable to access a social worker.

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 sustained increased cost of living. 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.

## 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 CF social workers have revealed a clear absence of a targeted strategy to attract professionals to specialised healthcare settings. This gap is especially pronounced for CF social workers, who lack a clear recruitment, training, and management structure tailored for specialised healthcare settings.

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

## Enhanced social prescribing

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 the community to address the practical, social, and emotional needs influencing 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 like CF. This would empower doctors to prescribe support beyond medical or physical care. For example, financial support for energy bills, essential domestic appliances so that people can live in warm and healthy homes, or transport and exercise options that promote healthier, more active lifestyles.

## 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.

## 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.

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 means 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.

## 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. For the third year in a row our survey showed that 1 in 5 people with CF have 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)

SSP represents a crucial, yet flawed, safety net for anyone with a long-term condition who is in employment. 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 £116.75 per week. This is simply not enough to cover the cost of living. With the cost of living significantly higher than it was a few years ago, SSP needs to be re-evaluated to be in line with a living wage.

The current three day wait on SSP is arbitrary and unnecessary there should be no reason to delay the start of this important safety net. Additionally, it is important that phased returns to work be compatible with SSP. Health is not linear and many people wish to return to work in a capacity that is compatible with their CF.

## 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. 21% of respondents had run out of food before they had money to buy more.
- **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:** Fuel bills are higher than they used to be, 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 39% of our respondents said they were currently choosing between essentials like heating their homes and putting food on the table.

# Eight steps to make PIP fairer

## Right decision first time

Cystic Fibrosis Trust is 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. Parents/carers 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 to keep healthy, 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.

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 review forms and processes claimant-friendly so that it is clear what evidence can be provided by the applicant that will help decision-makers
4. commit to fairer decision-making based on gathering evidence from 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, 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) [1]
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.

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[1] Supported by a parliamentary advisory committee

# Cystic fibrosis and sick pay

People living with cystic fibrosis are prone to exacerbations. In 2022, those with CF, age 18 and over, spent an average (median) of 13 days in hospital on IV antibiotics.[2]

Statutory Sick Pay (SSP) is the legal minimum which employers must pay all qualifying employees, when they are too sick to work. It is £116.75 per week and starts from the fourth day of sickness, unless you have previously been ill for more than three days within the last eight weeks.

Our survey found almost two-thirds (64%) of those with CF, age 18 and over, who are not in full-time education, reported being in work.[3]

Of those in work, almost three quarters (74%) reported taking sick leave within the past year and 1 in 10 reported taking at least a month in sick leave.

Of those in work, who had taken sick leave within the past year, 1 in 4 (27%) said they had received SSP and of those who had taken at least a month of sick leave over half (55%) said they had received SSP.

While those who had taken at least a month of sick leave in the last 12 months may have had multiple periods of sickness and therefore potentially not have qualified for SSP for all of them – due to the four consecutive days of illness requirement – assuming they did qualify for SSP for all these periods, that they were paid from the first day of sickness (rather than fourth) and their employer didn't pay them any more than required by law (i.e. just the rate of SSP), this would be equivalent to earning just £467 for one month of the year.[4] This is not enough for the average person to live on, let alone for those with CF, who already have to spend more simply to stay well.

Of the emergency grants Cystic Fibrosis Trust awarded in 2023/24, 42% were due to people experiencing an unexpected or prolonged hospital stay. We only award emergency grants to those with an urgent, short-term need, not those with an ongoing financial crisis, due to our limited budget. It seems likely that the low rate of SSP, is a primary cause for this sudden financial need. Those who are self-employed being ineligible for SSP could be another reason. 5% of those with CF, age 18 and over, reported being self-employed.

Moreover, these statistics only reflect how many days people with CF in work felt they could afford to take as sick leave, not how many days they were actually ill and shouldn't have been working.

Respondents were also asked how many days, if any, they had worked in the past 12 months, despite being ill, because they were unable to afford to take the time as sick leave. Half (52%) of those with CF in work had experienced this and over a third (35%) had worked for at least a week despite being ill, for this reason. This is likely due to both being unable to afford the three-day wait before being eligible for SSP, as well as the low rate of pay once receiving it. As well as this being an awful situation for people with CF, it's not good for the employer either, as it may mean they continue to work, feel worse, and in the long run take more time off sick.

When responses are filtered by those who answered that they had taken no sick leave within the past year, the results are almost unchanged, with 51% still saying they had experienced working despite being ill because they were not able to afford to take the time as sick leave. People should not have to choose between going to work whilst unwell or having a day off to focus on their health and the loss of income potentially leading to financial trouble later. During the COVID-19 pandemic the UK Government temporarily made SSP payable from day one of sickness because they recognised that making people wait risked forcing people to work when they were unwell.

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[2] UK Cystic Fibrosis Registry – 2022 Annual Data Report https://www.cysticfibrosis.org.uk/sites/default/files/2023-12/CFT_2022_Annual_Data_Report_Dec2023.pdf

[3] 40% said they were working full-time, 21% said they were working part-time and 2% said they were on a zero-hours contract.

[4] This also assumes they had previously been ill for more than three days within the last 8 weeks and therefore, would qualify for SSP from the first day of sickness.

When responses are filtered by those who answered that their yearly household income – including benefits – was less than £30,000, in the past 12 months, three quarters (77%) had experienced working despite being ill because they were not able to afford to take the time as sick leave. And almost half (46%) of this group had experienced working for at least a week despite being ill, for the same reason.

Under the current rules, SSP does not allow for phased return to work. Payment of SSP stops when an employee returns to work, even if they return on reduced hours. As the Government acknowledges in its 2016 Work, Health and Disability Green Paper,[5] this may mean "that people who are low paid may be deterred from returning to work on reduced hours because they would not qualify for Statutory Sick Pay and their earnings may prove to be less than the amount provided by Statutory Sick Pay. Or alternatively it may encourage them to return to their usual hours before they are ready, potentially leading to further absence or falling out of work altogether." Respondents were also asked within the last 12 months how many working days, if any, they booked off as annual leave to cover sickness and medical appointments. In the last year over half of people with CF in work (57%) had used annual leave to cover sickness and medical appointments and over a quarter (29%) had used at least one week of their annual leave to cover sickness and medical appointments. People should not have to use their annual leave when they are sick because they cannot afford to be on sick leave. This is not good for employers either, as it most likely leads to employees in this situation being less productive when they are working, due to not having had a true break.

## Policy recommendations

1. Raise the rate of SSP
2. Remove the three-day waiting period
3. Allow phased returns to work to be compatible with SSP
4. Abolish having to earn over a certain amount to be eligible for SSP (known as the Lower Earnings Limit threshold)
5. Make the self-employed eligible for SSP by creating an optional contributory sick pay scheme

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[5] Improving Lives: the Work, Health and Disability Green Paper (2016) https://assets.publishing.service.gov.uk/media/5a7f4d92e5274a2e8ab4b5bf/work-and-health-green-paper-improving-lives.pdf

# Financial cost of CF

## The average cost of living with CF surpasses £6,500 annually.

In 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 £6,700 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 of children 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 people with CF 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.

# Other costs of CF

Cystic fibrosis has inherent costs associated with it. The financial costs are now well established with the average family with CF losing out on over £6,700 each year. With this staggeringly high cost it is no wonder that 84% of respondents were worried about the cost of living.

70% felt CF had an impact on their employment. With many respondents saying the work they feel they can do is limited by their condition. Even those who were very satisfied with their careers expressed some frustration at employers not understanding the fluctuations in their health.

Diet is hugely important for people with CF, good nutrition and a healthy body weight have been directly linked to having better lung function, reduced frequency of chest infections and can help people feel better. Many people with CF have a healthy body weight and want to maintain this while making healthy food choices.

However, this year we saw the highest number of our respondents making impossible choices, with 40% choosing between essentials like putting food on the table and turning the heating on.

10% of respondents owe their energy provider over £250, with 2% owing more than £1,000. 25% of respondents said they had been uncomfortably cold in their home during the last year and worryingly only 17% said they had never been cold. For those on prepayment meters, a shocking 40% said they had been uncomfortably cold over the last winter and only 10% said they had never been cold. Moving to a prepayment meter is not recommended for people who have a serious health condition like CF, where going without heat or light might cause a serious health problem. Worryingly, those in this who reported being uncomfortably cold were more likely to have experienced food insecurity too.

This trend continued with 1 in 5 respondents saying they had run out of food before they had money to buy more. Despite this worrying stat only 3 out of every 100 respondents had accessed a food bank.

All people with CF require an array of medications to stay well and manage their life-long condition, despite this 1 in 3 respondents reported having to pay for their prescriptions. Although many in the community can afford the Prepayment certificate (PPC), its upfront cost of £114.50 can be prohibitive, particularly for those on modest incomes who narrowly exceed other financial exemption thresholds. Notably, 89% of all NHS prescriptions are already provided free of charge, underlining the importance of addressing this remaining gap.

> “The most challenging thing is the cost of everything and just living with CF and having to do treatments throughout the whole day can be tiring, again I think the misunderstanding of cystic fibrosis is really hard and this creates a lot of mental health issues like anxiety. And sometimes it can feel like a burden for workplaces or friends.”

> “It’s not just reduced income, it’s the opportunity to live as we grow. I can only cope with certain jobs, any more responsibilities would add pressure on me and thus negatively affect my health as finding a balance in life can be difficult.”

## We asked 'What would you like to do that you can't do, because of reduced income/ increased spending as a result of CF?'

### People with CF said…

"Buy more clothes that are actually able to fit me due to putting on weight. Being able to afford day trips and create memories."

"Spend more time with my loved ones instead of working six-day weeks and sleeping the rest of the time as I'm absolutely drained."

"To be able to afford simple things for myself and be able to afford having hobbies I enjoy."

"Because I'm living from pay check to pay check and barely scraping by, it's hard for me to afford the simple things like travelling to go see family that live an hour or more away. I can't afford to do anything really so I just sit inside and that takes a toll on my mental health. I can't afford the gym or any activities to keep me active and fit. I can't afford a better diet because I can only buy the bare minimum from shops."

"A holiday abroad is a dream for me. I don't think it'll ever happen."

"My wife had to take another job to make sure we weren't running short each month. We have turned the heating down in the house a few degrees to make it cheaper."

"I'd like to not have to worry about how much food is in my fridge or how long I have my heating on. A person with CF consumes more calories than the average person due to poor digestion, I find myself skipping meals in order to simply get by."

"Warm the flat and eat well."

"I rely on my own income so I have no one to pay half the bills or fall back on. So it's a constant worry about if I'm too ill to work. I try to wear extra layers so that I don't have heating on all the time as I can't afford it. I resent having to pay for extra stuff like my medication and travelling and parking at appointments. I've had five individual hospital appointments in the past six weeks which is a 50 mile round trip every time."

"I'd like to keep up with the lifestyles of my friends, I'm always falling behind because of prescription charges and other costs to do with my CF."

"It's not just reduced income, it's the opportunity to live as we grow. I can only cope with certain jobs, any more responsibilities would add pressure on me and thus negatively affect my health as finding a balance in life can very difficult. I've moved from owning my own house, to living with parents to now living in a rented council house. Because of cystic fibrosis. I don't have the same options as friends moving to bigger or more expensive houses. I have to live in a way that keeps me well so opportunities to increase my income are, I believe, limited. I do spend carefully and because I get PIP in the middle of the month I can manage."

"Be able to provide for my family after I am gone. Life insurance is extremely limited and very expensive in comparison to people who don't have CF."

### Parents, carers and other family members said…

"My child with CF is always hungry and needs more fat in food. I can only provide what I can afford.'"

"Do something 'unnecessary' rather than normal day-to-day life. Like go out for food, go to the cinema, etc."

"Get out more with friends to socialise but due to costs I have to sacrifice it sometimes. Not have to worry about cost of having to heat the house and having to go cold. Not having to worry if I have enough for food/essentials."

"I am unable to pay for petrol for my car due to heating costs."

"I would like to be able to have a safe environment to call our own home. Living with friends or family with a child with CF is very challenging. Due to sharing facilities and making sure everything is at a standard of clean that keeps her safe in someone else's home can be difficult."

"I would love to take the family on holiday, even if it was in the same country that we live in. I cannot justify the amount of money to go on holiday when bills continue to increase."

"Have enough money to live off. I'm a single parent and I feel daily I'm letting my child down."

"Pay all my debts off, and be able to have extra money to take my child out more."

"Sleep at night without worrying."

"Not have to use food banks or sit in the cold to try and save on heating costs."

## Employment, benefits and SSP

For many respondents, their career was cited as something they were proud of. Our survey showed that 55% of people with CF were in full time or part time employment, 5% were self-employed and 4% were retired.

With changes to CF care and predicted age of survival steadily climbing, the prospect of retirement has become a reality for many. Despite this, 37% of respondents were not making any provisions for their retirements.

We asked our community if they felt their CF / their caring responsibilities had an impact on their employment. 70% indicated that there had been some impact on their careers. A trend that came from the free text answers suggested that many employers were not understanding of employees working with a long-term health condition.

1 in 10 said they were currently unable to work due to their CF.

> "I have worked full-time jobs in the past, I end up getting really ill and it's simply not worth it. I work part-time and I'm happy with that, but it does impact my income."

> "I've not been kept on by many jobs because of my health."

## Home and travel

Travel is an essential part of life and for people with CF it is crucial that they can access affordable, clean and timely travel for appointments. Worryingly for the third year in a row, 1 in 5 were missing essential hospital appointments due to the cost. Attending clinics is a vital part of CF healthcare, and the Government must intervene to ensure that everyone can access the NHS and not be deterred by financial travel barriers.

20% had missed a hospital appointment because of the cost (transport, parking charges, unable to miss work etc.)

Most respondents relied on their own car to get to appointments but for many this wasn't an option:

25% relied on public transport to get to essential hospital appointments

4% relied on taxis to get to essential hospital appointments

17% relied on lifts from friends or family to access essential hospital appointments

### We're interested in your experiences of getting travel insurance if you've been abroad this year

| | |
|---|---|
| I haven't travelled abroad | 28% |
| I haven't travelled abroad because of the cost of insurance | 5% |
| I travelled abroad, and was able to find affordable travel insurance which covered CF | 30% |
| I travelled abroad, and didn't tell my travel insurance provider about CF | 8% |
| I travelled abroad, and didn't take out insurance because it was too expensive | 10% |
| I travelled abroad, and didn't take out insurance because I couldn't find cover for CF | 2% |
| Other – Please tell us about your experience of getting travel insurance | 17% |

## Mental Health, worries and hopes for a brighter future

### In the last 12 months, have you worried about the future?

| | |
|---|---|
| Yes – I worry about it everyday | 43% |
| Yes – I worry about it sometimes | 31% |
| Yes – I have worried about it, on and off | 17% |
| No – I don’t have regular worries about my mental health | 8% |
| Prefer not to say | 2% |

### In the last 12 months, have you worried about your mental health?

| | |
|---|---|
| Yes – I worry about it everyday | 31% |
| Yes – I worry about it sometimes | 30% |
| Yes – I have worried about it, on and off | 16% |
| No – I don’t have regular worries about my mental health | 21% |
| Prefer not to say | 2% |

2024 data shows that people with CF rated their average happiness levels as 5.6 out of 10 versus a national rating for the same question of 7.5 out of 10. 5.6 is 0.3 lower than the same question in 2023; showing a drop in happiness levels within the community in the last year. There has been a large drop in the last eight years as in 2016, people 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 4.9, this has risen by 4.6 in the previous year suggesting a more anxious community. This is significantly higher compared to the general population’s response of 3.12.

## Worries

"After the success of Kaftrio, I'm hoping further drugs can be developed to further enhance the lives of those with CF so that they can live a life unlimited. It would be great to be able to drop some of the daily treatment due to the improvements that these drugs are/could make."

"Simply that I have enough money to pay the bills."

"I worry about my lung function."

"I don't really have any at the moment. It's borderline constant panic/worry about my health and the effect on my loved ones."

## Hopes

"I want my conditions to remain stable and well managed, to continue to live independently and work. I want to be able to enjoy the same quality of life as my friends, family and colleagues."

"I hope I'm able to have a happy family eventually of my own and be able to broaden treatment so that I'm able to work more. I wish more people would understand CF as this would make things a lot easier. I want my income to be a little bit more but it's hard when there's a lot going on."

"I wish to swim with dolphins in the wild but terrified of the sea. Start my own photography business."

"I would like to settle down, get married and have kids, work a stable job in an industry I love and I don't want to spend my adult years in hospital."

"Continued good health thanks to modulator drugs. Live a happy fulfilled life, and have a family. Travel. Secure a future free from financial worry for family."

"Feels much more like opportunities or normal life achievements are getting more out of reach due to money and health uncertainty."

"Financial stability. Stable health."

## We asked ‘What is the most challenging thing about living with CF right now?

“People understanding that a transplant doesn’t mean you are ‘fixed’!”

“CF and its treatment has changed vastly since I was a child. I think access to some of the medications are still a real challenge and that CF is still not an exemption for prescription charges is baffling. I pay for the pleasure of breathing and now post transplant too, living. Without my medication I would be dead within about two weeks. So it’s basically a challenge to stay alive.”

“The most challenging thing is the cost of everything and just living with CF and having to do treatments throughout the whole day can be tiring. Again I think the misunderstanding of cystic fibrosis is really hard and this creates a lot of mental health issues like anxiety. And sometimes it can feel like a burden for workplaces or friends.”

“Doing everything – daily tablets, physio, enough exercise, eating properly to maintain weight and energy levels without interfering with my diabetes and gut health too much. And that’s on top of house work and a full-time job. It is regularly too much to handle and my health doesn’t always come first, which causes a vicious cycle of becoming ill, having less energy, eating poorly, taking less medication etc.”

“The time for appointments, treatments, especially trying to get through physio and getting medications in, getting two small children is hard to get everyone ready and out anyway, never mind the added things. And then the workplace expects you to be on time for 7.30/8am. It’s a challenge every day.”

“My employer doesn’t really understand my condition very well or understand the limitations it puts on me sometimes.”

“Finding energy to do medications after a full day at work when already feeling ill. Knowing meds will help me feel better, but having no energy to do them, bothers me as people I live with and am close to don’t understand I physically cannot do it sometimes. They then moan when I end up getting ill and blame me for it.”

“I want to live my life like it doesn’t affect me but I have to accept sometimes it does. Sometimes I can feel okay one day and the other not and getting my employer to understand that.”

“I struggle with having an active social life, I work really hard to maintain a good job and all of my treatments that I’m exhausted by the weekend.”

“That nobody understands the full scale of CF. People now assume that because of Kaftrio he’s cured and that’s simply not the case. I don’t think that anyone understands how hard this is for us every day. CF has changed every part of my life.”

“The adjustment of Kaftrio. Before I never really cared about my future, didn’t make healthy lifestyle choices because I thought it wouldn’t matter, now I have to start thinking of those things and planning for a future that I didn’t think I’d have. Also the mental burden as always, dwelling on the past and the burden it puts on my family, and also the uncertainty of not knowing when it’ll get worse again.”

“Mental health toll. Other than the usual physical culprits, the changes in expectation post-Kaftrio have led to new challenges. For example, previously had not really thought or prepared for the future beyond early to mid 20s but now am having to. It’s positive but also pretty challenging.”

## Physical health and burden of treatment

The era of highly effected modulators has changed life with CF for many. Despite incredible medical advances, medication, physiotherapy, and general health all must be considered when planning the simplest activity and being unwell frequently interferes with work and education for people with CF and their families.

Our survey asked the number of individual medications that you/your child takes in an average day. The answers varied from single figures to 150. With the average reported at 34 tablets a day.

Worries about physical health were prevalent in the community with 90% worrying about it at least sometimes, and 31% worrying about it every day.

### In the last 12 months, have you worried about your physical health?

| | |
|---|---|
| Yes – I worry about it everyday | 31% |
| Yes – I worry about it sometimes | 34% |
| Yes – I have worried about it, on and off | 25% |
| No – I don't have regular worries about my mental health | 9% |
| Prefer not to say | 1% |

1 in 5 said that their physical health had prevented them living life to the fullest every day, with only 20% reporting no effect as a result of their physical health.

### In the last 12 months, has your physical health prevented you from living your life to the fullest?

| | |
|---|---|
| Yes – everyday | 20% |
| Yes – sometimes | 37% |
| Yes – on and off | 22% |
| No | 19% |
| Prefer not to say | 1% |

Remote monitoring is becoming more prevalent in CF care, and many respondents spoke about the burden of daily monitoring. 38% were monitoring their health at home on a daily basis. And 42% ranked the burden of monitoring their health high or very high.

### How often do you monitor you health at home? (weight, spirometry, digestion, diabetes, infection control and medication dosing etc)

| | |
|---|---|
| Everyday | 38% |
| A few times a week | 20% |
| Once a week | 10% |
| A few times a month | 15% |
| Less than once a month | 13% |
| Never | 4% |

**How would you rate the burden of monitoring CF health at home? (weight, spirometry, digestion, diabetes, infection control and medication dosing etc)**

| | |
|---|---|
| Very high | 18% |
| High | 24% |
| Moderate | 31 % |
| Low | 18 % |
| Very low | 9% |

# Youth survey

## Children and young people

This year we ran two surveys for children and young people with CF. One for children aged 6-11 and another for young people aged between 12 and 17. Our Youth Advisory Group helped us to write the questions based on topics they felt strongly about. Parents of young children with CF and a CF psychologist reviewed the questions before we opened the surveys. 122 children and young people took part in the surveys.

## 6-11 age group

### Looking to the future

We asked what children wanted to be when they were older, here are some of their responses.

- Footballer
- Vet
- Doctor
- Nurse
- Singer
- Own a bakery
- Work with cars like my Dad
- Play rugby
- Be a scientist and a policeman and a fireman
- Teacher
- Police officer
- Accountant/Banker
- Beautician
- Fashion designer
- Space man
- Actress
- Ninja
- Scientist
- Archeologist
- Marine biologist
- King consort
- A nurse and help people like the nurses have helped me

### Emotions around CF treatments and going to hospital

65% said they felt bored

50% felt nervous

1 in 3 children said they felt sad

1 in 4 children said they felt proud

### School

We asked children whether people in their school were kind and helpful about their CF. Everyone who answered the survey said that at least a few people were kind and helpful, with 74% of respondents saying that "everyone" or "most people" were.

> "Stop being mean to me about my CF"

We went on to ask how they felt that people in their school could help them more. The most frequent response was around support with medication – particularly Creon. Many children said that they needed reminding to take their Creon and other medication, suggesting that at present they are left without this support and are forgetting to take their medication as a result.

Many respondents also said that they wanted people in their school to understand CF and be aware of the effects of the condition. Others expressed sadness due to bullying because of their CF and a lack of emotional support.

### Worrying about CF

We asked children whether they worried about their CF, and if they did, what they worried about. Positively, 40% said that they do not worry at all, while over 50% said they only worry a bit. Only 6% said they worry a lot and nobody said that they worry all the time.

> "I don't worry, I know I'm in the best hands with family and medical care."

The most common issue that children reported worrying about was being admitted to hospital and their health worsening. Children also worried about missing out on fun activities because of their CF and feeling different from their peers.

> "Worrying about how you can fix CF forever so I don't have to be different.".

## 12-17 age group

### Looking to the future

We asked young people about their hopes for the future, here are some of their responses.

- Travel all over the world and experience everything that I can
- Carpenter
- Dance choreographer
- Have a family
- Have a big house with lots of space
- Musician
- Artist
- Go to uni
- Lawyer
- Help find a cure for CF
- Vet
- Not take as much medication
- Astronaut
- Be healthy
- Wildlife conservationist
- Pediatric doctor

### Emotions around CF treatments and going to hospital

When we asked about children's feelings towards their treatments and going to hospital, some things seemed to stay the same for the older group.

68% said they felt bored

50% felt nervous

However, many responses indicated that feelings around treatments and hospitals get worse as children grow older.

A larger proportion of respondents felt embarrassed.

Fewer older children than younger felt positive emotions about treatments and going to hospital, such as feeling brave, confident, powerful or proud.

### Talking about CF

We asked young people if they told people about their CF or if they preferred to keep it private. 70% of respondents said that they told people about their condition, often saying that they want to share this part of their identity with people and raise awareness.

However, 30% replied that they preferred to keep CF to themselves, saying that they are afraid that people will make fun of them or treat them differently if they knew about their condition.

We also asked whether respondents cared whether people understand CF. 40% of respondents said that they cared a lot about this issue, while just over 35% said they only cared a bit, and just over 20% said that they did not care at all.

> “I'm proud of my condition, want to spread awareness and I really enjoy educating other people.”

> “Because I'm scared about what people may think of me and might use it against me.”

### School

We asked young people whether people in their school were kind and helpful about their CF. Similarly to the younger respondents, everyone who answered the survey said that at least a few people were kind and helpful. Over half the respondents said that “everyone” or “most people” were.

The respondents had many ideas of how people in their school could help them more with their CF. Many said that they would like to receive more emotional support, while others commented on having reasonable adjustments put in place and wanting to be treated like everybody else. Some respondents commented that they wished that people understood CF better, and similarly to the younger cohort, some young people wanted support to remember to take their medication while at school.

### Worrying about CF

We asked young people if they worried about CF, and if they did, what issues they worried about. Respondent's answers indicate that young people worry more about CF as they grow older. 40% said they worried “all the time” or “a lot”, in contrast to only 6% of the younger respondents. Young people's worries were varied, yet by far the most frequently mentioned were worries concerning physical health (60% of answers mentioned this). Young people also reported worrying about their future, suffering and pain, life-expectancy and death, what other people think of them, needles and their weight.

> “I worry about not making a difference in the world before I die, the pain I go through, and I worry about my friends and family when I'm gone”.

# Demographics

## Who took the 'Your life and CF' survey?

This year 1,105 participants took part in our survey. The break down is below.

| | |
|---|---|
| A person with cystic fibrosis | 40% |
| A parent of a child with cystic fibrosis | 33 % |
| A parent of an adult with cystic fibrosis | 12% |
| Other family member, partner, spouse or a carer of someone with cystic fibrosis | 11% |
| Other (please specify) | 4% |

As has been the case in previous years most responses identified as female, we took steps in our survey distribution to encourage non-female participants. This year for the first time just over 1% of respondents identified as gender nonconforming.

| | |
|---|---|
| Male | 23% |
| Female | 76% |
| Other genders (Non-Binary, Intersex, Agender, own term used) | 1% |

## Nation

As in previous years most of our responses came from England, this is to be expected as it has the highest number of people living with CF. Scotland and Wales were broadly proportional with a slightly lower than expected response rate from NI. We encouraged additional responses from the devolved nations through our social media channels, however responses remained in line with previous years.

| | |
|---|---|
| England | 78% |
| Scotland | 11% |
| Wales | 5% |
| Northern Ireland | 4% |
| Other | 1% |

| | |
|---|---|
| North East | 7% |
| North West | 17% |
| Yorkshire and The Humber | 12% |
| East Midlands | 7% |
| West Midlands | 10% |
| East of England | 7% |
| London | 7% |
| South East | 21% |
| South West | 12% |

## Youth survey demographics

This year we ran our youth survey for the first time. The survey was divided into two cohorts, 12-17 years and 6-11 years. The breakdown of respondents are below.

| | |
|---|---|
| 18 years or older | 7% |
| 12 – 17 years old | 39% |
| 6 – 11 years old | 38% |
| 5 years or younger | 17% |

*18 year or older were sent to the adult survey.

** 5 years or younger were unable to proceed with questions.

The gender split for our youth respondents were pretty evenly distributed. No respondents identified as gender non-conforming.

| | |
|---|---|
| Boy | 52% |
| Girl | 48% |

# We’re here to help

If you’re concerned about any topics raised in this report or need advice, please contact our Helpline at **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**

**Uniting for a life** *unlimited*