Cystic Fibrosis Trust

Your life and CF

2025 report

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Uniting for a life unlimited

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Contents

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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 2025, Cystic Fibrosis Trust launched its fourth UK-wide survey to gather crucial data and first-hand accounts on life with cystic fibrosis (CF). We gathered insights from over 1,000 people affected by CF, allowing us to establish trends over time and understand the realities of life with the condition in 2025.

The past four years have seen significant change for people with CF, with triple therapy modulators having a positive impact on the quality of life for many. Despite this, CF remains a chronic multisystem condition that requires lifelong specialist care. CF continues to make life too hard and too short for too many. In past reports we have shown the consequences of the cost of living crisis on people with disabilities, the devastating effect of record-breaking inflation, and the mental load that people with CF have to manage, a sad reality that people with CF and their families still contend with today.

To account for the important changes our community has seen, this year's **Your Life and CF** survey is our broadest data-gathering exercise to date, expanding into new areas such as neurodiversity. Our report reveals that 29% of people with CF identified as neurodiverse, of which 65% said it affected their CF care.

New analysis shows that when adjusted for inflation the cost of cystic fibrosis has risen to a staggering £7,087 per year. The rise in the cost of energy, transport to and from appointments, and other unavoidable costs has led to one in four adults with CF and over a third of parents of children with CF reporting struggling to meet monthly bills. The inherent cost of CF is only complicated by workplace barriers, with our findings showing that 44% of adults with CF report discrimination in work or job applications and 35% have lost or left a job because of their health. All this together means that 9 in 10 people surveyed worry about the future, with 45% reporting they worry all the time.

To create lasting improvements in health, care, and quality of life for people with CF, we need government to act. Key changes to the benefits system, a free hospital travel scheme, and a social energy tariff would make real change to daily life for those living with a chronic condition without a cure.

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.

Please get in touch with us on social media or by emailing **publicaffairsteam@cysticfibrosis.org.uk** to let us know any feedback on this report and the wider work we do.

We won't stop until CF does.

David Ramsden
Chief Executive, Cystic Fibrosis Trust

Background

There are over 11,000 people living with cystic fibrosis in the UK. In order to stay well, people with cystic fibrosis face a significant treatment burden – multiple medications (for some, over 100 tablets every day), daily exercise and physiotherapy, and regular appointments with their CF clinical team. 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 2025, Cystic Fibrosis Trust ran our **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 lifelong condition. Over the past four years we have demonstrated that the cost of living with CF has additional constant costs, meaning day-to-day living can present difficult financial choices.

This year, we expanded into new areas, as well as asking repeat key questions to establish and track ongoing trends.

Topics we asked about:

- Experiences of work
- Cross-infection guidance
- Finances and costs
- Hopes and aspirations
- Neurodiversity
- Worries and the future
- Children and young people

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

Work

44%
felt they had been discriminated against in work or when applying for jobs because of CF

20%
said they were unable to work due to health reasons

12%
didn't know they could have reasonable adjustments at work

15%
had reasonable adjustments turned down

40%
had to cut a hospital stay short or delay CF care as they couldn't afford time off work

35%
had lost their job or been forced to leave because of their CF

Wellbeing

People with CF told us they were most worried about:

- their mental health
- exhaustion or fatigue
- growing older with CF

70%
said in the last 12 months they had felt lonely because of CF

29%
stated they were neurodiverse. Of those, 65% said it affected their CF care

Daily pressures

40%
had to prioritise one essential over another

20%
were worried about losing their housing

90%
worried about the future, of which 45% said they worried all the time

From both parents/carers and people with CF

Work

75%
said that CF had affected their career

50%
felt that CF had limited their earning potential

34%
felt they had been discriminated against in work or when applying for jobs because of CF or their caring responsibilities

24%
had lost their job or been forced to quit due to CF

Wellbeing

23%
stated they were neurodiverse

94%
said they worried about the future

83%
felt like they have missed out on life experiences because of CF

Daily pressures

78%
worried about their daily expenses

38%
had prioritised one essential over another

11%
said they had mould in their property which hadn't been dealt with

Our asks in brief

Specialist care and support

- **Access to CF psychosocial specialists**
  The Government must ensure CF teams are resourced appropriately to ensure everyone with CF is able to access the CF specific psychological and social care they need.
- **Training and keeping CF specialists**
  The Government must swiftly implement a workforce strategy to tackle 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.

Financial security

- **Timms review of Personal Independence Payment (PIP)**
  The Government must ensure any changes implemented from the upcoming Timms review into PIP are co-produced with disabled people and in the best interests of the CF community.
- **A new guarantee on benefits**
  The Government must uprate benefits more frequently. Timely and inflation-accurate increases are vital to maintain the spending power of essential disability benefits.
- **Reform of Statutory Sick Pay (SSP)**
  The Government must re-evaluate the current level of SSP, which is not enough to cover the increased cost of living, to be in line with a living wage.

Healthcare costs and access

- **Free prescriptions for all**
  The Government must review the prescription charges exemption list. Everyone with CF should have access to free prescriptions regardless of where they live in the UK.
- **Free hospital parking**
  The Government must ensure that patients with lifelong conditions like CF have access to free hospital parking.
- **Hospital travel card system**
  The Government must implement a hospital travel card for those with CF, to provide subsidised journeys that are green (using electric vehicles), clean, and quick, giving direct access to hospitals whenever needed.

Energy

- **Social tariff for energy bills**
  The Government must create a social tariff for gas and electricity to ensure those in our community with the greatest need do not go without essential healthcare at home.
- **Reform of Warm Home Discount Scheme**
  The Government must increase the Warm Home Discount Scheme allowances and reverse to eligibility changes which have impacted those on non-means-tested benefits.

Financial cost of CF

Due to higher-than-average inflation over the past two-and-a-half years, the additional financial burden of CF has risen to £7,087 for the median family living with the condition. In a jobs market where salaries have failed to keep pace with rising costs, many people with CF are worse off than ever before.

In January 2023, the Trust united with the University of Bristol to release a groundbreaking research paper examining the financial toll of living with CF. The study uncovered a shocking truth: the cost of living with CF is more than £6,700 every year. This figure accounts for both additional expenses and the potential loss of earnings due to unpredictable health challenges.

Drawing on surveys, focus groups, and in-depth interviews, the University of Bristol found that a typical family living with CF faces a monthly loss of £564 (£6,768 per year). Parents of children with CF reported even higher financial impacts than adults with CF themselves.

When adjusted for inflation in 2025, the median cost to each household jumps to £7,087 annually – the equivalent of £590 per month in extra costs and lost income. The average adult with CF will now bear additional costs of £219 per month, while parents of children with CF endure an astounding £305 more per month. These expenses include transport to medical appointments, treatments, special dietary requirements, and escalated energy bills.

The research also exposed a troubling reality: CF families are more likely to experience financial hardship compared to the general UK population. Nearly a 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 17% of the overall UK households facing similar challenges.

Furthermore, individuals with CF face disproportionate financial obstacles when it comes to accessing insurance and benefits, coping with prescription charges, and finding suitable housing, which leaves families in an especially vulnerable position.

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 that worsen their daily struggles.

Demographics

This year, 1,024 people with CF or people with a connection to CF took part in the survey, representing almost 10% of the UK population with CF.

Connection to CF

A person with CF over 18	42%
A person with CF 12–17	5%
A person with CF 6–11	7%
A parent of an adult with CF	11%
A parent of a child with CF	24%
Partner/spouse	2%
Carer of someone with CF	1%
A bereaved parent or carer of someone with CF	2%
Other family member	6%

Age

71 years or older	1%
61–70 years old	4%
51–60 years old	10%
41–50 years old	17%
31–40 years old	21%
25–30 years old	15%
18–24 years old	8%
12–17 years old	10%
6–11 years old	13%

For parents and carers, the breakdown of the age of the person they support is below. Almost 25% of parents and carers had a child under the age of five.

Age of child

51–60 years	1%
41–50 years	3%
31–40 years	11%
25–30 years	10%
18–24 years old	14%
12–17 years old	17%
6–11 years old	18%
5 years old or younger	24%

Most respondents were from England, which is to be expected given it has the highest number of people living with CF.

Nation

England	81%
Scotland	7%
Wales	6%
Northern Ireland	3%
Other	3%

Due to the scale of respondents from England this year, we have further broken the data down by region. Most regions had similar response levels, with the highest coming from the South East.

Region within England

North East	9%
North West	14%
Yorkshire and the Humber	11%
East Midlands	9%
West Midlands	9%
East of England	9%
London	8%
South East	20%
South West	11%

This year saw the largest gender split among respondents, with 3 in 4 identifying as female.

Gender

Male	23%
Female	75%
Nonbinary	>1%
Prefer not to say	>1%
Used their own term	>1%

Youth survey demographics

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

Gender

Boy	41%
Girl	55%
Prefer not to say	3%

As with the adult survey, the majority of respondents were from England, correlating with the population data. For Scotland, Wales and Northern Ireland, respondent numbers were in line with those of the adult survey.

Nation

England	78%
Scotland	8%
Wales	6%
Northern Ireland	3%
Other	5%

Due to the scale of respondents from England this year, we have further broken the data down by region. Most regions had similar response levels, with the exception of the South East, which accounted for over 1 in 3 respondents.

Region within England

North East	2%
North West	17%
Yorkshire and the Humber	7%
East Midlands	4%
West Midlands	4%
East of England	9%
London	10%
South East	37%
South West	9%

Experiences of work

This year we asked about experiences of work. Topics included the impact of CF on careers, experiences of workplace discrimination, and knowledge of workplace rights.

Most respondents with cystic fibrosis felt that cystic fibrosis had an impact on their employment.

- 79% felt CF had affected their job/career.
- 34% felt CF had affected their career/earning potential.
- 15% chose a job/career that supports them to balance work and CF.
- 40% had been discriminated against in work.
- 22% had lost jobs or had to quit because of time off for illness.
- 17% didn't get the qualifications they needed because of CF health.
- 17% have been turned down for jobs because of CF.

One hundred and sixty-four people with cystic fibrosis responded to the open-ended question "What support would help you manage CF/caring responsibilities alongside your work or career?", sharing their needs and suggesting potential solutions.

- 45% would like to have more flexibility in their working lives.
- 20% would like their employers or colleagues to be more understanding around CF.
- 12% would like their employers to be more educated around CF.
- 10% would like better government benefits.
- 10% would like support from their friends and family.
- 6% would like better paid sick leave.

The 2025 results show that the careers of parent carers and partners of people with cystic fibrosis are also significantly affected by cystic fibrosis.

- 78% of parent carers and 55% of partners of people with CF reported that CF had affected their job/career.
- 24% of parent carers and 36% of partners of people with CF reported that CF had affected their career/earning potential.
- 16% of parent carers and 18% of partners of people with CF reported that they chose a job/career that supports them to balance work and CF.
- 18% of parent carers and 36% of partners of people with CF felt that they had never been discriminated against in work or when applying for jobs because of CF or caring responsibilities.

Ninety parent carers responded to the open-ended question "What support would help you manage CF/caring responsibilities alongside your work or career?", sharing their needs and suggesting potential solutions.

- 64% would like to have more flexibility in their working lives.
- 36% would like employers to be more educated or understanding around CF.
- 11% would like paid carer's leave.
- 4% would like childcare providers to be more educated or understanding around CF.

> "I feel like I can't be a carer and career driven. I don't see how the two are compatible when I already struggle with multitasking as it is. One would always suffer to the detriment of the other. I find it too overwhelming and stressful."
>
> Debbie*, who cares for someone with CF

> "Just more awareness for employers so they can support families with this diagnosis."
>
> Kim*, whose daughter Amy* has CF

> "Empathy, flexibility and allowing me to work around appointments and to catch up."
>
> Khaled, whose daughter Alia* has CF

Six partners of people with cystic fibrosis explained their needs or potential solutions, and all related to flexibility in the workplace.

In the same survey 24% of people with CF said they needed a personal support network to help them to manage their condition alongside work. It is therefore vital that workplace barriers are removed for these support networks, enabling them to provide the help that is needed.

> “I would just want to know that I am supported in leaving at the drop of a hat if necessary.”
>
> Ian*, whose son Charlie* has CF

What do we need to see?

- There are wider systemic issues which impact people with CF being able to find and retain fulfilling work. CF is a complex condition, with significant impact on mental health as well as physical health. People with CF need comprehensive access to specialist psychological and social care to support their overall wellbeing. This, in turn, can place them in a stronger position to participate in the workforce if they are well enough.
- People with CF often tell us about the challenges of explaining the condition to their employers. We believe they shouldn’t need to explain CF in order to access employment support, which is why we are best placed to provide it. Policymakers should recognise charities as key stakeholders and potential delivery partners, due to our specialist knowledge of the people we support.
- Government employment programmes for people with disabilities or health conditions should start with the perspective that there are structural barriers to employment. Because of these barriers, the workforce, and society as a whole, misses out on the extensive skills, knowledge, and potential of employees with disabilities. Policy change should focus on dismantling these barriers while strengthening and promoting workplace rights and adjustments.
- All young people should receive education in school on disability discrimination and the workplace rights of people with disabilities and health conditions, including flexible working and reasonable adjustments. Policymakers should aim to ensure future generations enter the workforce with this knowledge, whether they are people with disabilities themselves or their future colleagues. This would help create more inclusive workplaces in the future.

Cross-infection guidance

People with CF are vulnerable to different bacteria, or 'bugs', which grow in their lungs. While these bugs are usually harmless to people who don't have CF, they can settle in the lungs (colonise) and be harmful for those who do. Bugs such as *Burkholderia cepacia* complex and *Pseudomonas aeruginosa* can be transmitted from person to person by close personal contact, and for this reason, people with CF are advised not to meet in person. Avoiding lung infections is extremely important for people with CF, as it helps keep their lungs as healthy as possible for as long as possible.

For the first time in **Your Life and CF** we asked questions about cross-infection.

Which of the following statements do you agree with regarding cross-infection guidance?

I wish I could meet other people with CF in person	37%
I understand why I can't meet someone with CF in person	83%
I worry about cross-infection	33%
Cross-infection guidance makes CF feel more isolating than other conditions	49%
Connecting with other people with CF online is important to me	25%
Cross-infection guidance makes me feel safe	24%
The risk of infection from the general public in shared areas/transport/ clinical spaces worries me	56%
None of the above	6%

Loneliness

When asked if they had felt lonely or alone in the past 12 months because of CF, 70% of people with CF reported feeling lonely at least some of the time.

Have you felt lonely or alone in the past 12 months because of CF?

Yes, all the time	22%
Yes, sometimes	48%
No, never	29%
Prefer not to say	1%

Life and tough decisions

When asked if they felt like they had missed out on life experiences because of CF, almost 9 in 10 (88%) people with CF asserted that they had.

Do you feel like you have missed out on life experiences because of CF?

Yes, all the time	36%
Yes, sometimes	52%
No, never	12%
Prefer not to say	0%

Have you ever cut a hospital stay short, decided not to go to hospital, or delayed CF care because you couldn't afford to take the time off work as sick leave?

Yes	40%
No	60%

We asked people with CF how many hours they spent on treatment each day[1]. The mean average time spent was 3.7 hours. A huge time investment is made every day in managing the symptoms and to stay well with CF.

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[1] Answers that were greater than 24 hours and 0 were excluded.

Housing

When asked if they were living in a secure location at the time of the survey, respondents mostly said that they were. No one reported being without a steady place to live. However, there may be people with CF without secure accommodation who were unable to answer an online survey. One in five people said they are worried about losing their steady place to live in the future.

What is your living situation today?

I have a steady place to live	80%
I have a place to live today, but I am worried about losing it in the future	20%
I do not have a steady place to live (for example, I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, 'sofa surfing', in a car, abandoned building, bus or train station, or in a park)	0%

When asked about the previous winter, only 20% of people with CF reported never being cold in their property. 29% were cold constantly or quite often.

Between December 2024 and February 2025, how often were you cold in the property where you live?

Constantly	6%
Quite often	23%
Sometimes	30%
Rarely	20%
Never	20%

When asked if they had been forced in the last year to choose between essentials – such as heating their homes, reducing the quality or quantity of food, paying for prescriptions, or internet service – 4 in 10 respondents reported that they had had to make this impossible choice.

In the last 12 months, have you ever had to prioritise one essential over another?

Yes	40%
No	60%

This year, for the first time, we asked about mould inside properties. Mould has been shown to worsen respiratory problems in the general population and can lead to *aspergillosis* infections. Of all respondents with CF, 1 in 3 had experienced mould in their home, with 13% stating that it had not been dealt with. These figures jump up to 44% for those who rent privately or through council housing, with 1 in 5 dealing with an untreated mould problem.

In the last 12 months, have you had a problem with mould in the property where you live?

Yes, it has been dealt with	20%
Yes, it hasn't been dealt with	13%
No	67%

Neurodiversity

This year, for the first time, we asked respondents if they identified as neurodiverse and how this interacted with their CF and CF care.

"It can affect every aspect of care and treatment. It affects how I communicate to my CF team, often creating a gap of miscommunication between what I tell them to how they interpret it. A huge struggle with adding additional treatments and medications with no consideration for a disruption in routine, inability to incorporate new things into care routines, or understanding of executive dysfunction's impact on day-to-day tasks. Issues with sensory sensitivities particularly food related issues.

"Clinic and hospital visits are ordeals of stress, anxiety and sensory overload – complex noises, repeated noises, smells, large clusters of people, hard to navigate environments with densely packed information that can be hard to decipher, increased anxiety of germs and cross-contamination. Leading to an avoidance of appointments, delaying treatment if needed, and a strong aversion to hospital stays due to distress.

"There is an overall lack of knowledge on neurodiversity and its adaptations in general, mostly still stuck in stereotypical generalisations. Neurodiversity is also seen as a completely separate issue which has no involvement or effect on any aspect of CF and as such is not taken into consideration."

Kian*, who has CF

"Find taking in information during hospital appointments very difficult. As a child I couldn't tolerate physical touch, so physio was impossible and treatment difficult. I forget new treatments as they're not part of my daily routine. Figuring out medication, ordering and organising is tricky. General organisational tasks. Online appointments are hard."

Ella*, who has CF

"I get so focused on something else I may forget treatments then I'll remember but get distracted again."

Sebastian*, who has CF

Are you neurodiverse?

"Neurodiverse" refers to individuals whose brain functions and processes information differently from what is considered typical. This includes conditions such as autism, ADHD, dyslexia, and others. This can be a formal diagnosis or personal identification.

Yes	29%
No	71%

People who selected yes were then allowed to select which conditions they identified with from the following list, if any. Participants were able to select as many or as few as they liked.

Prefer not to say	5%
Autism, or Autism spectrum conditions	30%
Attention Deficit Hyperactivity Disorder (ADHD)	36%
Attention Deficit Disorder (ADD)	14%
Dyslexia	29%
Dyspraxia	3%
Dyscalculia	9%

For people with CF who identified as neurodiverse, almost two-thirds indicated that their neurodiversity affected their management of CF.

Does [neurodiversity] affect your CF care and treatment, such as attending clinic appointments or managing treatments?

Prefer not to say	10%
Yes, all the time	23%
Yes, sometimes	43%
No, never	25%

Is there any support you need that you are not currently getting?

No	59%
Yes	41%

“I have always had issues with compliance, especially when my treatment routine used to be longer and more boring. I struggle to form routines, so taking tablets can sometimes be difficult to remember, though I have put things in place which makes it easier to manage. I struggle to stick to sports, so maintaining a fitness routine has always been incredibly difficult. As I received treatment for my ADHD, and Kaftrio improved my CF, I found that I suddenly had a normal-ish life, this then brought its own challenges such as trying to mentally come to terms with the trauma of growing up with a life-shortening condition. My over-active brain and sensitivity to emotions has made this really difficult at times.”

Mya*, who has CF

Worries and the future

When asked if they worried about the future, 9 in 10 respondents said they worried at least some of the time, with 45% reporting they worried all the time.

Do you worry about the future?

Yes, all the time	45%
Yes, sometimes	45%
No	9%
Prefer not to say	1%

When asked if CF affected the choices they made about their lives, over 8 in 10 people with CF responded yes.

Does CF affect the choices you make about your life?

Yes	83%
No	17%

Do you worry about daily expenses?

Yes – I worry about it every day	37%
Yes – I worry about it sometimes	27%
Yes – I have worried about it, on and off	17%
No – I don’t have regular worries about daily expenses	20%

This year we asked respondents about their specific worries. Each participant could select as many or as few answers as they liked. Growing older with CF was the top worry, followed by exhaustion and fatigue.

Prefer not to say	1%
Growing old with CF/complications of generational health	72%
Exhaustion or fatigue	67%
Mental health	60%
Life expectancy	59%
Money	56%
Getting a chest infection	54%
Physical health	50%
Dealing with non-CF healthcare teams or departments, including GP services	49%
Long-term impact of medications	48%
Cystic fibrosis diabetes	47%
Medicines or medical equipment shortages	45%
Achieving my goals	43%
Hospitalisation	40%
Current antibiotics for chest infections no longer working (antimicrobial resistance)	39%
Gut health	35%
Work	35%

continues

continued

Future of CF care	34%
Cancer	31%
Infection exposure and management in shared healthcare settings and public places	31%
Cross-infection	30%
Pension	28%
Access to the newest treatments	28%
Regular prescriptions admin and management	26%
Self-advocacy/explaining CF (in healthcare, work, education, finance, life choices and options)	24%
Menopause	23%
Air quality	22%
Liver issues	22%
Planning/starting a family (including pregnancy, fertility, IVF)	21%
Retirement	21%
Secure housing (ie, not at risk of losing your home) / medically safe housing (ie, living conditions that do not endanger health)	18%
Prescription charges	17%
Emergency or out-of-hours CF team contact availability	12%
Being able to contact my CF team	10%
Moving from children's to adult services	2%

Children and young people

This is the second year we have run surveys for children and young people with CF as part of the wider **Your Life and CF** survey. This year we ran one for children aged 6–11 and another for young people aged 12–17.

Our Youth Advisory Group helped us to write the questions based on topics they felt strongly about. A CF psychologist reviewed the questions before we sent the survey out to children and young people. One hundred and sixty-six children and young people filled out this survey – a 36% increase on the number of people who responded last year. This included 71 children aged 6–11 and 54 young people aged 12–17.

6–11 age group

Positivity

Children gave us an insight into the richness and positivity of their lives. Their hobbies, things they love and sources of pride are exciting and diverse.

What are you most proud of?

- being me
- my family
- I'm good at physio
- having CF
- protecting my brother
- reading lots
- taekwondo
- being the owner of a bearded dragon
- my dancing
- switching to the tablet form of Kalydeco and Kaftrio
- when I make something out of playdough

What are your favourite things to do?

- going to see the lambs in the village
- singing
- drumming
- going on rollercoasters
- having a hot chocolate
- playing with my cat

What is the best thing about your life?

- my family
- my cat
- knowing that I am different to others and that makes me feel strong
- going to school
- I am unique
- I'm healthy and happy to be alive
- the ability to overcome hardships and appreciate what I have instead of wishing I had more
- hugging Mummy
- my sisters

How does CF make you feel?

Children told us they felt a range of emotions about CF. Children feel shy, powerful, bored, worried, happy, sad, and confident about CF. The most common emotions reported were feeling 'unique' (57% of respondents) and 'special' (40% of respondents).

23% of children said that CF makes them feel worried, and 20% told us it makes them feel sad. Children reported a range of fears and worries, the most common being that they are different from their friends and can't do all the same things that they can.

> **"I worry in case I can't do what my friends do."** – Yasmin*, who has CF

Children also worried about treatments and being admitted to hospital, death, what people think about them, and their physical health getting worse.

> **"I have anxiety about death and have panic attacks about it."** – Joel*, who has CF

We also asked if children would choose to change anything about their lives. Many responded that they would change the fact that they have CF and having to take medication and do treatments. However, some children did not mention CF at all, indicating that this is not at the front of everyone's minds.

> **"I wish I had a robo watch that did whatever I told it."** – Ashton*, who has CF

> **"Nothing. I am me."** – Demi*, who has CF

School

Children told us about a variety of things they liked about school (being with friends, learning new things), as well as things they did not like (SATs, boring teachers).

We asked children how people at school could help them with their CF. Some children replied that they already receive help with their CF at school, such as being reminded to take Creon, while others said they needed more help to take their medication during the school day. The most common response was that children wished people were more empathetic and understood their CF better.

> **"Be kind, try to understand my illness better. That is why my mum took me out."**
> – Katie*, who has CF

> **"Learn more about CF, give me emotional support, treat kids with CF the same as other kids."** – Harvey*, who has CF

> **"Listen to me when I say I can't do compost as it makes me poorly."**
> – Sascha*, who has CF

We also asked what they wanted people at school to know about CF. Many children replied that they want their teachers and classmates to understand their burden of treatment.

> **"That I have to have blood tests lots and it is really scary because I hate needles."**
> – Micha*, who has CF

> **"How many treatments we have to do a day and how annoying it is to be the only one in my family that has to do that."** – Nora*, who has CF

Others replied that they want people in their school to understand exactly what CF is and its symptoms.

"Everything, so that they would not ask me about my CF. I have no idea how to explain it." – Mohammed*, who has CF

Encouragingly, a few children replied that they would like others to understand how CF has made them stronger and unique.

"CF is my superpower." – Elizabeth*, who has CF

"That it's made me awesome." – Fatimah*, who has CF

12–17 age group

Positivity

There is a lot to feel positive about in this age group's responses. Young people provided a rich and varied list of things in their lives that they felt proud of.

"Writing our YAG dictionary, being elected Head Girl and winning Outstanding Young Advocate for CF." – Sarah*, who has CF

"How independent I am." – Gabriel*, who has CF

"My improvement in sports and all the meaningful friendships I've made." – Marcus*, who has CF

"My attitude towards life. My grit and determination. My ability to know when I need to put myself first." – Lily*, who has CF

They also provided an impressive variety of hobbies that they take part in.

- road cycling
- making lego
- reading
- writing my theatre blog
- playing guitar
- hair and makeup
- walking with my parents
- drawing
- spending time with friends
- frisbee
- weightlifting
- cooking
- marine biology

We asked whether there is anything that makes them happy that they could suggest to other young people with CF to improve their wellbeing. Many young people stressed how important friendships and family are to them, with several specifically referring to our Youth Advisory Group. Others pointed to physical exercise, being open with people about CF, and finding activities you enjoy.

> **“My advice would be to find things you enjoy, whether that’s art and crafts, going on a walk, music. Just find something that you can focus on. For me I like keeping busy so I don’t have to worry about everything too much.”** – Ayesha*, who has CF

> **“People are often nice about it if they ask about the condition, so don’t feel ashamed about yourself.”** – Yousuf*, who has CF

> **“I absolutely love YAG!! It’s always the highlight of my day and I would encourage anyone else to join!”** – Sophie*, who has CF

The future

We asked young people whether they predict that having CF will affect what they do in the future and the choices they make about their lives. 75% of respondents said that they feel it will have an effect, but their reasons for this varied considerably.

Some responded that their lives would be limited due to deteriorating health, needing to be close to hospital, and avoiding careers and activities that would be dangerous due to infection risk.

> **“It will stop me from doing certain jobs and I can’t just jump on a flight.”**
> – Lucy*, who has CF

> **“I want to join the Royal Marines and I don’t think they will let me.”**
> – Adam*, who has CF

However, several young people said that they feel that having CF will affect their choices for the better, pushing them to achieve, experience the world and help others.

> **“CF has nothing to do with the person I am it’s more of something that’s just kind of there.”** – Michael*, who has CF

> **“I guess the knowledge that life is more precious should hopefully inspire me to try everything and push myself.”** – Anna*, who has CF

> **“I’m excited to keep in touch with the Trust, fundraise, raise awareness and use my experiences of CF creatively in my future theatre and writing career.”**
> – Tom*, who has CF

School

We asked young people whether they have been taught about CF at school. 43% had been taught about CF and 57% had not. Of those who had been taught about CF, most felt that what they had been taught was brief, basic and in some cases outdated or factually inaccurate. We asked young people what they felt students and teachers need to know about CF. The most common answer was about how CF affects them and their lives.

> **“I am in pain a lot at school but don’t want to make a fuss about it. Teachers only see me being late or taking days off as slacking.”** – Naomi*, who has CF

Worrying about CF

We asked young people if they worried about CF, and if they did, what issues they worried about.

- 71% of young people reported that they worry about CF ‘a bit’.
- 25% of young people said that they worry about CF ‘a lot’ or ‘all the time’.

Young people’s worries were varied, yet by far the most frequently mentioned were worries concerning physical health and death. Young people also reported worrying about forgetting to take their medication, their opportunities in life being limited, physical pain, their future, and how their pain and death might affect their friends and family.

> “That it will always be this hard and it will never get better.” – Hanif*, who has CF

> “Passing away earlier than people I love and the impact it will have on them.”
> – Kristin*, who has CF

Adherence

We asked young people whether they had any suggestions which might help other young people to find time and remember to take their medicine and do their treatments. Respondents suggested:

- setting reminders and alarms on your phone
- setting a routine and always doing treatments in a specific order
- asking parents or other people you trust to help
- finding ways of making treatments enjoyable
- using an app.

> “I use an app called ‘Finch’ that sets reminders. Doing the tasks takes care of the little pet bird the game gives you.” – Louis*, who has CF

Topics of interest

We asked young people whether they would be interested in reading or watching short films about certain topics. Young people identified a range of topics and issues they would be keen to engage with content on, with ‘explanations of how drugs and treatments work’ and ‘updates on new developments in CF research’ being the most popular.

Reflections

These surveys reveal a resilient community, proud of their unique strengths and diverse interests despite the challenges they face. Both age groups express a desire for greater understanding and empathy from their classmates and teachers, while also highlighting the importance of support networks, hobbies, and self-acceptance in managing their condition. Young people acknowledge the impact of CF on their future choices but remain determined to live fulfilling lives. These insights emphasise the need for continued education, emotional support, and tailored resources to empower children and young people with CF.

Our asks in detail

This report highlights the significant challenges faced by people living with cystic fibrosis and the urgent need for policy change to address them. To create lasting improvements in health, care, and quality of life, we are calling on government to act on the priorities set out below. Cystic Fibrosis Trust will continue to work with policymakers and partners to make these changes a reality.

Specialist care and support

Access to CF specialists

It is essential that everyone with CF can access a CF social worker and CF clinical psychologist when needed, beyond the confines of annual reviews.

The responses throughout the survey made it clear that access to mental health support is increasingly needed. Our survey showed that over 1 in 2 people (55% of survey respondents) with CF worry about their mental health on a daily basis. Those who have benefited from highly effective modulators, such as Kaftrio, find themselves navigating life with a new lens and in some cases facing new worries.

Our latest staffing report revealed that 16 paediatric and 14 adult centres lacked a CF social worker on their multidisciplinary team (MDT). This is concerning because people with CF face significant financial challenges, made worse by the ongoing cost of living crisis, and CF social workers provide vital support and tailored advice on benefits, housing, finances, education, employment, and more. Their specialised expertise and knowledge of the condition is valued by people with CF and critical to high-quality, holistic care. All people with CF 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 cope with the cost of living.

The rising cost of living, combined with the additional financial burdens of a long-term, progressive condition like CF, can contribute to anxiety and other mental health conditions. Early intervention from psychologists can help, which is why we are also calling for bespoke funding to ensure access to psychologists and social workers for everyone with CF.

Training and keeping CF specialists

Discussions 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 psychological and social 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 wellbeing.

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, it could include 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.

Financial security

Timms review of Personal Independence Payment (PIP)

It is widely agreed amongst disability charities that Personal Independence Payment (PIP) needs urgent reform. Since its inception in 2013, Cystic Fibrosis Trust has been campaigning for this. But the assessment has never before been fully reviewed.

This year the Government has been looking at reforming PIP, first introducing the Universal Credit and Personal Independence Payment Bill which outlined damaging changes including 'the four point rule', a threshold which would mean any PIP claimant would need to score at least 4 points in a single category alongside other criteria to qualify for PIP. After push back from the public and organisations such as Cystic Fibrosis Trust, the Government was forced to drop PIP from the bill.

Sir Stephen Timms, the Minister for Social Security and Disability, will now lead a review of PIP, with assurances that no changes to PIP will take place until this review is complete. Cystic Fibrosis Trust will continue to input and influence this process to secure the best outcome for people with CF.

Eight steps to make PIP fairer

The review of PIP comes at a key time. Cystic Fibrosis Trust is seeing claimants with CF in despair when they receive their PIP decision. Our aim and the aim of the review must be to ensure people with CF get the right decision the first time. Currently, many do not – almost all (over 95%) of the PIP cases we have represented in the last decade have been overturned at appeal.

The consequences of PIP being incorrectly denied 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 PIP is withdrawn from an individual, there are only four weeks before payments stop, leaving very little time to adjust financially or make alternative arrangements for essential living costs. Very often a family will additionally 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 when it is not suitable.

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.

As part of the Timms review the Government must make key changes:

1. End repeat assessments for those whose health is unlikely to improve.
2. Reduce reviews by increasing the award length for all those with long-term conditions like 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 is lost).
8. Reduce backlogs and waiting times for appeals.

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 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. For example, shorter timeframes between upratings that genuinely reflect the inflation people are experiencing, and which improves the financial wellbeing of households who are reliant on benefits. 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.

Reform of Statutory Sick Pay (SSP)

SSP represents a crucial, yet flawed, safety net for anyone with a long-term condition who is in employment. It is also in need of reform. We recommend these key changes to make SSP fit for purpose:

- The Government must address the woeful level of SSP, which is currently £118.75 per week. This is simply not enough to cover the cost of living, which is significantly higher than it was a few years ago. SSP therefore needs to be re-evaluated to be in line with a living wage.
- Phased returns to work need to be compatible with SSP. Health is not linear, and many people wish to return to work in a capacity that works with their CF.

Healthcare costs and access

Free prescriptions for all

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 face ongoing costs for their daily treatments through the costs of prescriptions. A single prescription costs £9.90, a three-month Prescription Prepayment Certificate (PPC) costs £32.05, and a yearly PPC costs £114.50. While a PPC can save money, those unable to afford the upfront cost of a yearly PPC end up paying more over time – a direct penalty for not being able to afford £114.50 upfront.

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. People with CF in Scotland, Wales and Northern Ireland already have access to free prescriptions. The Government should review the prescription charge exemption list for England and include everyone with CF, acknowledging the financial challenges faced by people with long-term conditions.

Free hospital parking

CF can require constant and consistent medical interventions. Access to the specialist CF multidisciplinary team (MDT) is essential to staying well. For four years in a row, our survey has shown that 1 in 5 people with CF are missing hospital appointments in the last year due to the associated costs of attending. However, we know 1 in 3 will miss at least one appointment due to cost at some point in their lifetime. Those with a chronic medical condition should have access to free hospital parking provided by the individual trust.

Hospital travel card system

We are also calling for a hospital travel card system to be implemented for people with CF, which would provide subsidised journeys that are green (using electric vehicles), clean, and quick, giving direct access to hospitals whenever needed.

Energy

Social tariff for energy bills

The rise in fuel costs has had a particularly devastating effect on those with long-term health conditions like CF. People with CF face higher energy bills because they need to use more energy to stay well. This can be due to keeping their homes warm to stave off lung infections, washing clothes more often, needing an additional fridge to store medications, or running additional specialist equipment like ventilators. Introducing a social tariff for gas and electricity would ensure our community can pay for the energy required to keep healthy.

Reform of Warm Home Discount Scheme

We are calling on the Government to make a meaningful increase to the Warm Home Discount Scheme allowances to match the soaring costs of energy bills. We're also calling for the reversal of eligibility changes to the scheme that prevent those in receipt of non-means-tested benefits, such as Daily Living Allowance (DLA), PIP, or Attendance Allowance, from qualifying. People who are in receipt of disability benefits have faced huge rises in costs, meaning these benefits don't stretch as far as they used to.

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 advisers. 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 into how we can help. You can also find lots of information on financial support available on our website at **cysticfibrosis.org.uk/finances**

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

We understand it can be complicated to negotiate the benefits system. 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.

For more information, visit **cysticfibrosis.org.uk/benefits** or contact our Helpline.

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 (PPCs), and funerals. Visit **cysticfibrosis.org.uk/grants** for more information.

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. Visit **cysticfibrosis.org.uk/prescriptions** for more information.

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. Visit **cysticfibrosis.org.uk/workforwards** for more information.

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. Visit **cysticfibrosis.org.uk/incomemax** for more information.

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*Names have been changed throughout.

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*