

The Financial Costs of Cystic Fibrosis

The impact that CF can have on individual and family finances

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About this report

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Contents

Executive summary	4
1 Introduction	6
2 The overall cost of CF	9
3 Extra costs	15
4 Lost income	30
5 Conclusions and policy implications	41
Appendix	45

Executive summary

Cystic Fibrosis (CF) – like many long-term health conditions and disabilities – can have significant financial implications for those with a diagnosis and their families. People with CF face substantial extra costs and may also see their income reduced as a result of their condition, while access to financial services (such as insurance) can also be more difficult. Through both qualitative research and a survey of adults with CF and the parents of children with CF, we find that:

- **Families with CF are more likely to be struggling with their finances than the general UK population** – 24% of adults with CF and 35% of parents of children with CF described meeting their bills each month as a ‘constant struggle’, compared to 17% of UK households overall.
- **This leads to high levels of anxiety around money** – over three-quarters of adults with CF (76%) and 85% of parents of children with CF report that thinking about their finances makes them feel anxious.
- **A typical family with CF will lose £564 per month – or nearly £6,800 per year - as a result of the condition** – this median financial impact is higher among parents of children with CF (£825 per month) than among adults with CF (£388), primarily because a greater proportion of parents had incurred some form of income loss as a result of caring for their child with CF.
- **An adult with CF will typically spend £209 more per month on increased costs as a result of their condition, while parents of children with CF spend £291 more per month** – this includes costs associated with travelling to and from medical appointments, medical treatment, dietary requirements, higher energy bills and a range of other types of cost.
- **The more unwell a child with CF is, the higher costs are likely to be** – parents of children whose day-to-day activities are affected ‘a lot’ by CF reported incurring extra costs of £645 per month on average (with a median of £565).
- **Over half of adults with CF (59%) had incurred some form of income loss due to CF in the last two years** – the most common impact was taking unpaid leave to attend appointments (27%), followed by giving up work for the foreseeable future (22%), receiving a lower level of pay while sick (18%), temporarily giving up work (11%) and reducing working hours (8%).
- **More had decided not to pursue training, education or employment opportunities due to their condition (71%),** but it was not possible to attribute a monetary cost to such decisions.
- **Over three-quarters of parents of children with CF (77%) had lost income in some way due to CF in the last two years** – again, the most common impact was taking unpaid leave (46%), followed by giving up work for the foreseeable future (26%), reducing working hours (25%) and temporarily giving up work before returning (15%). These figures include the impact on both the responding parent and also their partner (if applicable).
- **Families with CF can also face a range of other financial issues, such as difficulty accessing insurance, finding suitable accommodation and accessing the benefit system** – for example, 64% of adults with CF who had a mortgage had tried to purchase mortgage protection or life insurance but had been unable to do so; 31% of adults with CF had moved to somewhere with a better environment for someone with CF; over a third (36%) of those not currently receiving disability-related benefits had previously been refused them.

More generally, the research highlights the great efforts that those with CF make in order to keep themselves as healthy as possible. This comes at a significant financial cost, but many consider it a price worth paying to improve their quality of life. The rising cost of living and increasing inadequacy of incomes, however, poses a substantial challenge in the coming months and years. While people with CF are appreciative of any help that they get, more is almost certainly needed.

In the words of families with CF

"I'm literally dreading this winter so much because my heating has always got to be on because I don't want her to get a cold, I don't want her to be ill, clothes can't go on the radiator, you know, can't have a clothes horse, [have to use] the tumble dryer which is just extortionate."

"My oxygen concentrator that's running most of the time, is usually sort of a third of our electricity bill...it's about 300 watts."

"You have to watch what you eat to stay well, and decent food is expensive."

"Having a baby with CF is very different from having a baby without CF... the absolute fear that is put in you as a parent when your child is diagnosed around the quality of the environment that you're bringing that child home to. So it might be things around maintenance like mould in your bathrooms, mould in your kitchens, you know, floor coverings when the baby started to crawl."

"Because [my son] was missing so much school for some number of years we did actually pay for him to go to extra learning ... which was about £100 a month at the time. But I had to stop that in the end because it was just, you know, too expensive."

"Generally if your work is understanding and gives you time off and you get it paid then that's going to make a massive difference ...I've spoken to other people who've been managed out because of the time off."

1 Introduction

1.1 Introduction

Over 10,000 people in the UK have been diagnosed with Cystic Fibrosis (referred to hereafter as CF) – a life-long inherited condition caused by a faulty gene, which leads sticky mucus to build up in the lungs. CF can lead to a range of symptoms which may include breathing problems, lung infections, digestive issues and CF-related diabetes. Great strides have been made in recent years to extend life expectancy of people with CF: predicted life expectancy for children born with CF passed age 50 for the first time in 2021; and modulator therapies are greatly improving day-to-day quality of life and overall health prospects for many.

Despite progress on the medical treatment of the condition, people with CF – like many people with long-term health conditions or disabilities – continue to face social and economic disadvantage. A survey conducted by the Cystic Fibrosis Trust (CFT) in Spring 2022 found, for example, that 69% felt they have less money compared to those around them, due to either their or their child’s CF.¹ With rising inflation and an economy with warning lights flashing, it is perhaps of little surprise that 87% of survey respondents said they were worried about the cost of living.

This research builds on CFT’s earlier work by measuring the extra costs faced by those with CF and their families, including both additional spending that is required because of the condition and also any impacts on household income caused by a CF diagnosis. In quantifying the financial impact, it is hoped that we can not only raise awareness of the financial challenges facing those with CF but also improve the targeting of support provided to those in need.

1.2 Measuring the cost of CF

The methodology for calculating the cost of CF is adapted from a previous study which calculated the costs of a cancer diagnosis on behalf of Macmillan cancer support charity.² The research involved two stages:

1. **Qualitative stage**, including focus groups and one-to-one depth interviews with 17 adults with CF and 12 parents of children with CF. The purpose of this stage was to gather information about what families with CF felt were the main costs and financial impacts that they incur as a result of their diagnosis – and how these financial impacts affect them and their wider quality of life.
2. **Survey stage**, with the questionnaire informed by the results of the qualitative research. The survey was conducted online in October-November 2022 and was completed by 174 adults with CF and 133 parents of children aged 18 with CF. The survey allows us to establish how often families with CF in the UK incur different types of cost – or income loss – and to determine the amount, in monetary terms, lost due to their condition. We also collected information on households’ general financial situation, which we can compare to data for the wider population in the UK.

Please see Figure 1.1 for an overview of the different costs and income impacts that were included in the research. Figure 1.2 includes a number of key points that should be borne in mind when interpreting the results of this research, while more detail on the methodology can be found in the appendix.

¹ Earlam (2022) The cost of cystic fibrosis 2022.

² Finney *et al* (2012) [The financial impacts of cancer.](#)

Figure 1.1 – Which financial impacts of CF are measured within this research?



The survey also includes questions on insurance, impacts on decisions about where to live, and whether CF has impacted career or education decisions - but we do not assign a monetary cost to these.

Figure 1.2 – Points to bear in mind when reading this report:

- The results have been weighted to be representative of the wider population of approximately 10,000 people in the UK with CF – based on data from the Cystic Fibrosis Registry.³ This weighting takes into account the number of adults aged 18 or over with CF and the number of children under 18 with the condition. For adults with CF, the results are also weighted based on sex and economic activity.
- Unless otherwise stated, the unweighted base for adults with CF is 174, while for parents of children with CF it is 133. Responses with an excessive number of missing answers and those who were ineligible (e.g. outside of the UK or a parent answering on behalf of their adult child with CF) have been excluded from the analysis.
- The sample for the research is self-selecting, in that participants were generally recruited via the Cystic Fibrosis Trust’s mailing list and social media. It may be the case that those who are more interested in the financial costs of CF would be more likely to respond to the survey. Re-weighting the results helps to take this into account to some extent.
- We have taken steps – described in more detail in the appendix – to remove extreme cases from the analysis which might otherwise incorrectly skew the results. This involves both removing outlier values (for each type of cost) and predominantly focusing on median results (as opposed to the arithmetic average, i.e. the mean).
- For brevity, throughout the report we use the term ‘parents’ of children with CF to also include parental guardians/carers of children with CF.

³ [UK Cystic Fibrosis Registry Annual Data Report 2019](#). Data for 2019 used to minimise impacts of the pandemic on data related to economic activity.

2 The overall cost of CF

2.1 The overall cost of CF

The overall financial impacts of CF are comprised of both additional spending and loss of income, and differ for adults with CF and parents of children with CF. As Figure 2.1 shows, for all households with CF – whether adults or children with CF – the median financial impact therefore is £564 per month, meaning that half of households with CF will lose under £564 per month due to the condition while the other half will lose more than £564. The mean average is larger, at £750 per month, as it is skewed by those households experiencing particularly high financial impacts (though, as noted in the previous section, we have already removed extreme outliers from the analysis which would otherwise have skewed the results further).

Figure 2.1 – Summary of the financial impacts of CF, per month

Group	Financial impact	25th percentile	Median	75th percentile	Mean
Adults with CF	Extra costs	£104	£209	£382	£286
	Reduced income	£0	£18	£575	£290
	Total financial cost	£189	£388	£873	£577
Parents of children with CF	Extra costs	£148	£291	£497	£362
	Reduced income	£11	£263	£1,036	£609
	Total financial cost	£280	£825	£1,457	£971
Total	Extra costs	£114	£240	£458	£320
	Reduced income	£0	£43	£781	£431
	Total financial cost	£209	£564	£1,095	£750

Notes: based on sample of 174 adults with CF and 133 parents of children with CF.

We find that parents of children with CF typically report higher financial impacts (median of £825 per month) than adults with CF (median of £388 per month). This is due partially to slightly higher additional costs (median of £291, compared with £209) but mainly as a result of higher reported knock-on impacts on the incomes of one or both parents (where the parent responding to the survey was in a couple), whereas for adults with CF we had predominantly been interested in only the impacts on the person with CF's income, not their partner's (if they have one). It should also be borne in mind that if a parent left work to care for their child with CF, it was not clear to what extent they would have done this anyway had their child not had CF. To some extent therefore the 'reduced income' cost for parents of children with CF also captures a general 'parenthood penalty'. The parent group are also older on average than those with CF, meaning that they are usually on slightly higher incomes in the first place, so have more to lose if they leave work, reduce their hours or take unpaid leave.

As mentioned, the median adult with CF incurs a total monthly financial impact of £388, with a mean of £577. The 25th and 75th percentiles meanwhile are £189 and £873 respectively, indicating that the middle 50% of adults with CF will incur costs somewhere between these figures. Median extra spending for this group is £209 (mean of £286), while median income loss is just £18 (mean of £290). The difference between the median and the mean indicates that most adults with CF incur low (or no) income loss as a result of their CF but that a smaller proportion are more significantly affected.

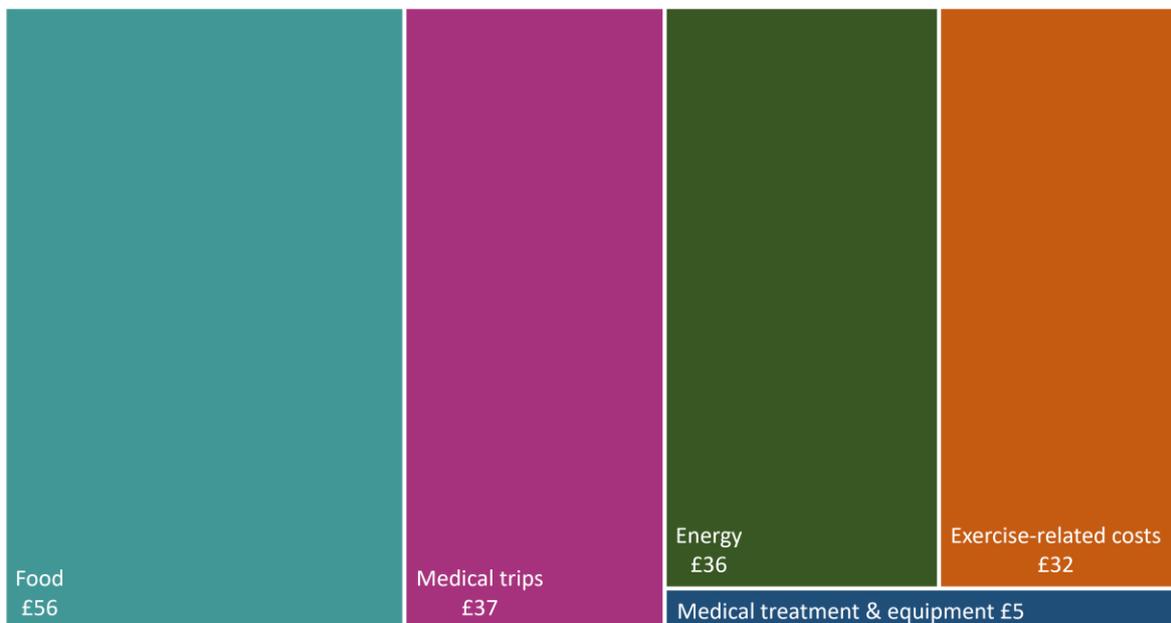
All additional costs and income loss figures are explored in more detail in the chapters that follow; however, Figure 2.2 gives an overview of the main composition of the extra costs that affect a) adults with CF and b) parents of children with CF:

Figure 2.2 – Median extra costs incurred by families with CF each month

a) Adults with CF – total extra costs = £209



b) Parents of children with CF – total extra costs = £291



Please note that, unlike for *mean* averages, the sum of individual *medians* is not expected to add up to the median total extra costs presented. Also note that these charts do not include categories of extra spending where the median monthly cost was £0, such as home modifications, purchasing specialist equipment, household assistance or catch-up tutoring. These categories of spending are, however, included in the figure for total extra costs.

The level of extra costs incurred by parents of children with CF are partly determined by the extent to which the condition affects the health of their child. Figure 2.3 highlights how the families of those children who are significantly affected by CF end up spending considerably more than those whose CF has limited impact (£645 per month, compared with £290). This is understandable given that children who are sicker are likely to need more appointments, a more specialist diet and more equipment to keep them well.

Figure 2.3 – Mean extra costs incurred among parents of children with CF, by impact of CF on their child’s day-to-day activities



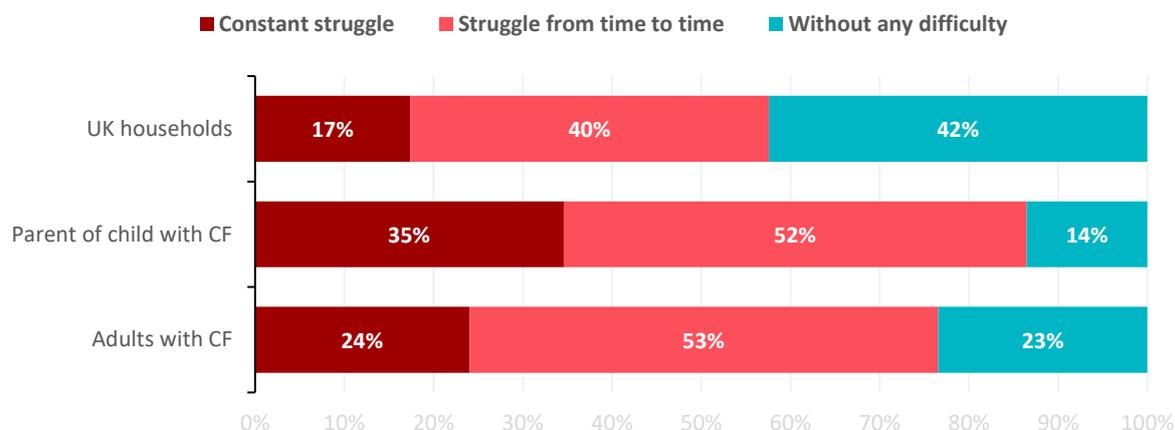
Notes: Median values as follows: No significant impact = £223; A little = £274; A lot = £565.

As the survey was conducted in October-November 2022, the results take into account the rising cost of living in the UK at that point in time. In other words, the figures presented give the additional cost over and above what we would expect a family unaffected by CF to incur at this time. Further inflation would of course increase the costs incurred both by families with CF and families without CF. This would lead to a higher figure for the ‘total cost of CF’ in absolute terms, but not in real terms – though it is important to note that families’ ability to meet any extra costs will depend on the extent to which their income rises in line with inflation. As incomes for many households have not been keeping up with inflation, this means that the additional costs of CF will currently be even harder to bear.

2.2 Financial wellbeing of families with CF

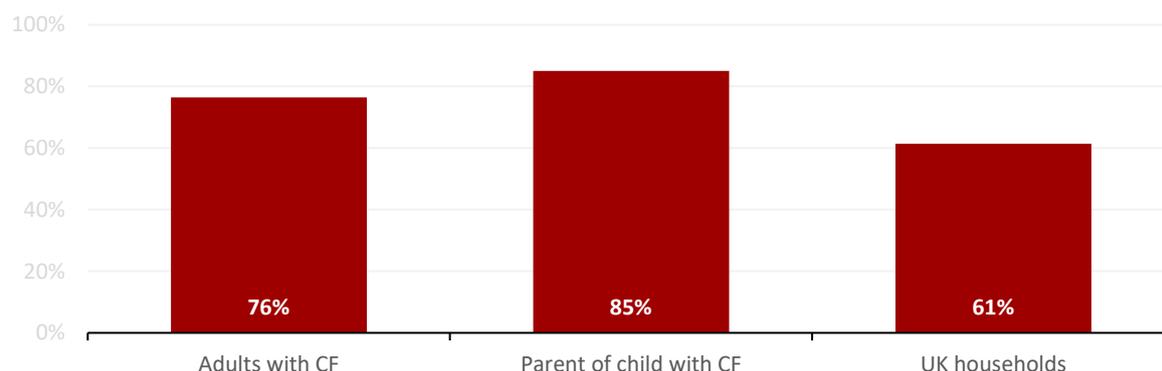
As we see in Figures 2.4 and 2.5, adults with CF and parents of children with CF who responded to the survey were more likely than UK households overall to report that they are struggling with their finances or that thinking about their finances makes them feel anxious. For example, around 17% of UK households describe meeting their bills as a ‘constant struggle’, while this rises to 24% and 35% respectively for adults with CF and parents of children with CF.

Figure 2.4 – How well families with CF are managing to meet their bills each month, compared to UK households overall.



Notes: Figures for UK households taken from Evans & Collard’s (2022) financial tracker survey, based on a nationally representative survey of 6,108 households conducted in October-November 2022 at a similar time to the survey with families with CF.

Figure 2.5 – Percentage of families with CF who agree that thinking about their finances makes them feel anxious, compared to UK households overall.



Notes: Figures for UK households taken from Evans & Collard’s (2022) financial tracker survey, based on a nationally representative survey of 6,108 households conducted in October-November 2022 at a similar time to the survey with families with CF.

The cost of living was a huge cause for concern among those we spoke to. As Figure 2.5 shows, this is a concern for the majority of people in the UK but is felt more keenly by those whose households are affected by CF, given the higher reliance on energy, or more expensive dietary requirements. Many were particularly worried about the impact of rising heating costs, and the cost of energy more broadly. For those who were unable to work, there was worry over needing to have the heating on all day, and the rising costs over food. The recent increase in interest rates was worrying for those who had mortgages, as any slack that they had in their budget to account for the cost of living would be taken up by increased housing costs.

“I’m literally dreading this winter so much because my heating has always got to be on because I don’t want her to get a cold, I don’t want her to be ill, clothes can’t go on the radiator, you know, can’t have a clothes horse, [have to use] the tumble dryer which is just extortionate.” (Parent of child aged under 5)

This was even more noticeable among parents of young children with CF, as they were more likely to be at home, and more vulnerable to infections.

For these parents, the fear was that this would result in rising and potentially unmanageable debt, as 'going without' was just not an option. There were examples of some households already struggling with debt, primarily as a way of meeting these costs. The child's illness could cut off many of the options that other families may be able to pursue to save money.

"There's no way I would take [child] on a bus to the hospital, okay it's only a couple of pounds, he would get on free, I'm not putting him in the middle of winter on a bus of people." (Parent of child aged under 5)

As we discuss later in the report, many of those with CF or whose children have CF are just not in a position to increase their income through paid employment, and those who were reliant on benefits, even partially, were concerned that they would not have enough money to get by. Even those who had previously felt that they were in a reasonably secure financial position were now concerned that they will struggle to have a decent standard of living. Some were already relying on their savings to meet their day-to-day expenses, and others had cut back on any non-essentials.

"We used to go to the cinema when my husband first retired. We used to go to the Wednesday afternoon silver, slightly cheaper ticket and you got tea and a bun and it was a really nice, 30 quid gone but you didn't think about it...So life has changed and I don't know whether that will ever come back really...we've got enough money to survive but it's kind of like oh we'd better not do this, this month, we'd better not do that and you know, I haven't had to think like that too much before." (Adult, not working, over 40)

3 Extra costs

3.1 Extra costs as a result of CF

In this chapter, we consider the wide range of additional costs that families with CF incur as a result of the condition. As described previously, the median additional costs faced by adults with CF is £209 per month while for parents of children with CF it is £291. The mean costs rise to £286 and £362 respectively, as a result of some households incurring particularly high costs.

3.1.1 Medical appointments

As Figure 3.1 shows, the costs of attending medical appointments were incurred by the majority of those we spoke to; very few were immune to these costs, although the amounts incurred varied considerably.

Travel costs

As attending clinics was a regular occurrence, unlike seeing the GP, or hospital visits, it was these trips that were most discussed in terms of costs. Most participants attended these by car, often with a journey time of around 30-40 minutes, with the consequent fuel costs that this would necessitate, as well as parking costs unless eligible for free parking. Obtaining free parking, within England at least, depended largely on whether the person in question qualified for a Blue Badge, and there were few among our participants who had. Some had applied for one but were deemed ineligible. Some were able to get financial support from charities or elsewhere to cover unusually high travel costs, for example, when someone needed to travel across country to a specialist centre.

However, there were many examples of situations where costs were much higher, and journey times or routes more difficult. Young adults, who may have recently moved away from home may end up living further away from their childhood clinics, but would prefer to continue with the same treatment team. Students in particular may not wish to register somewhere where they may only live temporarily, but this can mean a premium in terms of travel costs, let alone travel time.

“I had to go between [my current city] and [my old city] about 6 times for medical needs this year and each way is 15 quid and plus your lunch or whatever costing you.... [my new local CF centre] practically said unless you cut ties with [my old CF centre] we're not going to help you in any way unless it's some sort of an emergency or something that would be too silly to go back to [my old city] for.” (Student)

“The reason I haven't been to a GP or to a CF clinic is because I can't afford to, not because I don't need to.” (Adult with CF, responding to survey)

Generally speaking, few had any real control over how easy their journey could be, and so the costs incurred were also out of their control. For some families, childcare responsibilities could mean that public transport and other expenses were incurred for more than one child, adding to the overall expense of a visit. Alternatively, childcare costs were incurred to accommodate leaving the other children behind. A longer journey time could also add a layer of complication and costs, in terms of

either public transports costs or fuel. However, one or two did receive help towards their travel costs from charities linked to their hospital.

Finally, an understandable fear of getting Covid in recent years has exacerbated existing concerns over the infection risks of travelling by public transport. While some had always used alternative modes of transport, recently, even those who had previously travelled to appointments by public transport were looking for alternative ways, which could be hiring a car, or asking a relative for a lift, then covering the fuel and subsistence costs for the person who came with them.

Refreshment and entertainment costs

Including travel and the appointment itself, most of those we spoke to would at least buy some form of refreshments while visiting the clinic. The visits could be draining and therefore a 'treat' made them seem less onerous.

"After a long visit, you need a cup of coffee and a bun to keep you going" (Adult with CF, not working, over 40)

While these costs may be small, they were regularly incurred, and could be difficult for those who were on low incomes. Furthermore, the longer the journey, the more likely it would be that meals and refreshments would be bought outside of the home. For those whose children had CF, this could mean buying more than just food.

"When they were little, it was a treat at the end, from the shop... a magazine or a cuddly toy or something like that, especially if the treatment had been quite long or he hated getting his bloods done when he was little, do you know what I mean?" (Parent of child aged 10-15)

Hospital visits were even more costly from this perspective, as they involved longer periods of time away from home. While the children who had been admitted were provided with food, the parents, and any other visitors would need to provide their own, sometimes for weeks as at time. If the hospital had a 'one parent staying' rule, then the other parents may have to find their own accommodation costs as well. Parents often bought food for the children while they were staying, as they were fed up with hospital food.

Ensuring that children had what they needed to entertain themselves when they were in hospital was a priority. Many of the parents we spoke to talked of buying a tablet or games console for visits to the hospitals or clinic, especially as children with CF were often isolated from the general ward.

"The children have to be in isolation, so it's been really difficult over the years, they're not allowed out onto the ward, they're not allowed in the playroom." (Parent of child aged 10-15)

However, it wasn't just children who needed to buy extras for a stay; adults also talked of buying, paying for Wi-Fi at the hospital, or even buying a portable TV or iPad.

"I do bring my iPad in and I watch Netflix on that... Day-to-day I wouldn't use it [iPad] because I've got the phone to be honest but that's the only time I ever use it. I wouldn't have bought it otherwise, to be honest." (Adult with CF, working, over 40)

In our survey, 91% of adults with CF and 100% of parents of children with CF had incurred some kind of cost related to medical appointments in the past six months. Approximately half (51%) of all families with CF had incurred costs visiting their GP surgery to see a doctor or nurse, while 88% had incurred costs visiting their CF team at a CF centre and 65% had done so visiting other consultants or specialists at a hospital or other clinic (for example, a diabetes clinic).

Figure 3.1 describes typical costs incurred visiting medical professionals. Adults with CF typically spent £22 per month in total travelling to and from their medical appointments and paying for parking, refreshments, accommodation and childcare related to this. For parents of children with CF, this figure rises to £37 – which may reflect additional costs associated with transporting both adults and children to appointments via public transport or with purchasing refreshments for everyone (potentially including any siblings).

Figure 3.1 – Costs incurred per month related to medical appointments

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Visiting GP or nurse: travel, parking & refreshments	£0	£1	£4	£5	52%	£3
	Visiting CF team: travel, parking & refreshments	£3	£9	£20	£18	83%	£13
	Visiting other specialists: travel, parking & refreshments	£0	£3	£13	£12	62%	£9
	Other medical trip-related expenses, such as accommodation & childcare	£0	£2	£4	£4	-	£3
	Total cost of medical trip-related expenses	£7	£22	£50	£38	91%	£26
Parents of children with CF	Visiting GP or nurse: travel, parking & refreshments	£0	£0	£8	£10	50%	£8
	Visiting CF team: travel, parking & refreshments	£8	£15	£33	£30	96%	£15
	Visiting other specialists: travel, parking & refreshments	£0	£5	£17	£13	68%	£10
	Other medical trip-related expenses, such as accommodation & childcare	£0	£4	£17	£12	-	£8
	Total cost of medical trip-related expenses	£17	£37	£80	£64	100%	£37

Notes: 'Other medical trip-related expenses' relates to costs other than travel, parking and refreshments across visits to all types of medical practitioners, including CF centres, GP surgeries or other healthcare settings.

3.1.2 Medical treatment

The majority of those we spoke to were either entitled to free prescriptions, or paid for the NHS Prescription Prepayment Certificate, which costs £108.10 for 12 months. While few were particularly bothered by this expense, and indeed one person bought smaller items, such as Movicol themselves, to save the NHS money, the disparity between those who were eligible for free prescriptions and those who weren't, was commented on: there didn't seem any reason why those who also had diabetes were exempt from prescription charges, whereas those who had CF only were not. The unfairness of how those with CF incurred prescription charges was a clear cause for concern among many of the adults with CF that we spoke to.

However, there were also examples of where participants had paid for extra treatments and supplements, and these were generally with the aim of preventing them suffering more serious illness and infections. One parent bought her son probiotics, to counteract the side effects from antibiotics; another had paid for the chicken pox vaccine, as this is not routinely available for children. Among both children and adults, there were quite a few who bought vitamin supplements or fish oils, in a bid to keep themselves as healthy as possible, given the increased likelihood of infections.

Among adults with CF in England, 47% had purchased an NHS Prescription Prepayment Certificate (PPC) in the past 12 months. At a cost of £108 per year for a 12-month PPC, we therefore can establish that nearly half of adults in England with CF were spending approximately £9 per month on PPCs – which averages out across the entire sample of adults with CF at a mean of £4 per month.

Turning to spending on medicines, dietary supplements and vitamins not covered by a PPC, we find that the median adult with CF or parent of a child with CF spends under £2 per month (with a mean of £8). It is not the case, however, that those who purchase a PPC do not incur these costs; rather, we find that 68% of adults with CF (in England) who purchased a PPC had also incurred these other costs, compared to 42% of those who hadn't bought a PPC.

Over a third of adults with CF (35%) and parents of children with CF (38%) had spent money on other medical equipment or home treatments, such as sterile water or ice packs, in the past six months. This means that the median household spent £0 on such equipment or treatments, but with a mean average of approximately £4.

One-in-five adults with CF (20%) and one-in-ten parents of children with CF (11%) had paid for some form of private medical treatment in the past six months, including counselling, private physiotherapy and drugs not available on the NHS. For those incurring such costs, the median monthly cost was £17.

Figure 3.2 – Costs incurred per month related to medical treatment

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	NHS Prescription Prepayment Certificate	£0	£0	£9	£4	40%*	£9
	Medicine, prescriptions, dietary supplements not covered by PPC	£0	£2	£10	£8	70%	£10
	Other medical equipment or home treatments	£0	£0	£3	£4	35%	£5
	Private treatment, inc. counselling, physiotherapy & drugs not on NHS	£0	£0	£0	£6	20%	£17
Parents of children with CF	NHS Prescription Prepayment Certificate	N/A	N/A	N/A	N/A	N/A	N/A
	Medicine, prescriptions, dietary supplements not covered by PPC	£0	£2	£8	£8	65%	£8
	Other medical equipment or home treatments	£0	£0	£3	£3	38%	£5
	Private treatment, inc. counselling, physiotherapy & drugs not on NHS	£0	£0	£0	£7	11%	£18

* Rises to 47% if only households in England are included. Unweighted base for adults with CF living in England = 143.

3.1.3 Dietary requirements

Eating well is of vital importance to the health for those with CF. Good nutrition and a healthy body weight have been directly linked to having better lung function and a reduced frequency of chest infections. Having CF can increase the body's energy needs by 150-200% or even higher if lung function drops or if the body is fighting an infection. CF treatment teams will have specialist dietitians to advise on nutritional needs, and all those with CF will receive personalised advice about their diet.

The cost of food was the area that was raised first when discussing extra costs, and the area where the extra costs were most noticeable. The combination of needing a high calorie diet while also buying healthy food resulted in a very high shopping bill.

The different dietary requirements were considerable; foods that are high in fat, high in protein, and foods that are salty, such as nuts, yoghurts, avocados, eggs, cheese, or chocolate. Supplements were sometimes needed, such as high calorie drinks, and milkshakes or smoothies to get extra fruit or vegetables into a child's diet. Many highlighted the sheer volume of food that was needed to stay healthy – one mother would pay for school dinners for her daughter but also send her in with a packed lunch.

The CFTR modulator therapy *Kaftrio* was perceived to have made a positive impact on changing the dietary requirements for some who were using it, but not everyone with CF will be eligible for this treatment (due to their gene variants, their age or risk of it interacting with other drugs/treatments). However, many of those we spoke to had other conditions, some related to CF, others not, that added to the complicated dietary requirements. Diabetes is a common comorbidity with CF, and those with diabetes needed to consider sugar intake. One man noted that the sugar tax impacted on him because he used fizzy drinks to regulate his blood sugar levels. Others with diabetes found eating little and often helped, meaning they therefore needed to buy healthy snacks. Allergies would also restrict what food could be bought and from where, and also how much it would cost; one mother gave the example of an ordinary pack of toaster pancakes being 35p whereas the dairy- and wheat-free ones were £2.80. Vegan milk is low in fat so some people were using Oatley cream to provide a higher fat content. They previously had been able to get a range of gluten free food on prescription at the discretion of their GP.

“You have to watch what you eat to stay well, and decent food is expensive.” (Adult with CF, not working, over 40)

“I mostly cook from scratch but when I'm ill our costs skyrocket if we eat more takeaways or ready meals. Also if I'm an inpatient my husband brings in food and takeaways to encourage me to eat and that can escalate costs.” (Adult with CF, responding to survey)

“So he used to get the biscuits and the bread and pasta and things like that, staples, and they used to be delivered to the house and it would be a big box that would last through the month but they've scrapped it all because of costs.” (Mother of child aged 5-10)

“We spend more on food because we try to ensure we have foods that our children with CF will eat and I often cook many different meals at dinner time which is not very cost efficient, but we are desperate for particularly our 9-year-old to put on weight.” (Parent, responding to survey)

Students, or adults on a low income, can find it hard to pay for the amount and type of food needed – one young man was buying seafood as a healthy source of protein, but couldn't afford to keep doing so. And children with CF, like all children, can be picky with food, change tastes or have preferred brands, all of which will add to the cost of providing a healthy diet. Food, therefore, is a complicated and expensive part of life with CF.

To estimate the extra food costs borne by families with CF, we asked survey respondents to tell us how much they typically spend on food and non-alcoholic drinks in their grocery shop each week. We then compare this to comparable figures from the ONS for households of the same size and a similar age profile. This indicates that around two-thirds of adults with CF (65%) and a similar proportion of parents of children with CF (63%) spend more on food than would otherwise be expected. The median extra monthly food costs are nearly £60, equivalent to an extra £10-15 per week.

Figure 3.3 – Extra food costs per month

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Additional food costs	£0	£59	£234	£150	65%	£172
Parents of children with CF	Additional food costs	£0	£56	£199	£151	63%	£154

Note: 'Additional' food costs mean the difference between what a household with CF spends per month and what a 'typical' comparable household in the general population spends.

3.1.4 Exercise

As with good nutrition, physical exercise is a key part of the management of CF, as it can help clear mucus from the lungs, and improve overall health. This was the case for most of those we spoke to although there were a variety of ways in which this necessity was met, and as a result, considerable differences in costs incurred.

The main concerns for parents whose children had CF was to keep them interested enough to regularly do their exercises, and to balance their needs with those of other siblings. Keeping children interested often involved buying different types of equipment over months, or even years. It was not a case of buying sports equipment as a 'one off', and that was that. Equipment might include a trampoline, blowing toys, football equipment, a running machine, roller skates, or a space hopper. Hygiene concerns could also increase the cost of keeping fit – any toy aimed at improving lung capacity through blowing would need to be replaced regularly. Formal activity and sports were common as well, which came with membership fees as well as equipment costs. While it was accepted that they may have been taking part in some of the activities regardless of CF, in the families we spoke to, the children often did multiple activities; for example, swimming and football as well as

“Having one child who you need to keep active and do stuff that costs money to keep him busy and active because it's got to be interesting, he doesn't want to just go ride his bike around the park, he wants to do fun things for his physio because he gets bored of doing activity, you know, well then it's having to pay for four children to do it instead of one.” (Parent, child aged 5-10)

having a trampoline at home. Unlike families without CF, however, these were not activities that could be dropped if finances were tight – as part of the management of the child’s CF, they were very much an essential.

In families where there were siblings, then often these costs were multiplied; it appeared unfair to give one child something that was denied to others, particularly when aware that they may miss out in other ways.

For adults with CF, the most common cost was a regular monthly gym membership, although some kept fit by running; the cheapest and easiest option for them. However, this was not an option for all – the local area may not be safe, or have high levels of air pollution, and for others, the choice may be driven by finances rather than preference. Parents of children with CF (77%) were more likely to report spending money on forms of exercise for their children than adults with CF (51%) – and also typically spent more when they did (median of £37 for those incurring this cost, compared with £25 for adults with CF).

Figure 3.4 – Costs incurred per month related to exercise

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Exercise classes, gym memberships or sports clubs	£0	£5	£25	£17	51%	£25
Parents of children with CF	Exercise classes, gym memberships or sports clubs	£5	£32	£58	£39	77%	£37

3.1.5 Energy bills

Along with food, energy bills were the biggest financial concern among those we spoke to, as both were absolutely essential to the health and quality of life of people with CF, and the costs of which were increasing at an unparalleled rate.

As Figure 3.5 shows, those with Cystic Fibrosis have much higher energy use than others, for many reasons. Firstly, it is essential to keep the house warm, as a cold environment can be harmful to the chest. Others noted that hot baths can help relieve other ailments, such as sore joints or IBS health issues. Secondly, essential equipment such nebulisers, air filters and CPAP machines all use high levels of electricity to run. To ensure good hygiene, given excessive sweating, incontinence issues and the generally higher risk of sickness among those with CF, washing machines may need to run more frequently than in other households. Families with CF are also often actively advised not to have washing drying around the house or on radiators because of the harmful damp atmosphere this can create, so drying clothes via a tumble dryer was often the most realistic option, particularly for families with children. Many ran more than one fridge, to store medicines, and nebulisers and extra food. Oxygen concentrators were noted as particularly energy intensive, and while there is some

rebate towards the cost of these, there was a fear that this rebate wouldn't keep up with the current costs.

“My oxygen concentrator that's running most of the time, is usually sort of a third of our electricity bill...it's about 300 watts... there is the rebate, which often takes 3 to 6 months to come through and then I get a reimbursed payment... but obviously the rate for that has got to be keep being increased as the energy cost increases otherwise it's not an actual rebate.”
(Adult with CF, over 40)

In a similar way to how we estimate additional food costs, we can compare the energy bills of households with CF in September 2022 (prior to the roll-out of Government support with energy costs) with what would be expected (based on Ofgem data) for households of a similar size on the energy price cap. This allows us to estimate the extra energy bills incurred by households with CF, likely because of higher energy usage due to the factors described above.

We find that, for the median adult with CF, their energy bill will be £26 higher per month than 'typical' households, while for parents of children with CF this figure rises to £36. Most families with CF (84% for adults with CF and 87% for parents) incur extra energy costs to some extent.

Figure 3.5 – Costs incurred per month related to exercise

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Additional energy costs	£26	£26	£32	£40	84%	£26
Parents of children with CF	Additional energy costs	£5	£36	£36	£43	87%	£36

Note: 'Additional' energy costs means the difference between what a household with CF spends per month and what a 'typical' comparable household in the general population spends.

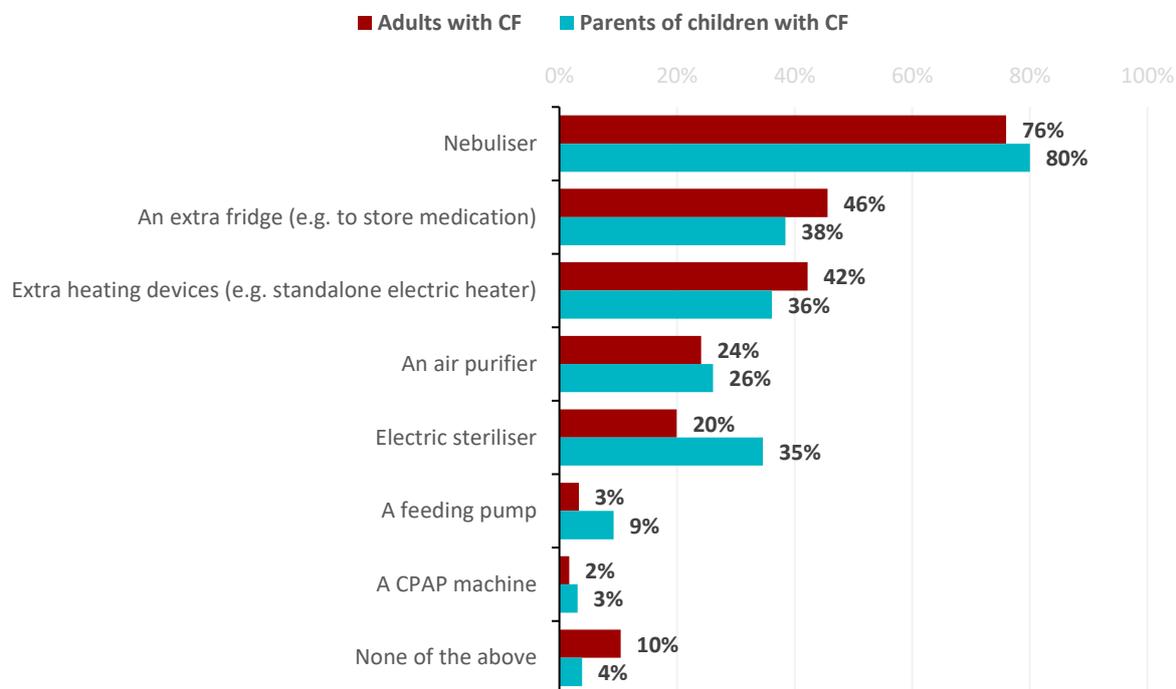
As well as asking survey respondents about their overall energy costs, we also asked them about whether they run specific items of equipment because of their CF. The energy costs of running each of these items of equipment explain at least some of the additional costs that those with CF can face. As Figure 3.6 shows, nebulisers were the most common item of equipment (used by 76% of adults with CF and 80% of parents of children with CF), followed by running an extra fridge and additional heating devices (such as standalone electric heaters). Air purifiers were used by around a quarter of respondents, while electric sterilisers were more common among parents (35%) than adults with CF (20%).

While not captured directly by the survey, all these items of equipment would have costs associated both with buying the equipment in the first place and then the cost of the energy to run them. For example, a mini fridge for medicine can cost around £100 and would cost an estimated £6 per month in electricity.⁴ Air purifiers start at around £40 but can quickly become more expensive for more advanced versions; if run for 12 hours per day, monthly electricity costs would be around £3 – and there may be costs associated with replacing filters. Small electric heaters can be purchased relatively

⁴ Based on stated wattages of products available online and a cost of 34p per kWh of energy used.

cheaply (starting at £20 or so) but running one for six hours a day for half the year could cost as much as £60 per month on current energy prices.

Figure 3.6 – Equipment used by those with CF



3.1.6 Home modifications, specialist equipment & household assistance

The majority of equipment needed by those with CF was provided by the NHS. However, some had bought items to try to make their life with CF easier – one man bought a spare nebuliser so that he was able to do this in the car on the way to work, and he paid for medical grade water for his CPAP machine, to stop it from smelling and scaling up. FFP3 masks were another expense for some, once returning to work after Covid lockdowns. Other equipment purchased included sterilisers, ultrasonic cleaners, air purifiers and conditioners, and even medical supplies such as wound dressings or incontinence products when needed. Some bought supplies that they were entitled to from the NHS, but these were slow to be delivered or lower quality than they were prepared to use.

However, a few parents had spent a lot of money upgrading some of the equipment that was provided for their child, such as buying an eFlow machine, as the one they had was ‘noisy’ and took a long time to work.

“I used to have to literally pin him down on the floor and sit on him and put this nebuliser. It was the only way I could do it; it was awful. And in the end it got so distressing for him that we heard about these eFlows, so we invested in one of those because obviously it was quiet, it was quick compared to what he was doing.” (Parent of child with CF)

There were also examples of parents fundraising to provide expensive equipment that may not be considered essential by the health service but would make life easier or improve the health of their children, such as a physio vest or a therapy bed. Both of these would cost thousands of pounds and would likely have been out of reach financially without the support of others. It is clear that the best interests of children are paramount, and parents will do whatever they can to improve the quality of life of their children with CF. This is a theme that runs through many of the extra costs that are incurred.

Some families with CF had paid to have modifications to their house, such as damp proofing or insulation, to improve the temperature and air quality in their home. Generally speaking, maintaining the home in good condition was more urgent for families where there is CF, as a bad environment could be damaging, such as having damp or mould in the house. Maintenance therefore needed to be done immediately, rather than waiting to save up before having work done.

A quarter of adults with CF (27%) and nearly half of parents of children with CF (48%) had incurred some cost in the past five years making modifications to their home or purchasing specialist equipment. For those who had incurred such costs, the median monthly cost (bearing in mind these costs are spread out over five years) was £8 for adults with CF and £10 for parents of children with CF.

“Having a baby with CF is very different from having a baby without CF... the absolute fear that is put in you as a parent when your child is diagnosed around the quality of the environment that you're bringing that child home to. So it might be things around maintenance like mould in your bathrooms, mould in your kitchens, you know, floor coverings when the baby started to crawl.” (Parent of child with CF)

Approximately one-in-five families with CF had incurred costs in the last six months related to some form of household assistance – such as a cleaner – where CF would otherwise make it difficult to manage without. Those adults with CF who incurred this cost had spent a median of £40 per month, while parents of children with CF who had done so spent a median of £100. It should be noted though that many of these costs may only be available to those who have extra money to be able to afford them; many others with CF might also benefit from home modifications, equipment or household assistance but can't currently afford them. This may exacerbate health inequalities between richer and poorer households.

Figure 3.7 – Costs incurred per month related to home modifications, specialist equipment and household assistance

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Home modifications & specialist equipment	£0	£0	£1	£7	27%	£8
	Household assistance	£0	£0	£0	£13	23%	£40
Parents of children with CF	Home modifications & specialist equipment	£0	£0	£10	£16	48%	£10
	Household assistance	£0	£0	£0	£17	19%	£100

Note: The time period asked about for home modifications and specialist equipment was five years. The costs given therefore are monthly averages over this five-year period (whereas for household assistance and most other items of spending asked about the time period was six months).

3.1.7 Catch-up private tutors for children with CF

A number of parents of children with CF described how they had acquired private tutors for their child after they had missed a considerable number of days of school due to poor health or attending appointments. In the survey, one-in-ten (10%) parents had incurred such costs, spending a median of £80 per month (or a mean of £118). This might pay for approximately three to five hours of tutoring per month. As with the previous section, this is another cost that is likely to currently only be incurred by those families who can afford it, although many more children might benefit from catch-up tutoring. This means there is a risk of widening educational inequalities between those children with CF from more affluent and poorer families.

Figure 3.8 – Costs incurred per month for private tutoring

Group	Reason for cost	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Parents of children with CF	Catch-up private tutoring	£0	£0	£0	£11	10%	£80

“Because [my son] was missing so much school for some number of years we did actually pay for him to go to extra learning ... which was about £100 a month at the time. But I had to stop that in the end because it was just, you know, too expensive. He would go after school or at the weekends twice a week, because I felt like his health had impacted on his education hugely.”
(Parent of child with CF)

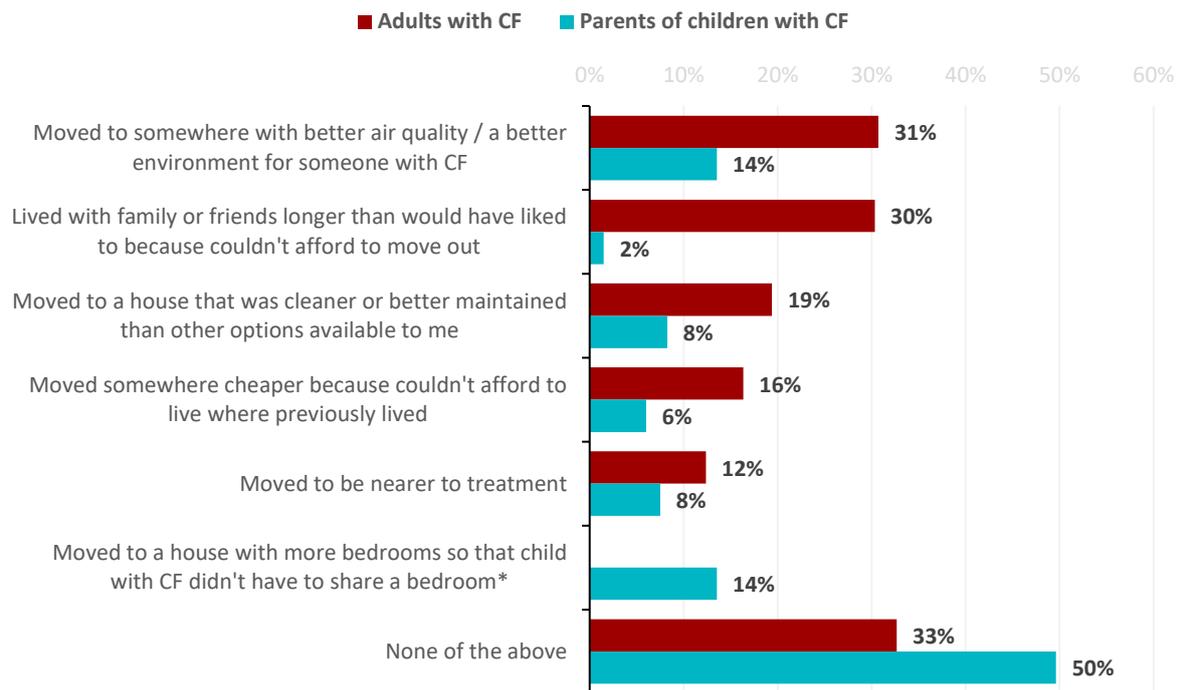
3.1.8 Other costs

There were a range of other costs that were raised in our interviews where the financial cost itself was not possible to quantify. For the majority of these – described below – we were able to capture some data to indicate prevalence, but further research would be necessary to establish the actual costs that those with CF faced.

Impact on housing

While we were not able to fully quantify the costs of how CF affects family choice of housing, we captured data on the proportion of adults with CF and parents of children with CF who had made different housing choices because of the condition (Figure 3.9). The most common impact for adults with CF was moving to somewhere with an environment more suitable for someone with CF (31%). This might mean moving somewhere more rural with better air quality. Second most common was living with family or friends for longer than they ideally would like due to a lack of money (30%). This is not uncommon in younger generations due to the high cost of housing, not only those with CF, but it does illustrate the significant impact that limited money can have for people’s independence, especially where health conditions have a knock-on impact on finances. Similarly, 16% had moved somewhere cheaper because they couldn’t afford to live where they had done previously.

Figure 3.9 – How CF has affected choice of housing



* Only asked of parents of children with CF.

Around one-in-five adults with CF (19%) had moved to a better maintained or cleaner house than other options available. This was something that had been raised particularly in interviews with students, who found that a significant portion of student housing in the private rental sector was simply unsuitable for someone with a health condition like CF (due to mould, damp, etc.).

One-in-eight adults with CF (12%) had moved to be closer to where they receive treatment. Some interviews mentioned that they had done this to save money – and also time – travelling to and from appointments.

Parents of children with CF were less likely to say that their child’s CF had impacted their choice of housing (50% said ‘none of the above’ impacts, compared with 33% of adults with CF). The most common impacts, however, were moving to a better environment and moving to a house that was big enough to allow their child with CF to not have to share a room with other children – both impacting 14% of respondents.

For young adults, moving into independent accommodation for the first time, they may have many more things to consider than other young people in the same situation. A few have chosen the location of their home with their clinic’s location in mind – paying the premium for living in London to be nearer to a CF clinic, for example, or thinking about moving nearer to the hospital in the future.

“You're hyperaware when you've got CF, when we were looking around student accommodation, a lot of student accommodation can be quite cramped and quite mouldy and you have nowhere to dry your clothes so everybody does it inside, that kind of stuff, and we looked for a really spacious flat, which luckily we found, and we had these massive windows that we could open. That's probably still something I've always looked for, so when me and my partner moved here, it was just thinking about having a garden with some doors that we can open and lots of windows and things like that so that, you know, you're not drying all your clothes inside and it gets all damp.” (Young adult with CF)

Insurance

Interviewees described the difficulties that CF can cause in relation to insurance, such as raising the cost of their insurance, rendering them ineligible (or certainly believing themselves to be ineligible) and taking out policies that do not fully meet their needs or cover everything they need them to.

Many had taken out travel insurance at one point or another, but all agreed it was very costly. One man gave the example that he could pay up to £100 for insurance while his partner was paying £6, and many talked of travel insurance costing hundreds of pounds. One woman commented that the price of insurance for her and her son to fly to America was equivalent to another ticket. For others, the price was prohibitive, and they hadn't travelled abroad for a long time; some took the risk of travelling without insurance. One parent also described how travel insurance policies could leave their child with CF covered for only part of their treatment abroad: for example, if their child broke their leg abroad and needed treatment including an anaesthetic, this would be covered, but people with CF generally also need a course of IVs following anaesthetic – and these IVs would not be covered.

Another woman with CF felt that insurers' assessment of risk wasn't reflective of how people with CF actually manage their condition when travelling.

“You optimise treatment to make sure that you're as well as possible for [holidays, special events] and what you get asked on insurance policies are when did you last have hospital treatment or something like that, you know, when were you last an inpatient. Well if you've had optimisation treatment and it's included IVs it might mean that you've had some time in hospital, whether it's just one night or two nights to get going on a course of treatment – and that immediately either puts your premiums up hugely or means you're not even eligible for the insurance. But what you're actually doing is a good thing because you're preparing yourself to mean that you're less at risk of falling ill while you're away.” (Young adult with CF)

There were also extra costs associated with travel as well, such as paying for extra luggage to transport a nebuliser, or buying an extra battery for a CPAP machine, hiring an oxygen concentrator, or paying for a fit to fly test.

Life insurance or critical illness insurance was also an issue for many; few had been able to get any. One woman noted that they were able to get life insurance until 50, but after that, nothing, even though they had a note from her doctor saying her CF was mild, and her life expectancy good. A young man who was currently renting expressed his concerns over buying a house, and the consequences of not being able to pay a mortgage if his health were to deteriorate.

“We have no insurance at the minute for me. I'm the higher paid in the house, my husband is on a lower income, so if anything happened to me, God forbid, we have very little to cover us” (Adult with CF, over 50)

In the survey, respondents were asked about obtaining different types of insurance and whether cost had been a factor for those who had been unable to obtain it. Across both adults with CF and parents, 45% had obtained travel insurance in the past 12 months, with a further 44% not wanting/needing it; 6%, however, had tried to obtain it but had been unable to.⁵ It should be noted of course that these figures are based on the post-pandemic situation in late 2022, so may not be reflective of either the pre-pandemic situation or what the future may look like. Looking at adults with CF who had a mortgage, just 15% had obtained mortgage protection or life insurance, while 64% said that they had tried to purchase it but had been unable to do so (with 15% saying they did not want/need it).⁶ Of those who had tried but been unable to obtain any form of insurance (travel or mortgage/life), a quarter (25%) said that cost had been a factor which had prevented them from doing so.

Other costs

There were a number of costs that were raised in interviews that we were unable to quantify, but nonetheless are worth documenting. It was noted that sheets and clothes could wear out quickly, as CF could make you sweat more than normal, and both that, and the consequent washing at higher temperatures necessitated replacing them more frequently. The parents of children with bowel issues needed to replace underwear, clothes and sheets more often. Mattresses also needed to be replaced through extra wear. All of these costs could add up to a substantial amount over the years.

Meeting the exacting levels of hygiene that were needed to keep healthy also meant more costs. While the costs may be relatively minor, a few commented on the amount of cleaning products they had to buy, and toothbrushes, water bottles and Sippy cups all needed replacing regularly.

There were other, occasional travel costs arising; travelling to pick up a prescription that was not easily available, or having to take a taxi or car (even for short journeys) when health made it difficult to walk.

⁵ 4% responded 'not sure' when asked about travel insurance.

⁶ 6% responded 'not sure' when asked about mortgage protection or life insurance.

4 Lost income

4.1 Lost income as a result of CF

Many people with CF incur a ‘double-hit’ to their finances: not just being forced to spend more to keep themselves healthy, but potentially also losing income as a result of poor health, taking leave and making different decisions about education or employment opportunities. In this section, we explore some of the income-related impacts, starting first with those that impact adults with CF and then discussing those that impact parents of children with CF.

4.1.1 Adults with CF

The ill health suffered as a consequence of CF was the main reason why those we spoke to weren’t working – for some it was a recent change, for others, their ill health had impacted on their ability to work for a long time. Those who were aged over 40 seemed more likely to have accepted that they were unlikely to be well enough to work again, but others were hoping to go back when their health improved.

The relative health of a person made a huge difference to their ability to hold down a job, and those who had been working for years could struggle when they had a period of ill health. One man who was able to work full time described himself as ‘privileged’ in that his health was stable enough to mostly keep working. He noted that on the few occasions that he wasn’t able to work, his family were in a position to help him, but as he gets older, this would become more difficult.

Covid had unsurprisingly had a further impact on the working status of some of those we spoke to – and there were concerns over the impact that Covid may, given existing health vulnerabilities, have on future work choices. One man we spoke to changed jobs recently, in part due to the ambivalent attitude his employer had towards any health issues, including Covid.

“So when my oldest was born, Covid happened and I was offered voluntary redundancy and I think Covid played quite a bit part in my decision just because I was on maternity leave at the time and I was starting to get a bit worried about when I go back to work, having a child and then also still trying to do the amount of exercise I want to do.” (Adult with CF, not working, aged 30-40)

John is in his thirties, and previously worked in construction, but when he was moved to a larger site, it became too physically demanding, with long hours, and he ended up leaving. If he had been able to work part time, he may have stayed in the industry, however, in the future he will look for part time work elsewhere.

Many also believed that they had adjusted their job expectations, or moved role, due to their CF. Notably, some had chosen part-time work, although they often expressed a desire to work full time if their health was up to it. The ability to move between full- and part-time work with ease would help a lot of people to continue working while keeping themselves healthy, as this was an issue raised by a number of people. One man had an understanding employer, who allowed him to work part time and remotely when his health was bad, even on occasions while he was in hospital.

Work choices can have a considerable cumulative impact on wages over the lifetime. One woman had changed careers at an early stage, because she didn’t feel the initial career route she had chosen would work with her health condition. Looking at salaries in that field, she believed it possible to calculate a large loss in the subsequent years. Two of the younger adults we spoke to had been considering medical careers – one had been working towards becoming a scientist, but a severe lung

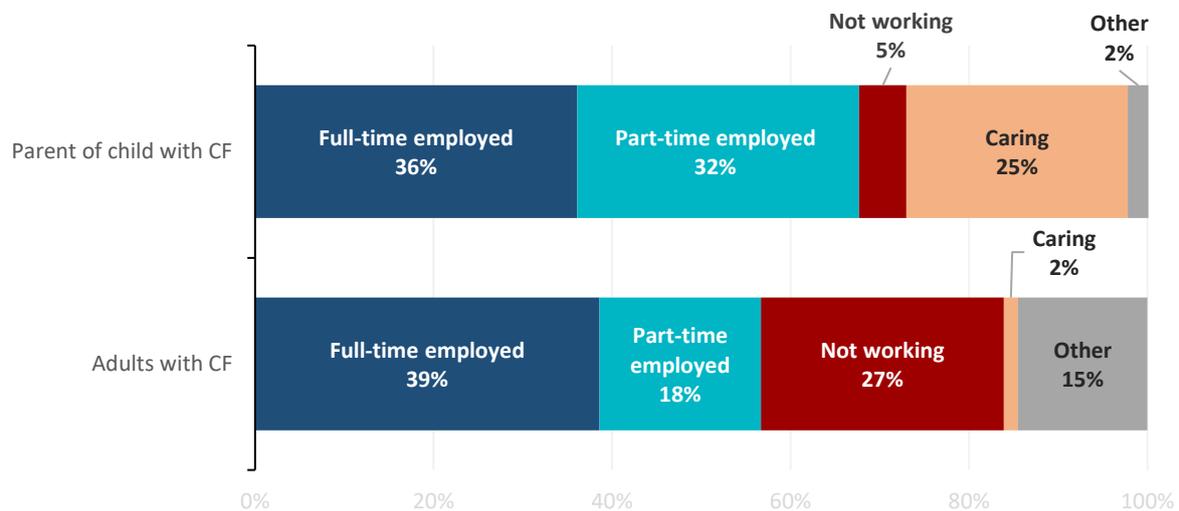
infection meant that he was advised against working in a laboratory for health reasons; the other was told for similar reasons not to pursue a career in medicine. Another man was advised against becoming an electrician, as the workspace would be too dusty. While it is hard to calculate the financial impact of this situation, it certainly highlights the emotional and psychological effect that a lack of control over your future can have. Those who retired young expressed a similar upset, with a worry over income in older age.

The impact of caring responsibility was not exclusively about parents giving up work for children either; the impact of CF could also have a knock-on effect on partners' employment. One woman's husband took early retirement at the same time that she did; she was struggling with her ill health at a particular point, and he was working long hours, and felt unable to support her. In the end, they agreed the best option was for him to retire to help look after her.

"I almost went through a kind of a grieving process, because I thought that's it, I'm done, I'm facing now what my friends are looking at in their mid-60's 70's or whatever and I'm kind of thinking that's it, washed up at 40 odd, and it's frustrating. But because I'd only been working part-time up until I took the medical retirement, of course my National Insurance contributions were less, weren't they." (Adult with CF, not working, over 40)

As we see in Figure 4.1, over half (57%) of the adults with CF that we surveyed were in work, with 39% being employed full time and 18% working part time. Just over a quarter (27%), however, were not working – either for health reasons, general unemployment or (for a minority) because they had retired.

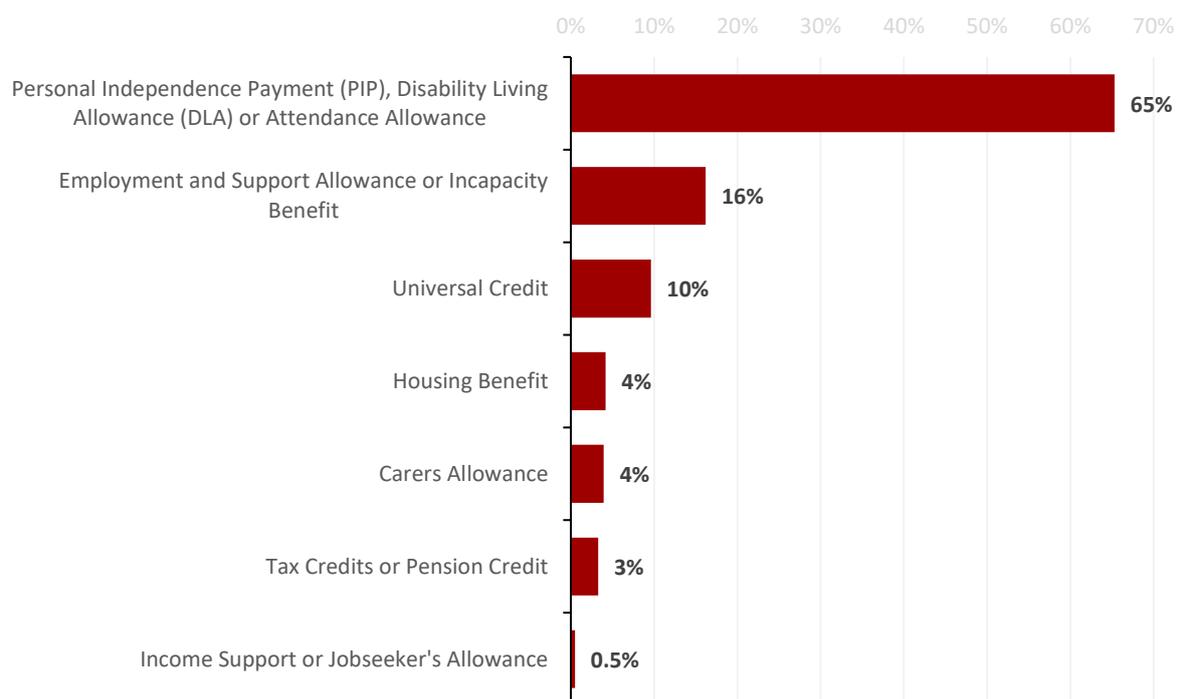
Figure 4.1 – Employment situation of survey respondent



Note that this only includes the employment situation of the survey respondent, not their partner.

The majority (68%) of adults with CF were claiming at least one form of benefit, with a quarter (27%) claiming two or more types.⁷ As shown in Figure 4.2, most common by far were disability-related benefits including Personal Independence Payment (PIP), Disability Living Allowance (DLA) and Attendance Allowance (65%). This was followed by Employment and Support Allowance (ESA) or Incapacity Benefit (16%) and then Universal Credit (10%). Breaking these results down further by current employment status, we note that 41% of those in full-time employment were in receipt of PIP, DLA or Attendance Allowance; 14% of those in part-time work were in receipt of Universal Credit, as were 25% of those out of work – with 52% of those not working in receipt of ESA or Incapacity Benefit.

Figure 4.2 – Different types of benefit received by adults with CF



One issue raised by interviewees was the difficulty of applying for disability benefits. Overall, 12% of adults with CF were not currently receiving disability-related benefits but had previously been refused them. This equates to over a third (36%) of those not currently receiving PIP, DLA or Attendance Allowance.

Given that more than half of the adults with CF who responded to the survey were in work, our calculations suggest that the median amount of income lost per month due to CF is just £18 for an adult with CF. This median, however, disguises the fact that a smaller proportion of adults with CF incur much higher income loss – so if we use the mean instead we see that the average income loss is £290 per month, with a quarter of adults with CF (those above the 75th percentile of income loss) losing more than £575 per month as a result of their condition. Over half (59%) of adults with CF had lost some form of income due to their condition, and if we exclude the 41% who have not lost *any* income due to CF, the median income loss is £421 per month while the mean rises to £493.

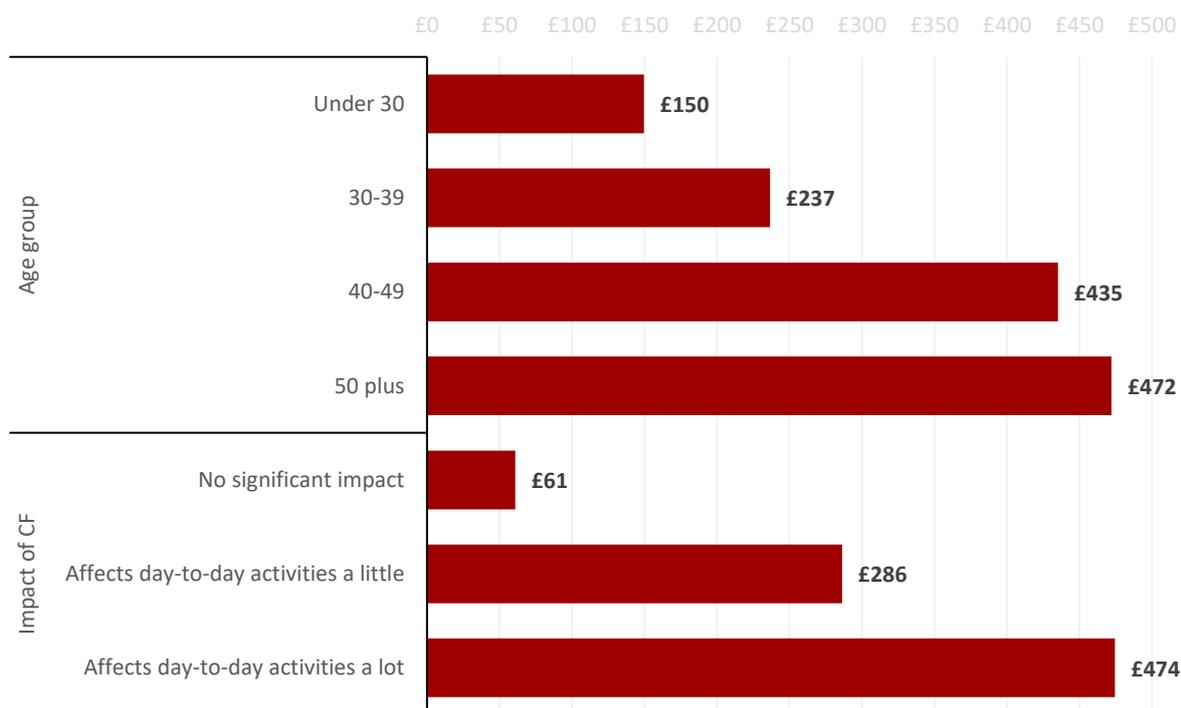
⁷ This includes: Personal Independence Payment (PIP), Disability Living Allowance (DLA), Attendance Allowance, Employment and Support Allowance (ESA), Incapacity Benefit, Carers Allowance, Tax Credits, Pension Credit, Income Support, Jobseeker's Allowance, Housing Benefit.

Figure 4.3 – Income loss incurred by adults with CF and parents of children with CF

Group	Reason for financial impact	25th percentile	Median	75th percentile	Mean	% incurring cost	Median (of those incurring)
Adults with CF	Overall income loss	£0	£18	£575	£290	59%	£421
Parents of children with CF	Overall household income loss	£11	£263	£1,036	£609	77%	£767

Unsurprisingly, the level of income loss incurred by adults with CF increases with age and the extent to which the condition affects their day-to-day activities. As Figure 4.4 shows, while those under 30 lost an average of £150 per month in income due to CF, this rises to £472 for those aged 50 and over. While this is partly because those who are older usually have more income to lose in the first place, it is predominantly due to CF typically having a greater impact on day-to-day activities with age, causing more older adults with CF to give up work completely (50% of those 50 plus, compared with 9% of those under 30).

Figure 4.4 – Mean monthly income loss among adults with CF, by age group and impact of CF on their day-to-day activities

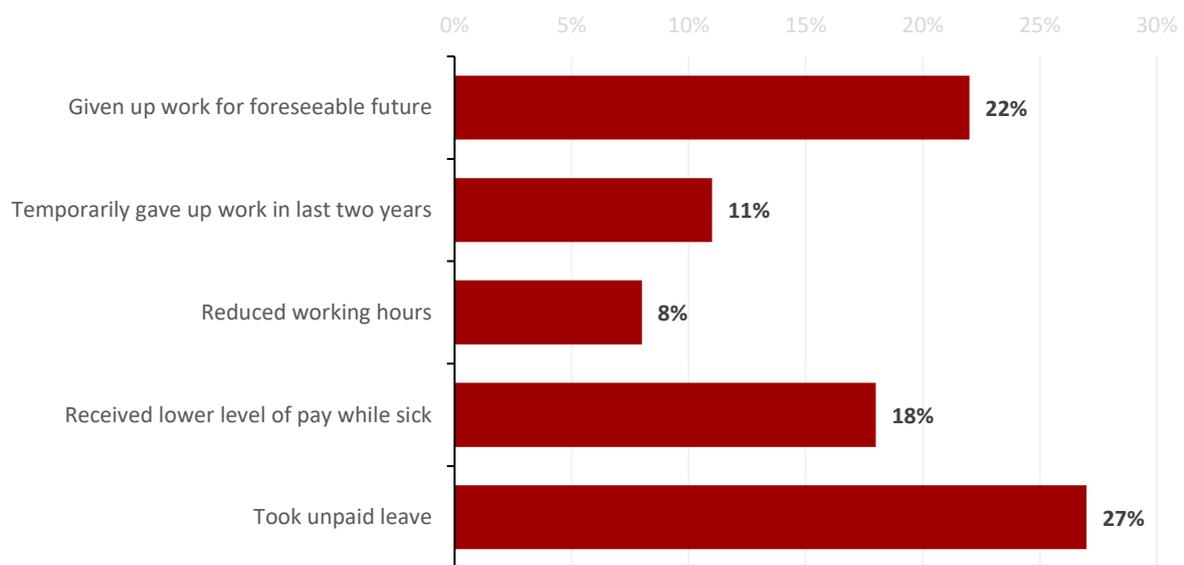


The income loss calculation is based on whether respondents had experienced any of the impacts shown in Figure 4.5, the duration of such impacts in the last two years and how their income was affected. The most common impact, incurred by 27% of adults with CF, was being forced to take unpaid leave from work due to ill-health or to attend appointments. The median number of days lost to unpaid leave was ten days in the past two years.⁸ This averages out to less than half a day per

⁸ Base is those who had taken at least one day of unpaid leave. Unweighted base = 49.

month, meaning that the overall contribution to total income loss caused by unpaid leave is relatively low. Just over one-in-five (22%) had given up work for the foreseeable future, while one-in-ten (11%) had temporarily given up work at some point in the last two years. The median time taken off work in the past two years by those who had temporarily left their jobs was 6 months.⁹ One-in-six (18%) had received a lower level of pay at some point while they were sick, with the median time on sick pay being four weeks.¹⁰ Finally, one-in-twelve (8%) had reduced their working hours to help them manage their condition, with those who did so typically halving the number of hours they worked.¹¹

Figure 4.5 – Proportion of adults with CF who had incurred different impacts on their income in the last two years



It is important to note that there were some income-related impacts that it was not possible to fully quantify in our survey. The above income impacts all enable us to see whether someone has lost income relative to their previous income – but they do not allow us to determine whether their current or previous income has always been lower as a result of their condition. In the survey we therefore asked adults with CF whether they felt their condition had changed their career plans or caused them to pass up opportunities. This reveals that nearly half of adults with CF (48%) had changed their job or career at some point because of their CF, while 71% had missed out on certain training, education or employment opportunities due to their condition. To understand the possible scale of this impact, it is instructive to consider ONS analysis of the wider disability pay gap, which shows that median pay for those whose day-to-day activities are limited ‘a little’ by their health is 12% less than for those with no disability, while it is 20% less for those whose activities are limited ‘a lot’.¹²

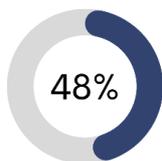
⁹ This figure should be treated with caution because it is based on a small sample. Unweighted base = 20.

¹⁰ This figure should be treated with caution because it is based on a small sample. Unweighted base = 33.

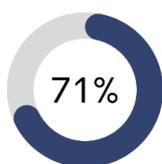
¹¹ This figure should be treated with caution because it is based on a small sample. Unweighted base = 18.

¹² ONS (2022) [Disability pay gaps in the UK: 2021](#).

Figure 4.6 – Potential impacts on the incomes of adults with CF that aren't captured by our income loss calculations



48% of adults with CF had changed their job or career because of CF



71% of adults with CF hadn't pursued certain training, education or employment opportunities because of their condition

4.1.2 Parents of children with CF

For parents, it was the unpredictability of dealing with their children's illness, not just having to take a lot of time off, but not knowing when they may need take the time off. Jobs such as teaching make it particularly difficult to manage, as someone is needed to directly cover any absence, and therefore employers may be reluctant to allow parents the flexibility they need. Some parents – though exclusively mothers – we spoke to had tried to make employment work, but the stress and worry of sudden absences meant that ultimately they chose to leave their job.

"It's difficult for employers to understand that you might just not be able to be there."
(Parent, child aged 5-10)

The level of care that children with CF need can be hard to manage alongside work. One young adult with CF was home-schooled by his mother which obviously prohibited her from working. Their sibling also has CF, and as a family, they decided that this was the best option, albeit one that came with a financial cost.

"My dad really wanted me to go to school but it was just not practical. You know, I had to be given tablets every time I ate, especially when I was younger when equipment wasn't so advanced as it is now, I had to be put on this big triangle block and just sort of bashed on the back for 10, 15 minutes, but the biggest thing was having to come out of school and go to hospital every 6 weeks or so for appointments and tests and what not; it wasn't practical." (Young adult with CF, working)

As with the health of adults with CF, it is the changeable nature of health in children that made the difference. The mothers who were holding down jobs admitted that they were lucky that their child had been relatively healthy, and most care had involved routine visits to the clinic. One mother had worked until her child was six, but a series of hospitalisations resulted in her work putting pressure on her, and she turned to ACAS. While it was eventually resolved, the combined stress of worrying about her child while also worrying about work led her to resign. This was a common theme among parents: that they wanted to be able to give the best care to their children.

While it was very common for one parent, often but not exclusively the mum, to have given up work, in many cases the level of care needed was such that both parents work could be affected. A number of parents where the father was self-employed cited lost money when both parents were needed, for

example if one child went to hospital and siblings needed care separately. In some families, often where there were health issues among the parents as well, it wasn't possible for either parent to work.

Smaller issues could also arise, but that have financial consequences. For example, one woman took three months unpaid maternity leave, as she was advised not to put her child with CF into childcare until they were at least a year old.

As shown in Figure 4.1, in our survey parents of children with CF were overall more likely to be employed than adults with CF, but were more likely to be in part-time employment (32%, compared with 18% of adults with CF) and much more likely to not be working due to caring responsibilities (25%, compared with 2%). Parents of children with CF were also more likely to be in receipt of benefits than adults with CF: 83% were receiving one or more types of benefit, while 41% were receiving two or more types (compared with 68% and 27% respectively for adults with CF). This is mainly as a result of parents of children with CF being more likely to receive Carers Allowance (31%), tax credits (22%) and, to a slightly lesser extent, Universal Credit (18%). Almost two-thirds (61%) were receiving PIP, DLA or Attendance Allowance.

As shown previously in Figure 4.3, the median income loss for parents of children with CF was £263 – substantially higher than for adults with CF (£18). Mean income loss meanwhile was £609. The primary reason for these higher figures is that for parents of children with CF, we consider the impact of CF on both the responding parent and their partner (if they have one). This means that the vast majority (77%) of parents with CF reported at least some form of income loss as a result of their child's condition. It should also be noted that it was not possible to determine *to what extent* income impacts were related to CF, only that they were at least in part related to the condition. For example, it may be the case that a parent would have given up work or reduced their hours anyway had their child not had CF.

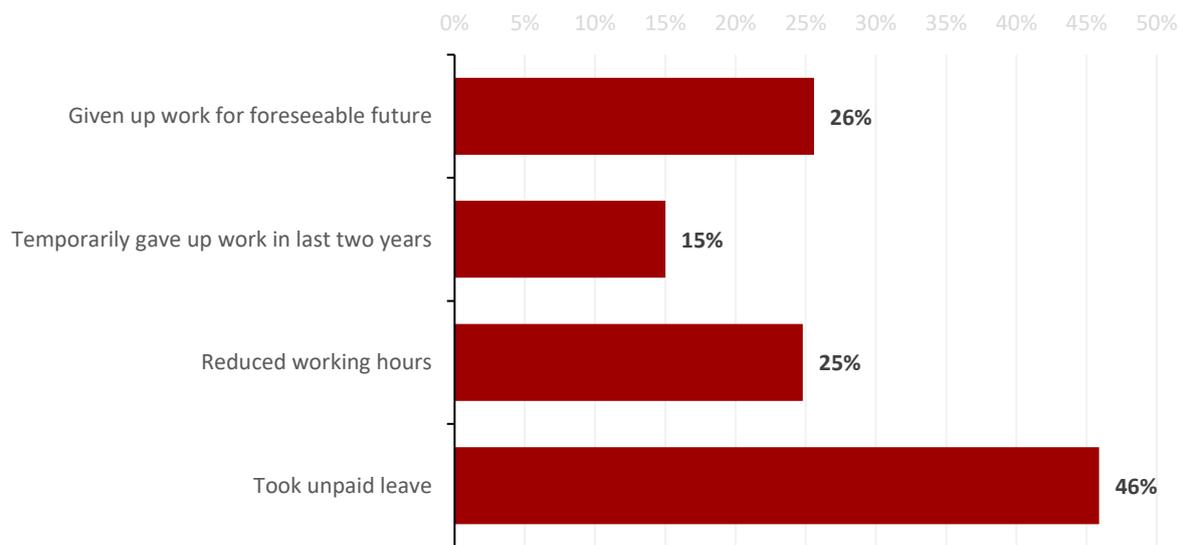
As with adults with CF, the most common income impact for parents was taking unpaid leave (46%), with the median parent taking ten days of unpaid leave in the past two years.¹³ A quarter (26%) had given up work for the foreseeable future, while 15% had temporarily given up work during the last two years. A quarter (25%) meanwhile had reduced their working hours during the past two years, typically by 58% - which would be equivalent to a 35-hour week being cut to about 15 hours.¹⁴

Again, like adults with CF, there were also employment impacts for parents where we were not able to calculate a direct figure for income loss. We find that 51% of responding parents said that they had changed their job or career as a result of their child's CF, while 8% said that this was the case for their partner. Nearly three-quarters (74%) meanwhile said they had missed training, education or employment opportunities at least partly due to their child's CF, with 15% saying this had affected their partner.

¹³ Base is those who had taken at least one day of unpaid leave. Unweighted base = 47.

¹⁴ This figure should be treated with caution because it is based on a small sample. Unweighted base = 17 (based only on reduction in working hours for the responding parent, not their partner).

Figure 4.7 – Proportion of parents of children with CF who had incurred different impacts on their income in the last two years. Based on respondent or their partner.



Steve, a man in his 50s, received a transplant a few years ago. In the time leading up to the transplant, his health deteriorated, and he needed oxygen 24 hours a day. Nonetheless, he was able to keep his job throughout, as his employer was prepared to make adjustments. He was able to continue his work while needing oxygen, and as he had worked for the same company for over 20 years, was paid his full salary while recovering from the operation, and his team was reconfigured to allow him a phased return.

“Generally, if your work is understanding and gives you time off and you get it paid then that's going to make a massive difference ...I've spoken to other people who've been managed out because of the time off.”

4.1.3 Employment issues

Overall, the ability to keep working appeared to be very dependent on whether the employer, or even the line manager, was understanding about time off when ill, and prepared to make adjustments to place or hours of work. We came across examples of good practice, and this had allowed people to carry on with their careers. One mother of an eight-year-old boy, worked in Special Educational Needs within a school environment, and found it extremely difficult to go back to work after maternity leave. Her employer was very supportive and persuaded her to stay as they valued her contribution. They allowed her to start back in a part-time capacity and gradually work her way up to full-time hours. They were also prepared to find cover at short notice when she needed to take time off.

Conversely, many of the reasons why some had struggled to continue in their job was through the lack of any support or allowances by their employer. One woman had been working short shifts in retail and didn't qualify for breaks as a result. Her manager refused to let her take a quick break to have some water, even though they were aware of her health condition – diabetes as well as CF. In the end, she felt there was no option but to leave. Others mentioned how attitudes towards them changed once they had extended periods of sick leave, and while few were actually sacked, there was a belief that they were 'edged out' through micromangement, or through making it difficult to take the time off.

There were some examples of employment practice that could assist those with CF in continuing to work; one man had an annualised hours contract, which meant he could make up hours that he lost during periods of ill health. Similarly, some were offered flexibility in terms of the number of hours worked, or whether they were allowed to work from home or not. A formalised carers leave policy would be of great benefit to parents of children with CF.

4.1.4 Issues with benefits

DLA/PIP was the most commonly claimed benefit, unsurprisingly, but a surprising number of those with CF had either been turned down or hadn't applied for it because they expected to be refused. One man who was refused was on an IV waiting list for a transplant at the time. While one parent had to go to appeal before their child was awarded higher-rate DLA, and in her own words, she was 'good at filling in forms'. She believed that many people with CF, or those whose children had CF would not be getting the benefits they were entitled to, and that support in claiming would be useful to many. Quite a few people didn't know if they were entitled to any support, and others had only claimed because a social worker or nurse had suggested that they do so. While clearly the ill health impacts for CF varied enormously between people, it did appear as though it was harder to qualify for DLA/PIP through the changeable level of disability caused by CF.

Those who had moved from DLA to PIP noted that it was no longer a permanent award, but one that needed to be renewed every three years. There were also a few examples where receipt of certain benefits had a negative impact on eligibility – for example, receiving DLA resulted in no longer getting council tax relief, or the Carers Allowance amount deducted from Universal Credit payments.

4.2 Cumulative impact of the costs of CF

Fundamentally, both extra costs and lost income had a major impact on the lives of those with CF in different ways. For those whose employment and income prospects had been affected by their health, the lost income was considerable, but by and large, households had adjusted. In some cases, the changes happened a long time ago, and so the lifestyle had been gradually built up on the basis of the reduced income. Those who were partnered were better able to weather the loss in income, but nonetheless, for many, it was now a matter of juggling to manage. Some were already implementing coping strategies, such as selling at car boots sales, or borrowing from family when needed.

For some, these strategies could include borrowing as a way of smoothing income. One woman who worked in a school didn't get paid during the six-week summer holiday, and so put her expenses on a credit card to manage this period. Another took out loans during the early years of their child's life, which they were still repaying. It has long been recognised that a drop in income can be a trigger for problem debt, and it is clear that where there is CF in households there is a higher chance of a temporary or permanent loss of income.

Even where it didn't result in credit use, the reduction in family income could mean an inability to save, concern over a lower pension in the future through lower contributions and missing out on 'luxuries'. As discussed previously, it is hard for someone with CF, or with caring responsibilities for a child with CF, to change jobs as a way of increasing income. Many were struggling to manage the job they already had, and it could be risky to move from a sympathetic employer to increase their salary.

However, when the reduced income is trying to cover the higher costs involved with living with CF, then it becomes even harder to manage. The current cost of living crisis was already hitting many of those we spoke to, and the first response was invariably to cut back. However, having CF made participating in life harder, and more expensive, and the loss of income or extra costs amplifies the difficulties in doing so. It was the social side of life where those with CF lost out, as this was where cutbacks were made, and from an already disadvantaged position. Unfortunately, many were struggling to afford to travel to see family, or friends, and this could mean missing out on the emotional support that these can offer. When only one person was well enough to work, they ended up working so many hours that they didn't have the time – let alone the money – to socialise.

For parents whose children had CF, there is also an element of wanting to give their child everything possible to make their life easier, to compensate for the difficulties they face as a result of their CF. As we have already noted, this can mean spending money on sports subscriptions, or on toys for hospital visits, but it can also mean spending more on days out or holidays when the child is well enough, as they will be missing out on much at other times. For some, however, due to cost of living increases, and through loss of an income, this was no longer possible.

Parents who also had children without CF were unable to compensate them for the amount of time and energy that had to go into caring for a child with CF, particularly when they are in hospital, or needing a treatment. One mother talked about her three healthy daughters, and how extra money would allow her to have paid for things to make their life easier, but it is equally applicable to anyone whose family is impacted by CF. The time and effort it takes to travel to the clinic or hospital, to deal with invasive tests or treatments, or to do the extra loads of washing, or to fit in the physio could be made easier with the money to buy support for housework or occasional takeaways. Quality of life could be improved with more money for holidays or day trips, but in the context of a cost of living crisis, these seem to be getting further out of reach for those with CF.

“At the moment I don't have a social life, it's my friend's birthday next week and I just looked at my financial situation and I can't afford it. She invited me and my partner to have a meal and a couple of drinks and we simply can't afford it and that has a huge impact.” (Young adult with CF)

“I do put a lot more money into days out and holidays out because I've got this constant guilt. To keep his mental health well, so rather than thinking about the physical health, I will be saying what do you want to do, let's go to Sealife Centre.” (Parent, child aged 5-10)

“It was a tight budget anyway but that was planned, to be able to have that day out, buy lunch, buy an ice cream, maybe have a look and get a coffee at the shop and it's gone.” (Parent of child under 5)

“They've all struggled with lack of support, It's been difficult, you know, at times when the schools have been really hard on them. Our kids' school is very strict and it's an automatic 6pm detention for being 1 minute late and they've got no parents at home doing their washing or cooking them dinner ... you know, if you had plenty of money you could solve half of these problems. You could make sure that the kids got an Uber in an emergency or a taxi or you know, you'd make sure you'd left them with plenty of food that was easy to cook but you're still trying to save costs.” (Parent of child under 5)

5 Conclusions and policy implications

5.1 Conclusions and policy implications

This report highlights the substantial financial impact that CF can have for those with the condition and their families. The vast majority of people with CF will incur additional costs of some kind in a given month, whether it be travelling to and from appointments or spending money on diet, exercise, equipment, treatment or good hygiene, simply to keep healthy. A significant proportion will also incur some form of income loss as a result of the condition, with this varying from the need to take a small number of days of unpaid leave (to attend appointments, etc) to leaving the workforce entirely. The impacts of this on quality of life can be dramatic.

There were also costs that could not easily be quantified within this report. These include the costs associated with moving to different accommodation in order to have a better environment for someone with CF or to be nearer to treatment, as well as extra costs related to obtaining the right level of insurance. We also do not attempt to calculate the income loss caused by taking different career or education decisions as a result of CF, which may ultimately set someone with CF on a vastly different career trajectory. As previously mentioned, to understand the possible scale of this impact, one can consider ONS analysis of the disability pay gap affecting those with disabilities more broadly; this shows that median pay for those whose day-to-day activities are limited 'a little' by their health is 12% less than for those with no disability, while it is 20% less for those whose activities are limited 'a lot'.¹⁵

The results of the research illustrate the importance of preventative spending for people with CF. Participants described the additional costs they incur as absolutely essential because the things they spend money on help to keep them healthy and avoid exacerbations of their CF. Extra spending on food, exercise or ensuring a healthy environment are all critical – but there is a real risk in the current cost of living crisis that families with CF are forced to eventually put their short-term finances ahead of their longer-term health. It is crucial therefore that policymakers do all they can to protect this essential preventative spending.

This report adds evidence in relation to a number of policy areas:

- **Reducing costs for those with CF** – while many of the everyday costs that people with CF face were often seen as an unavoidable part of life, policymakers can consider a range of ways to ease the burden of these costs on those with CF. Such measures to reduce costs may be particularly beneficial where they can be done in ways that are essentially universal – in other words, where they are contingent only on having CF, not on having to already be claiming disability-related benefits to be eligible. This is important because – as we describe below – some people experience difficulties claiming for benefits or may find it stigmatising to access benefits.

The cost that could most easily be reduced appears to be that of prescriptions in England. Those in Scotland, Wales and Northern Ireland already have access to free prescriptions, while people in England with CF tend to only be exempt where they also have CF-related diabetes not because of CF itself. CF could therefore be added to the [list of medical conditions that are exempt](#) from prescription charges. While those in receipt of benefits due to their low income are entitled to free prescriptions, making CF exempt would add another, arguably more straightforward way for people with the condition to receive free prescriptions.

¹⁵ ONS (2022) [Disability pay gaps in the UK: 2021](#).

Hospital parking is another area where costs can add up. [Current guidance](#) from the Department of Health and Social Care for NHS trusts in England makes it mandatory for parking to be free for those with Blue Badges, those attending as an outpatient three times a month for at least three months, and parents of sick children staying overnight – but (save for the latter) it is generally rare that those with CF meet these criteria. Hospital parking in Scotland and Wales has been free for patients since 2008, while parking charges are to be scrapped in Northern Ireland from 2024.

The [Healthcare Travel Costs Scheme](#) (HTCS) can help those on low-incomes claim back the costs of their travel to and from appointments, including car parking charges. These require the patient to be in receipt of one of a number of means-tested benefits or to self-declare that they are on a low-income (by completing a 20-page HC1 form and providing proof of any earnings, such as payslips). The patient then needs to take travel receipts, proof of their appointment and proof of their benefits/low income to a nominated cashiers' office (usually located in the hospital or clinic) or retrospectively obtain and complete a printed claim form which can be posted to the NHS up to three months post-appointment. Previous research has highlighted issues with the scheme, including limited publicity of the scheme and difficulties accessing cashiers' offices – either due to them being 'hidden away' or having limited opening times.¹⁶ It is also unclear in what circumstances NHS Trusts will pay travel costs in advance for those who could not otherwise afford to attend their appointment. Simplification and greater awareness-raising of such schemes would be welcome.

The cost of purchasing refreshments at hospitals appears to have received little focus to-date. For example, NHS England's ['National standards for healthcare food and drink'](#) do not currently refer to a need to ensure that affordable food is available in hospital cafes and canteens.

The ability to conduct some medical appointments remotely in recent years was also mentioned by some as a positive way of reducing the cost (financially but also in terms of time and energy) of attending appointments. This option should therefore be available to people with CF where medically appropriate.

The costs incurred by people with CF could also potentially be lowered through social prescribing schemes; for example, by providing people with CF vouchers to pay for sports clubs, gyms, etc. In recent months, there have also been examples of NHS services providing vouchers for energy costs – though this should arguably be considered an absolute last resort measure. More broadly, it will be critical throughout at least 2023/24 that Government support with energy bills is sufficient to meet the extra energy costs incurred by those with CF, or other disabilities that necessitate high energy use. While around two-thirds of adults with CF were in receipt of some form of benefit, making them likely to be eligible for a) inflation-linked benefit uprating, and b) cost of living payments, the remaining third may require further support to ensure that energy bills don't become unmanageable.

Lastly, while the costs of insurance are not calculated directly within this report, it is clear that those with CF can incur high costs to get insured – even if they have taken as many steps as possible to minimise their risk.

¹⁶ Manchester Health Authority (1997) 'Hospital Travel Costs Scheme—Current Practice and Best Practice Guide'. In: House of Commons Health Committee (2006) ['NHS Charges. Third Report of Session 2005-06'](#).

- **Ensuring adequate incomes for those with CF** – clearly it is neither feasible nor desirable to design schemes to reduce every additional cost incurred by those with CF; rather it is critical that the Government ensures that families with CF are able to access incomes that are sufficient to meet the costs required to live a healthy life. This means that disability-related benefits and benefits for those on low incomes need to be sufficient, while the process of applying for disability benefits needs to recognise the reality of living with a condition like CF. The effects of CF can be highly changeable, leading people with CF to have ‘good days’ and ‘bad days’. This can lead to those who apply for disability benefits on a ‘good’ day either being declined or otherwise being forced to describe their condition as it is on a ‘bad’ day which can lead to feelings of guilt, shame and stigma. Similarly, for long-term conditions such as CF it is important that unnecessary benefit reassessments are brought to an end, so as to avoid people with CF continually going through benefit assessments despite no improvement in their health.

Employers also need to take steps to ensure that working conditions are suitable for those with CF. While we heard examples of employers making positive reasonable adjustments, we also heard of poor treatment and inflexible working practices that in some cases ultimately left people leaving the workforce altogether. This also applies to organisations who employ those who are parents of children with CF. Encouraging employers to implement a policy to deal with employees who have disabilities would be a positive step, as would implementing one to address the issue of carer’s leave.

Statutory Sick Pay (SSP) may also warrant reform. In a previous report, [The cost of cystic fibrosis - June 2022](#), Cystic Fibrosis Trust note both the reliance on SSP by those with CF, and the low level of income replacement that it offers.¹⁷ Our research confirms the need to raise the level of SSP from £99.35 per week, as well as removing the 28 week cap on eligibility.

Overall, the research highlights not only the financial burden that CF can create but also the effects that consequent financial issues can have on people’s mental and physical wellbeing. We heard stories of people with CF skipping important medical appointments because of their finances, cutting back to an extreme extent and missing out on important life moments or social events. It is vitally important that we as a society work together to ensure that people with CF – and other long-term health conditions – are treated with dignity and respect. As the cost of living rises, the need for action has never been more urgent.

¹⁷ Cystic Fibrosis Trust (2022) [The cost of cystic fibrosis](#).

Appendix

Appendix

Qualitative research methodology

The qualitative interviews were recruited via a survey distributed on CFT’s social media accounts, asking for people who may wish to take part in this research to complete the survey. The responses were sent directly to the University research team, and participants chosen based on recruiting a cross section of ages, sex and working status. Some of those who replied initially were not eligible to take part, but in total we received 178 responses from people who were eligible, and we spoke to 29 people. Our aim in recruiting was to understand the diversity of experiences amongst those who have CF, speaking to both adults with CF and the parents of children with CF.

<i>PARENTS (age of child)</i>	<i>child under 5</i>	<i>Aged 5-10</i>	<i>Aged 11-17</i>
	3	5	4

	<i>Under 30</i>	<i>30-40</i>	<i>40+</i>
WORKING ADULTS	4	3	2
NON-WORKING ADULTS	1	4	3

We spoke to a mix of men and women, although more of the parents were mothers, to people across the nations of the UK, with a mix of housing tenure, working part and full time, and who were in different financial positions. We conducted the research using a mix of one-to-one depth interviews and mini groups of 2-3 people who had common experiences.

All qualitative research was conducted online, and participants received a £30 gift voucher as a thank you for their time. The interviews were anonymised and transcribed, then analysed using Framework Analysis.

Survey methodology

Design

The survey was designed to quantify the financial impacts that families with CF face, identifying the prevalence of different financial impacts and the monetary cost incurred as a result of these impacts. This meant asking both about extra spending due to CF as well as loss of income as a result of the condition.

The questionnaire for the survey was based on the questionnaire from our earlier research for Macmillan which explored the financial impacts of a cancer diagnosis and was adjusted based on the qualitative research with adults with CF and the families of children with CF. Appendix Table 1 gives an overview of the financial impacts that were included in the survey and which of these were also included in our overall cost calculation of the financial cost of CF (as some could not feasibly be quantified to a monetary amount without very detailed questioning or significant further research).

The table also shows which costs were asked of adults with CF and which of parents of children with CF, as well as decisions taken about how each question should be asked. These decisions relate first to whether or not to ask respondents directly about the cost incurred; for example, a respondent might

not know how much a specific piece of equipment costs them to run in energy bills or they might not be aware of how much ‘extra’ they spend on food relative to other households, but they would know (approximately) how much they have spent on purchasing certain treatments/equipment (that a family without CF typically would not have to purchase). The second decision was in relation to the appropriate time period to ask about, that would balance being a long enough period that some respondents would have been likely to incur the cost within and being short enough that participants could reasonably be expected to accurately recall what costs they had incurred. For energy bills, respondents were asked about their bill for September 2022 (with those on non-direct debit tariffs asked to average out their costs for the year), as this was prior to Government energy rebates which would artificially cut energy bills on only a temporary basis.

Appendix Table 1 – Financial impacts asked about in the survey

Financial impact		Adults with CF	Parents of children with CF	Directly asked cost?	Time period asked about
Costs included in cost calculation	Travel to appointments, inc. travel costs, parking, refreshments, accommodation, any other related expenses.	Yes	Yes	Yes – number and average cost of trips.	6 months
	Cost of Prescription Prepayment Certificate (PPC)	Yes	No	Asked if they had bought a 3- or 12-month PPC.	12 months
	Medicines, dietary supplements or vitamins not covered by a PPC / provided by NHS	Yes	Yes	Yes	6 months
	Private medical treatment, including counselling, private physiotherapy or drugs not available via the NHS	Yes	Yes	Yes	6 months
	Other medical equipment or home treatments not already covered (such as sterile water, CPAP filters or ice packs)	Yes	Yes	Yes	6 months
	At-home care or assistance with household chores, such as a cleaner (where this is required because your condition makes it hard to manage without help)	Yes	Yes	Yes	6 months
	Exercise classes, gym memberships or sports clubs	Yes	Yes	Yes	6 months
	Private tutors (e.g. to help child catch-up after missing school due to ill health)	No	Yes	Yes	6 months
	Home modifications or purchasing specialist equipment	Yes	Yes	Yes	5 years
	Extra energy costs	Yes	Yes	Yes – total energy bills	Bill for Sep 2022
Extra food costs (groceries and non-alcoholic drinks)	Yes	Yes	Yes – total food cost	‘Typical week’	
Costs <u>not</u> included in cost calculation	Impacts on choice of housing, such as moving nearer to CF centre	Yes	Yes	Asked if ever impacted	Ever
	Insurance: travel and mortgage protection/life insurance	Yes	Travel only	Asked if purchased or not. If not, asked if cost was a factor.	12 months
	Running additional equipment, including extra fridges for medication, CPAP machine, air purifier, feeding pump, electric steriliser, nebuliser, extra heating devices, other.	Yes	Yes	Asked if they currently run any of these.	‘Currently’
	Free-text question for respondent to mention any other costs not already mentioned	Yes	Yes	N/A	N/A

Income loss included in cost calculation	Giving up work for foreseeable future	Yes	Yes	Asked current and previous income	Currently
	Temporarily giving up work	Yes	Yes	Asked income while gave up work, and how long for	2 years
	Reducing number of hours worked	Yes	Yes	Asked current and previous hours worked	2 years
	Receiving reduced pay while sick	Yes	No	Asked number of weeks on reduced pay	2 years
	Days of unpaid leave in last two years	Yes	Yes	Asked number of days of unpaid leave	2 years
	Income loss impacts for partner (all income loss components above repeated)	No	Yes	As for each income impact above.	2 years
Income loss <u>not</u> included in cost calculation	Changed job or career	Yes	Yes	Asked if this had ever happened	Ever
	Didn't pursue certain training or educational/employment opportunities	Yes	Yes	Asked if this had ever happened	Ever

For travel costs, participants were asked how many trips to each type of medical practitioner they had had in the past six months and to estimate (to the nearest pound) how much their travel costs had been *per trip*. Those that had driven there and who wouldn't know the exact cost were told to assume that each mile of driving costs 45 pence, so a ten-mile round trip would cost £4.50 (which should be rounded up to £5). They were given the guidance that a 10-mile trip might usually take 20-30 minutes (depending on the level of traffic).

It should be noted that there were a number of costs raised in the interviews that were not asked about in the survey because it would have been impractical to do so or where there would be difficulties obtaining a 'baseline' cost for households not affected by CF. These include the cost of additional cleaning products used, the cost of replacing clothing that has worn through quicker due to increased sweating and washing at higher temperatures, and the cost of replacing items like water bottles and toothbrushes that might wear out quicker due to increased high temperature washing. In this regard, one might argue that the cost calculated is an under-estimate; though in reality we expect that this would balance out against participants' possible over-estimation of some of the costs that were asked about.

Recruitment and data collection

The survey was administered online, using Typeform, with respondents completing the survey between 4th October and 3rd November 2022. Participants were initially invited to take part in the survey as part of a news item within the Cystic Fibrosis Trust monthly email newsletter; however, this generated a limited number of responses. The survey link was then advertised via a dedicated email to those on the CFT's mailing list, which generated a more substantial response, before also being advertised via CFT's social media accounts. A small number of CF centres also advertised the survey via a poster. No incentives were offered to participants for taking part in the survey.

Analysis

Data cleaning

In total 399 responses were received, but this was ultimately reduced to 307 (consisting of 174 adults with CF and 133 parents of children with CF) after data cleaning. This involved removing those who: neither personally had a CF diagnosis nor had a child under 18 with CF; lived outside of the UK; had not completed a sufficient number of questions; or had completed the survey more than once (based on duplicate IP addresses and responses evidently being from the same person).

Throughout the calculation of the monetary cost of the financial impacts of CF, we also took steps to deal with extreme values that would otherwise have a disproportionate influence on the results. For each component of expenditure, we removed values that exceeded 3.29 times the standard deviation above the mean. These values represented the most extreme one per cent of cases in a normal distribution. The reported values for these cases were replaced with the median value among non-zero cases – and these imputed values were carried through into the total cost calculations subsequently calculated from each component. It should be noted, however, that such outlying values are not necessarily always invalid or erroneous, as some individuals may have incurred extremely high costs – however, for the purposes of ensuring that the results are representative of the population with CF at-large, it makes sense to bring the average results in line with the average for the majority of respondents. In producing all results, we also report the median alongside the mean to highlight to the reader any differences between the 50th percentile (the median) and the arithmetic average (the mean).

For all cost components, we also ensured that participants could not incur a negative value. For example, some participants reported having lower food or energy costs than predicted for a household with their characteristics – so in these cases, we assigned them a cost of zero for this component as no ‘extra’ costs were being incurred.

Finally, despite having removed cases with high levels of missing data, some missing values still existed. In these cases, we assumed a cost of zero for that particular question.

Calculation of financial impacts

Appendix Table 2 describes the process by which monetary costs were assigned to each of the financial impacts that we measured in the survey.

Appendix Table 2 – Assigning monetary costs to each financial impact included in survey

Financial impact		Description of cost calculation
Extra costs	Travel to appointments, inc. travel costs, parking, refreshments, accommodation, any other related expenses.	For trips to each of a) GP surgeries, b) CF centres, c) other clinics or specialists, we calculate a 6-month cost of travel based on number of trips in last 6 months multiplied by cost per trip. Costs for each of the three types of medical practitioner are added together, along with other related costs incurred in last 6 months. 6-month cost is divided by 6 to obtain a monthly average.
	Cost of Prescription Prepayment Certificate (PPC)	Participants asked if purchased a 3-month PPC or a 12-month PPC in last 12 months. We assume annual cost of 12-month PPC is £108.10 and cost of 3-month PPC is £30.25. We assume that those who bought a 3-month PPC had only purchased one in 12 months. Annual cost divided by 12 to obtain monthly cost.
	Medicines, dietary supplements or vitamins not covered by a PPC / provided by NHS	For these costs, participants were asked for the total 6-month cost of each. To obtain a monthly figure, we simply divide the 6-month cost by 6 (having removed extreme values).

Private medical treatment, including counselling, private physiotherapy or drugs not available via the NHS	
Other medical equipment or home treatments not already covered (such as sterile water, CPAP filters or ice packs)	
At-home care or assistance with household chores, such as a cleaner (where this is required because your condition makes it hard to manage without help)	
Exercise classes, gym memberships or sports clubs	
Private tutors (e.g. to help child catch-up after missing school due to ill health)	
Home modifications or purchasing specialist equipment	Participants asked for 5-year cost. This is divided by 60 to obtain a monthly cost.
Extra energy costs	<p>We calculate the 'extra' cost for families with CF compared with those without CF. This means that, unlike most other costs, the baseline is not zero but is the amount a 'typical' household spends. For this, we use Ofgem data suggesting that for September 2022, the energy price cap would lead to an average monthly cost for gas and electricity of: £114 for a household with low usage (flat, apartment or small property with 1-2 occupants); £164 for medium usage (medium-sized property with 3-4 occupants); £228 for high usage (large property with 5 plus occupants).</p> <p>We therefore assigned households from our survey into low/medium/high expected usage based on number of occupants (as above). For those currently on the energy price cap for both gas and electricity we therefore calculate the difference between their energy bill for September 2022 and the expected figures above. For those not on the energy price cap, we assign them the median extra cost incurred by similar sized households who were on the price cap.</p>
Extra food costs (groceries and non-alcoholic drinks)	<p>As with energy, for food we are interested in the 'extra' amount spent on food (groceries and non-alcoholic drinks) relative to 'typical' households. The data for 'typical' households comes from the ONS 'family spending workbooks' for financial year-end 2021, showing how much households of a) different compositions, and b) differently aged 'household reference persons' spend on food and non-alcoholic drinks per week.¹⁸ The ONS, for example, provides data showing that 'non-retired one person households spent £36.30 per week on food and non-alcoholic drinks in FYE 2021, while other data they provide shows that the typical household headed by someone under 30 spends approximately 84% of what the average household aged under 65 spends on food (with a figure of 93% for those aged 30 to 49 and 115% for those aged 50 to 64). This means we calculate that a non-retired one-person household headed by someone under 30 would spend £30.37 on food per week. This is repeated for a variety of household compositions and for the following age groups: under 30, 30 to 49, and 50 to 64 (older ages ignored as no one in our survey sample was over 65).</p>

¹⁸ [Family spending workbook 2: expenditure by income - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/family-spending-workbook-2) and [Family spending workbook 1: detailed expenditure and trends - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/family-spending-workbook-1)

		<p>Having obtained detailed estimates of weekly food costs for different sub-groups for 2021, these were then inflation-adjusted, based on an inflation rate for food of 18.3% from March 2021 to October 2022. A limitation of this approach is that different households are likely to incur different levels of inflation, a problem worsened by the high rates of inflation occurring at the time of analysis. These costs were then rounded up to the nearest pound. These were the values used as the baseline estimate for ‘typical’ households not affected by CF.</p> <p>We then simply subtract the baseline figures for each sub-group from the weekly food cost given by respondents to our survey (having already removed outlier values as defined as 3.29 standard deviations from the mean or those who reported spending more than £200 per person per week on food). The weekly cost was then multiplied by 26 to give a 6-month figure and this is divided by 6 to give a monthly figure.</p>
Income loss	Giving up work for foreseeable future	<p>Those currently out of work were asked if they had given up work for the foreseeable future due to CF. Those who had given up work due to CF were asked what their monthly income was before they stopped working and what year they last worked in. They had also been asked what their current income was. Collectively, this allows us to estimate the income loss incurred as a result of giving up work.</p> <p>We use ONS earnings growth data over time to estimate what their previous income would be worth in 2022 and calculate the difference between the two incomes.</p> <p>Note that take-home income is used for all income calculations, which better reflects the direct impact on household finances after tax deductions.</p>
	Temporarily giving up work	<p>All respondents were asked if they had temporarily given up work in the past two years. Those who said they had temporarily given up work and who were currently out of work were asked what their income was before they had given up work, while those who had temporarily given up work but were now back at work were asked what their income was while out of work. Both groups were asked for how many months in the past two years they had been in this situation. The income loss per month is therefore calculated as the difference between their income in work and income out of work multiplied by the number of months in the last two years and this is then divided by 24 to give an average income loss per month over the last two years.</p> <p>To avoid double-counting, those who have an income loss for ‘giving up work for the foreseeable future’ are assigned an income loss of zero for temporarily giving up work.</p>
	Reducing number of hours worked	<p>Those who said they had reduced their working hours were asked how many hours they currently and previously worked. Using this information and what we know about their current income from employment (i.e. without benefits), we can estimate their previous income. We then calculate the difference between this and their current income (including benefits, which makes this a somewhat conservative estimate as some would have lost more income had benefits not made up the difference to some extent).</p>
	Receiving reduced pay while sick	<p>Those who received reduced pay while sick were simply asked how many weeks they had received this lower level of pay for in the last two years. It was necessary therefore to make assumptions about what their lower level of pay had been</p>

		during this time. Figures from the DWP indicate that just 26% of workers would rely solely on statutory sick pay (SSP), while analysis by the Resolution Foundation suggests that SSP replaces just 24% of income but with this varying substantially by income group (from 71% for the lowest income decile, 49% for decile 2, 34% for decile 3, down to 7% for the highest decile). Given that analysis of our survey data suggested that most had taken only a few weeks off work at most, we worked on the assumption that many would continue to receive full- or near-full-pay during this time. We therefore assumed current weekly income (from employment) would be around 25% lower – and multiplied this income loss by the number of weeks on reduced pay to give a two-year figure for income loss. This was then divided by 24 to obtain an estimate of monthly income loss.
	Days of unpaid leave in last two years	Those who had taken unpaid leave were asked about the number of days taken in the past two years. We calculated typical daily earnings by dividing monthly earnings by 21 (working days) and then multiplied this by number of days off to give an income loss figure for the past two years. This is divided by 24 to obtain an estimate of monthly income loss.
	Income loss impacts for partner of parent with child with CF (all income loss components above except for reduced pay while sick are repeated for partner)	The survey only collected data on whether or not the respondent's partner had incurred the above income impacts, not their exact income loss as a result. For this reason we apply the median income loss for each component (among respondents who had lost income) to those partners who had incurred these income effects.

Total financial impacts are therefore simply calculated as the sum of all additional spending and income loss incurred by adults with CF and parents of children with CF.

Weighting

Prior to producing the results, those in the final sample were given weights to ensure that the sample more accurately represented the composition of the wider population in terms of age split (under 18s vs those aged 18 and over), sex (male/female) and economic activity (full-time employment/part-time employment/not working/student or 'other'). The data for the wider population was taken from the 2019 CF Registry report – with 2019 chosen because the data was likely to be less impacted by the coronavirus pandemic than 2020. The most significant element of re-weighting was to up-weight adult males and down-weight adult females: while 29% of all people with CF are adult males (or 52% of adults are male), in our sample just 22% were adult males; for adult females these figures were 27% and 34% respectively. The weighting exercise causes a slight decrease in the additional costs of CF calculated, as males typically had reported lower costs than females.

Analysis

Descriptive statistics and cross-tabulations were produced for adults with CF and parents of children with CF across all of the cost components measured by the survey. T-tests were also conducted to identify significant differences in mean costs by a variety of sub-groups, including household composition, housing tenure, employment status and number of earners in the household, age group, sex, qualifications, number of cars, region and nation of UK, household income quartiles, impact of CF on day-to-day activities and age of CF diagnosis. Only statistically significant relationships (where $p < 0.05$, i.e. 95% confidence level) are reported, unless otherwise specified.

