

Cystic Fibrosis a fight we must win

Cystic Fibrosis Insight Survey
– Report on the 2017 and 2018 Surveys

Fighting for a *Life Unlimited*

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Thank you to all of the people who participated in the development and evaluation of both surveys, and to everyone who shared their experience of cystic fibrosis (CF) through this project. The insight you have given us is truly invaluable and will enable the Cystic Fibrosis Trust to have a much more rounded understanding of the impact of CF on the lives of people living the UK.

Cystic Fibrosis Trust

Cystic Fibrosis Insight Survey – Report on the 2017 and 2018 Surveys

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1. Overview of participation

The contents of this report are the result of the first two Insight Surveys, which looked at different aspects of the life experience of people with cystic fibrosis (CF) and families living in the UK. The surveys were intended to explore aspects of care and life that were not being recorded elsewhere, for example through in-clinic Patient Experience surveys, the UK Cystic Fibrosis Registry and the Question CF (Research Prioritisation) project.

The surveys were co-developed by people with CF and their families, and with colleagues from the Cystic Fibrosis Trust. Involvement took place through online group discussions, email conversations and one-to-one telephone calls.

The first survey was open for five weeks from November to December 2016 and had 870 complete responses and another 95 substantially complete. An at-a-glance report was published in April 2017. Material from the survey greatly supported the development of the Clinical Trials Accelerator project and fed into the activities of the Information and Support Team as well as Involvement and Engagement initiatives.

An evaluation exercise was completed in Spring 2017 which led us to decide that we should park most of the questions from the first survey for at least 12 months as little would have changed if the second survey was to launch within the same operational year. Feedback from the community told us that people wanted to be asked the same questions throughout, and that partners, in particular, felt that there was not enough for them to contribute in the first survey.

The second survey launched in January 2018 and was open for three weeks and four days. The survey generated 1095 complete responses, with another 400 substantially complete.

To maintain the integrity of the figures presented, we have only included the complete responses from both surveys in this report. However, we have used some of the most interesting quotes from incomplete surveys.

1.1. Impact of the access to medicines campaign

A few days after the second survey launched in January 2018, the focus of Trust communications was shifted to support the community-led access to Orkambi petition. This had an impact on the survey's reach in two ways; firstly, it became less of a priority than the need for the Trust to be actively communicating what it had been doing already in relation to access to medicines. Secondly, many responses to the survey questions demonstrated the strength of feeling on this important issue.

Responses – relationship to CF:

Survey 1	
People with CF	338 (38.9%)
Parents	366 (42%)
Partners	38 (4.4%)
Others eg. siblings, friends	128 (14.7%)

Survey 2	
People with CF	213 (20%)
Parents	543 (51%)
Partners	75 (7%)
Others eg. siblings, friends	224 (21%)

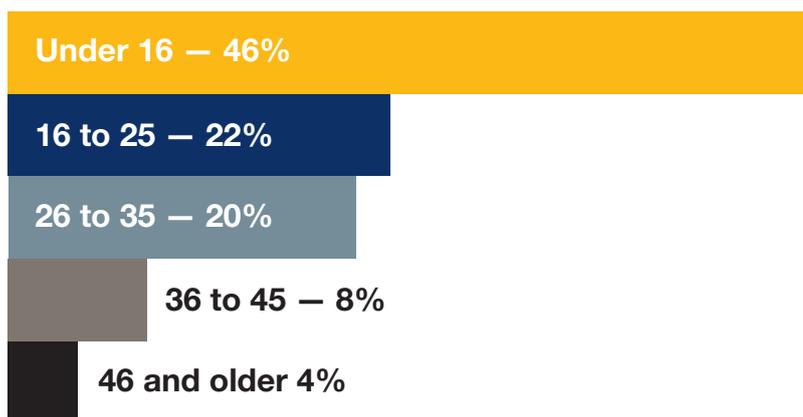
- In Survey 1, we asked families, partners and others to answer based on their knowledge of the person or persons with CF they were closest to.
- In Survey 2, we worded questions so that partners, families and others were responding based on their own experience, rather than that of the person with CF.

1.2. Gender and age

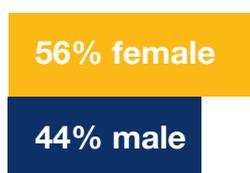
In both surveys, more women than men participated. The first survey had 66% female and 33% male respondents with 1% not disclosing their gender. The second survey responses were 76% female and 23% male with 1% not disclosing their gender. This ratio changed when looking at different groups; for example, among parents, the female to male ratio was very consistent (70/30), but among older people with CF, the responses were closer to 50/50. One very under-represented group across both surveys is men under 25 years of age, with completed surveys from male partners and fathers also appearing less frequently than female partners and mothers.

For the first survey, we also asked parents and other relatives to state the age and gender of the individual with CF that they were closest to, which generated the following:

Age of person with CF closest to you:



Gender of person with CF closest to you:



The figures above are close to UK Cystic Fibrosis Registry data, but there are differences, particularly in relation to gender (623 less females than males in the UK with CF according to Registry figures).

1.3. Geographical spread

The surveys were only actively promoted to the UK CF community, and survey information stated that we were seeking input on experience of life in the country; therefore, 97% stated that they lived in the United Kingdom. The remaining respondents were from the USA, Republic of Ireland, Australia, Spain, Italy, The Netherlands and New Zealand.

In terms of distribution within the UK, all of the regions of the country were represented generally in line with figures from the 2014 UK Cystic Fibrosis Registry online map, with the exception of Northern Ireland which was slightly under-represented in both surveys. Interestingly there was a slight decrease in the percentage of responses from Greater London in the second survey and an increase in the other regions; this meant that the second survey was closer to the UK Cystic Fibrosis Registry figures than the first.

2. Time commitment

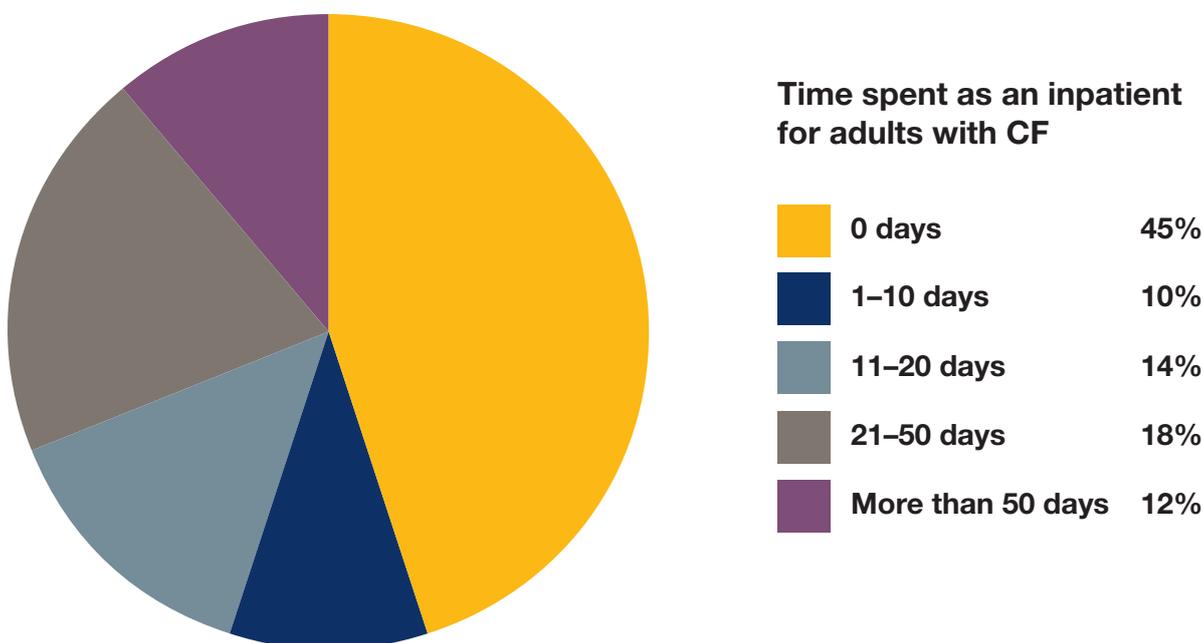
2.1. Time spent on care

In the survey, we asked how long participants spent on CF care, for example tablets, nebulisers and physio per day during the last month.

The time spent on care by adults with CF is considerable: an average of 150 minutes/2.5 hours a day. The group who spent the greatest is 26–35-year olds, who gave 163 minutes per day on average. Overall, women spent slightly longer than men (about 151 to 148 minutes).

Parents of children with CF reported an average of 137 minutes per day spent on care, 13 minutes less than the adult with CF average. One quarter (25%) spent more than 3 hours per day, 35% between 2 and 3 hours and 40% spent less than 2 hours.

2.1.1. Time spent as an inpatient in the last 12 months



The mean number of days spent as inpatient in the last 12 months among adults with CF who completed the survey is 19, with 30% spending more than 20 days as an inpatient (of these, 12% spending more than 50 days as an inpatient).

Two further points from the survey: first, it appears that as people with CF age, they will spend a greater amount of time in clinic as an inpatient. Second, satisfaction with care drops as people spend longer as an inpatient, (the very satisfied mean is 17 days; the not very satisfied mean is 20 days).

Parents of children with CF:

The mean time spent as an inpatient is lower among children: less than half that of the adults (9 days compared to 19 days). However, a small number (10%) spent more than 20 days as an inpatient in the last year. Fifteen per cent spent between 1 and 9 days, and 12% between 10 and 19 days.

Like the adults, those who spend greater time as inpatients are slightly less satisfied with the care received in their centre.

2.2.2. Number of visits to CF centres for outpatient appointments in the last 12 months

Note: we did not ask respondents to separate out scheduled check-ups.

Number of visits	Count of responses
0-4	19%
5-9	45%
10-14	23%
15-19	5%
20-24	3%
25+	5%

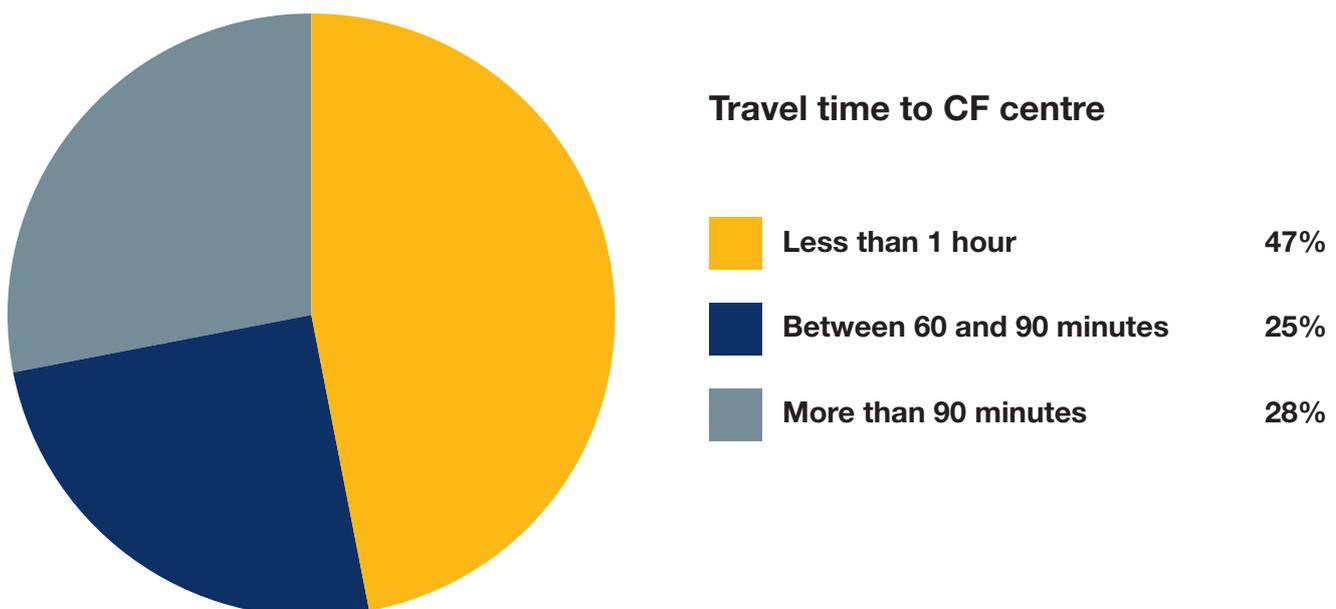
From the responses, it appears that parents of under-16s reported more outpatient appointments than the parents of older children. This is interesting to note because according to the survey responses, adults with CF and parents of adults reported a lower number of outpatient appointments, but a higher proportion of time spent as an inpatient. A tiny percentage (less than one per cent) reported no outpatient appointments.

2.2.3. Which CF centres people use

In the first survey, respondents were asked which centre people attend most frequently. The figures reported seem consistent with the known capacity of centres and show that the survey respondents were from across the UK without any particular bias.

2.3. Travel time

We asked people how long it takes to travel one-way from home to the CF centre they attend most often.



People with CF:

While London has a lower mean travel time of 58 minutes one way, the South East has a very high mean travel time (91 minutes), meaning if you live near but not in London you have an extra hour of travel both ways.

At the extreme end, three per cent of people with CF have to travel more than three hours to get to their CF centre.

Parents of children with CF:

Ten per cent of parents of children with CF travel for more than 90 minutes (one way) to reach their centre.

While the mean journey time is a little shorter than for adults with CF, only a very small percentage have short journey times: one-in-five (20%) travel less than 30 minutes to their CF centre.

2.4. Time spent on outpatient appointments including travel by people with CF

People with CF were asked the typical duration of an outpatient appointment.

The average is 154 minutes (just over 2.5 hours). With the mean travel time, an average outpatient appointment for people with CF takes 4 hours and 50 minutes.

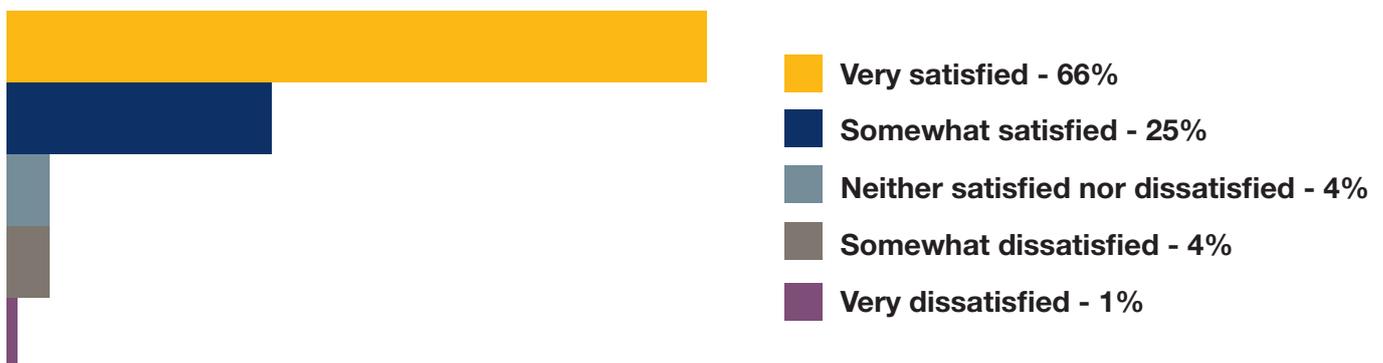


3. Experience of care

3.1. Overall satisfaction with CF centres

People were asked how satisfied they were with the care received at the CF centre they attend most often.

Adults with CF and parents of under 16s were the most satisfied with care; however, all other groups indicated they were predominantly very satisfied (at least 50% very satisfied). One in 20 are dissatisfied with the care they receive at their CF centre.



3.2. Strengths / improvements in care

3.2.1. Strengths of care

We asked adults with CF to tell us the best thing about the care they have received from the centre they attend most frequently.

Most frequent comments (with roughly equal frequency):

- Friendly, caring team; welcoming; polite and helpful
- The team know and understand my needs
- Prompt response if there is a problem; good access to service at short notice
- Good information and advice; knowledgeable, trusted expertise
- Patient feels they have choices / some control



“Everything. The Consultants are lovely, approachable and caring. They listen and work with you. The liaison nurses are hard-working and positive. The physio team are just as good. I don’t have much involvement with the dietician, but I have no complaints.”

“The ability of all of the CF team to adapt their information and treatment advice to my intellectual level and engage with my methods of self-care.”

“A team who understands my life and can help me work treatment around it - not the other way around.”

“The staff are lovely and will listen to any concerns I have even if they are stupid and they take the time to listen, and they understand that I know my body and my symptoms and let me have a say in my treatment.”

“The staff are great, really personable and easy to get along with. Makes outpatient appts and inpatient stays much easier.”

“The personal approach: I always feel like the nurses and doctors care about my individual health and do everything in their power to help. Like scheduling extra appointments for me when I’m having a blip and seeing me as often as needed. I never feel like just another CF patient.”

3.2.2. Changes to care

We also asked people what they would change about the care they receive.

People with CF:

Many wanted to be geographically closer to their centre, and therefore for care to take less time. When we move onto the next level of suggestions, however, we see a significant percentage of the improvements fall under the remit of the service providers, for example, clearer communications, personalisation and staff attitude. The least satisfied people are the ones who are most likely to mention communications, personalisation and attitude.

Improvement	
Less time spent	25%
Clearer communication	17%
Facilities	16%
Personalisation	15%
Staff specialism	12%
Attitude of staff	10%
Technology	4%

Included above but cutting across several of the areas were issues relating to loneliness and access to mental health services.

“Free WIFI; there’s nothing that I would change treatment wise.”

“I would prefer that the clinic be exclusive rather than shared with general lung clinic. A lot of the staff who treat you are not CF specialists and often glaze over when you start talking about specialist medications and clinical trials. The centre should be far more pro-active about both being involved in clinical trials and informing patients about new treatment developments. The mental health side of things should have equal weight to physical health.”

“The IV times when an inpatient needs to get more sleep. Sometimes I did not finish the night one till midnight and some nurses like to start the morning ones at 5am. I have never been so tired as my time in hospital.”

“If a mobile clinic was available as it is a long way for me to travel I feel. Although it isn’t very often so I can’t complain. Or if needing hospitalised

if possible to have my care in a closer hospital which would make it easier for visitors and less lonely whilst being admitted.”

“Greater emphasis on exercise and importance of self-care, getting enough sleep, etc. It’s very hard to attend appointments from different clinics, all within a few days of each other — if appointments could be scheduled on the same day that would be an enormous help as I often miss out on sinus/gastro appointments as I can’t take additional time off after regular CF clinics.”

“Doctors and nurses not having enough time to do the best they can — often feel like small things are missed; not followed up on at next appointments due to poor admin.”

“Better communication post appointments. Clinic and discharge letters are often delayed and would be far more helpful if sent by email.”

What parents said:

Like adults with CF, 42% of comments relate broadly to how parents are treated: behavioural rather than structural factors. Access to specialised staff is a slightly greater issue to parents of children with cystic fibrosis.

Improvement	
Less time spent	25%
Personalisation	20%
Staff specialism	19%
Communication	16%
Facilities	15%
Attitude of staff	6%

“Sometimes the CF nurses make me feel like a bit of a pain.”

“One size fits all does not work.”

“More emphasis on schools to take CF seriously, and advise parents about coughs, colds, etc.”

“More interesting physio for my daughter who is a toddler.”

“The feeling sometimes our child is on loan to us and not our own as we are told what to do. Maybe it's the way the message is put across.”

4. Clinical trials

4.1. Adults

Forty per cent of adults with CF in the survey have participated in a trial (19% have taken part in more than one). A further 21% have been invited but declined. The remaining 39% have not been invited. Of those who have taken part in a trial or trials, 73% regard the experience as broadly speaking positive, with 8% viewing it as negative. The greatest predictor in the data of why someone found it negative or positive is the clarity of communication before, during and after the trial.

“Medication didn’t work for me and I’ve heard nothing more about results for other people.”

“Trials have both been fine but no feedback at the end so as a patient I’m none the wiser for my effort.”

“Excellent care and explanations from trial doctors.

In my experience, the trial team were hugely helpful and appreciative of the time patients are giving and tried to be really flexible for the participants.”

“It’s down to the staff; they made some dull breathing exercises enjoyable!”

4.2. Children with CF

19% of children with CF have participated in trials. 9% have been invited but declined. 72% have not been invited.

The reported satisfaction with the experience is lower (obviously as reported by their parents), with 51% describing the experience as positive. Once again, communications appear to drive positive evaluation of the experience.

“We didn’t get any feedback on the results.”

“They took no notice of our feedback on ease of use.”

5. Technology

We asked people what they did/did not find useful in terms of technology or apps to assist with CF care. The question was deliberately broad and produced some interesting results.

In order of frequency, the responses relating to the most useful items were:

1. I-neb
2. Fitbit
3. iPhone health app
4. Carbs & Cals app
5. My Fitness Pal app

Seventy different apps or pieces of tech were found useful by survey respondents. The top five is very representative of the kinds of technology named.

Not everyone likes using what we would traditionally think of as tech; some noted they keep a diary or use a notebook to track meds and food. Far less responses were received about tech or apps that are not useful; no common themes emerged with the exception that people noted that self-monitoring too much can lead to stress for some people.

Comments:

“Gives patients more autonomy over their management and allows easier ways of viewing progress.”

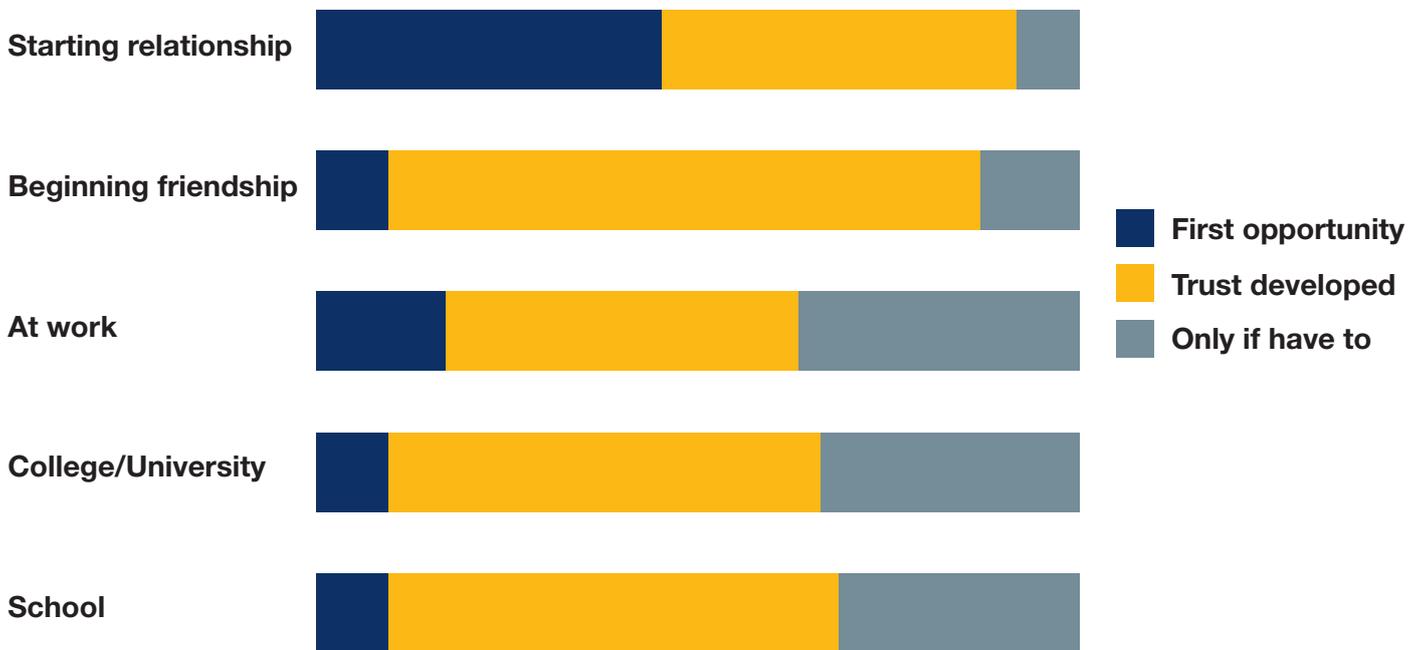
“Having reminders is a real help for someone who is forgetful or might remember but get distracted. So, having the little notification on my phone to make me go ‘Oh! Need to do that now’ is great.”

“Apps are good, but they need to be accurate — for example would a home FEV₁ kit measure the same as the one at clinic?”

“I would hope that one day there would be an app to test lung function which would allow me to firstly not need to go all the way to my CF centre when they want a result but also use it as motivation to work hard and do all my treatments.”

6. Revealing CF by situation

We asked people when they felt comfortable revealing that they have CF in different situations.



People feel the greatest caution with colleagues at work, where two in five (39%) will only reveal they have CF if they absolutely have to.

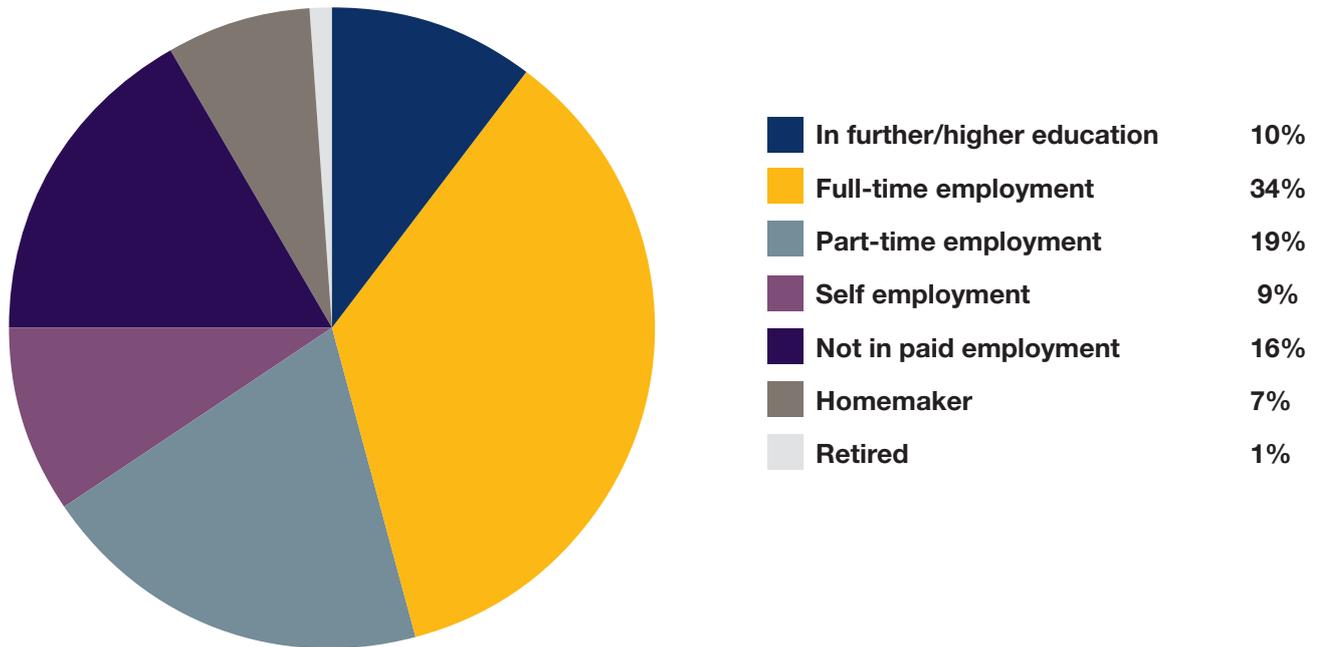
The greatest openness is in relationships where over 40% will reveal they have CF at the first opportunity (men are slightly more open: 42% to 39%).

The responses to this question in year one lead us to want to investigate further into people’s experiences in education and employment.

7. Employment

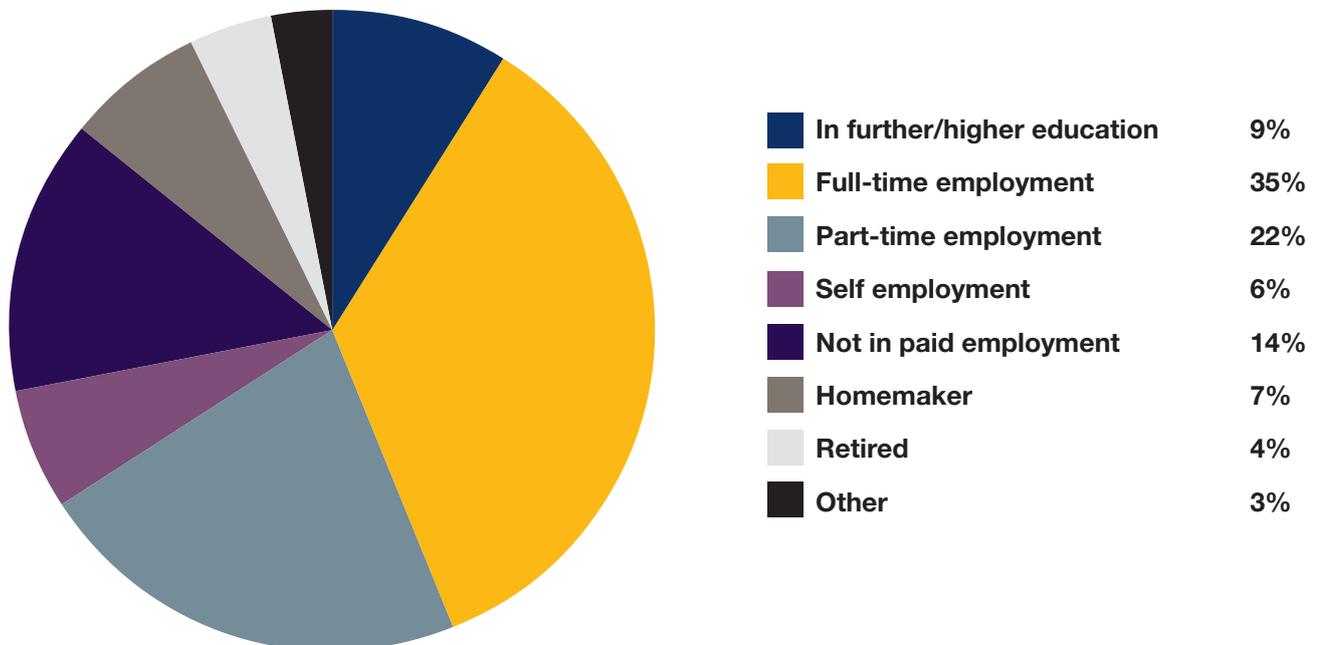
7.1. Employment status

In the first survey, people with CF said their employment status was:



Sixty-two per cent of those who completed the survey are in employment (self, full or part-time).

In the second survey, people with CF said their employment status was:



Sixty-three per cent of those who completed the survey are in employment (self, full or part-time).

7.2. Employment and education – impact of CF

In the second survey, we asked more questions relating to people’s education and employment.

7.2.1. Impact of CF on education or careers for people with CF

Seventy-seven per cent of those with CF who participated in the survey feel that CF has impacted upon their career or education. Men and over-36s with CF are slightly more likely to say their career/education has been impacted.

“I was bullied because of my CF which really held back my education.”

me back.”

“I am restricted by treatment during the evening, meaning I can’t do long days, so this holds

“Exhaustion caused by CF and not being able to do a customer-facing role for fear of cross-infection has severely held back my career.”

7.2.2. Impact on education or career for people with a close relationship to CF

Sixty-five per cent of parents of under-16s say their career or education is impacted, and while this number drops for parents of adults, the drop is marginal as 58% of parents of over-16s say their career or education is impacted.

Approximately one-third of partners feel their education or career has been impacted

“There are limited jobs in the area, but my partner is uncomfortable moving out of this GP area.”

“It’s hard to find an employer who is understanding enough to be flexible with shifts during bad periods.”

7.3. Support in the workplace or education

Interestingly, the groups most likely to say they do not get the support they need are parents of adults and partners.

Do not receive required support

Receive support	
People with CF	24%
Parent of under-16 with CF	21%
Parent of over-16 with CF	35%
Partner of someone with CF	34%
Facilities	15%
Attitude of staff	6%

Obviously, this shows the majority who answered the question felt they do receive the appropriate support:

“Occupational health has made it possible for me to work at home when needed, to administer IV antibiotics in a first aid room in my department, and to be able to work in a smaller office where I am less likely to be exposed to viruses.”

However:

“My old head-teacher forced me to retire on ill-health grounds. She was awful. She took my teaching room away from me and stopped me from eating between reasons.”

7.4. Volunteering

Each group was asked if they would like to volunteer in the future. Overall, 39% of participants are not currently volunteering but would like to at a point in the future. The largest percentage of potential volunteers is among partners (52%) and parents of under-16s (43%). Additionally, 42% of people with CF and 27% of parents of adults with CF are not volunteering but would like to. Twenty-five per cent of the community currently volunteers in some capacity.

8. Finances

8.1. Financial impact of having CF

In both surveys, we asked the same question in relation to the anxiety caused by the financial impact of having cystic fibrosis.

In survey 2, over three-quarters (77%) of people with CF who completed the survey answered that it caused at least some concern, while one-fifth (22%) experience considerable anxiety.

Overall, the percentages feeling anxiety are remarkably consistent across the populations.

Seventy-nine per cent of parents with under-16s experience anxiety, 77% of parents of over-16s and 71% of partners suffer financial anxiety.

8.2. Benefits

Eighty-two percent of people in the survey who have recently claimed benefits found the process at least somewhat difficult. Within this 82%, 33% describe claiming benefits as extremely difficult.

Eighty-five percent of those with CF found it difficult to some extent, while 39% of people with CF found it very difficult. Difficulty is most pronounced among younger and older respondents, and also for male participants.

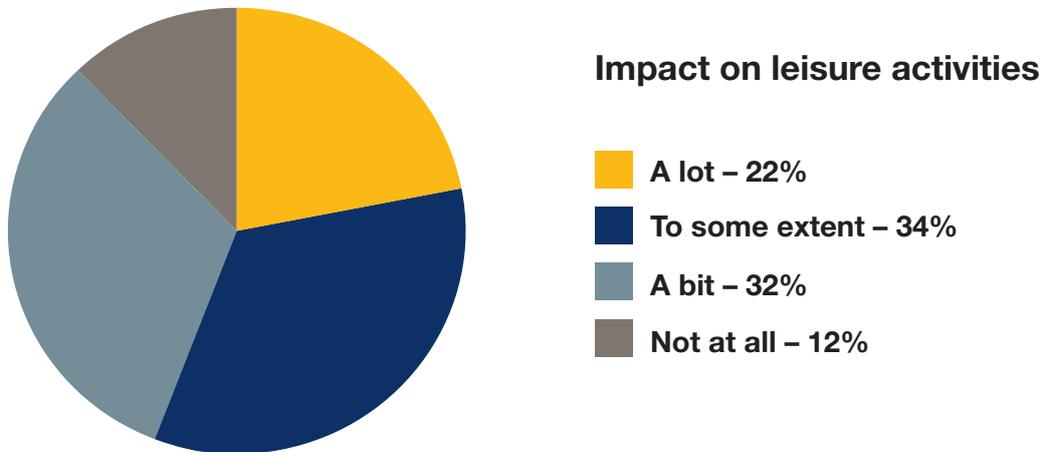
For those with secondary-level education, the difficulty level increases further. It is a small sample, but 96% found it difficult, with 50% describing it as very difficult.



9. Free time

9.1. People with CF

Eighty-eight per cent of the respondents with CF have had their leisure activities impacted by cystic fibrosis. Of these, 22% answered that CF impacted their leisure activities a lot.



When asked in what ways it has impacted, beyond the expected physical restrictions placed by CF, a number of other themes recurred. In order of frequency, these additional explanations were first **time**: the limitations placed by physio and medicine make it difficult to carve out sufficient time to commit to leisure activities. The second explanation is concern of **cross-infection**: leisure activities are often communal but also often sweaty and hot, where the risk of infection is perceived to be high. Third on the list of additional explanations (beyond actual physical capability) is **self-consciousness**: a sense of exercising in front of people who do not understand why activities are especially difficult for someone with cystic fibrosis.

It is slightly more common for men with CF to feel their leisure activities are impacted: 91% compared to 86% of women, and for older people with CF to feel greater impact. The research suggests it is men over 35 who feel this most acutely.

Accompanying quotes

“Struggling makes keeping up with my peers difficult, which in turn demotivates me.”

“I choose not to do evening classes after work because I wouldn’t have the time or energy to do physio afterwards.”

“I feel embarrassed and uncomfortable exercising.”

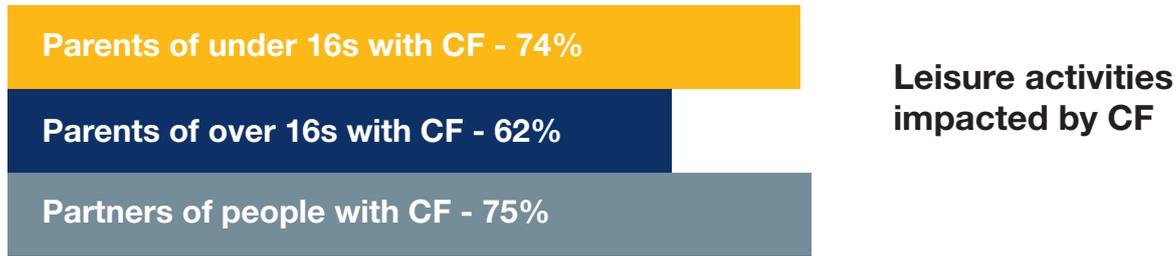
“I like music festivals but they’re so hot and humid, with so many infections bouncing about.”

9.2 Other members of the community

Looking at other groups within the community, we see that in each instance more than half of them say their leisure activities are impacted by cystic fibrosis.

Take for example parents of under 16s: three-quarters (74%) have seen their leisure activities impacted. Also, 75% of partners in our survey report that their leisure activities are impacted by their partner’s condition. Interestingly, partners are slightly more likely than other members of the community to feel CF has a major impact upon their leisure activities (21% of partners compared to 15% of parents of children with CF).

The population with the lowest impact upon their leisure activities are parents of adults (over-16s) with cystic fibrosis. However, still more than three out of five respondents (62%) have their leisure activities impacted by their child's condition. Thirteen per cent of this population feel their leisure activities have been impacted a lot. A glance through the quotes left by parents of adults with CF shows clearly that parental responsibility certainly continues into adulthood.



“Time spent in hospital visiting and collecting from university when our son is ill uses our leisure time often.”

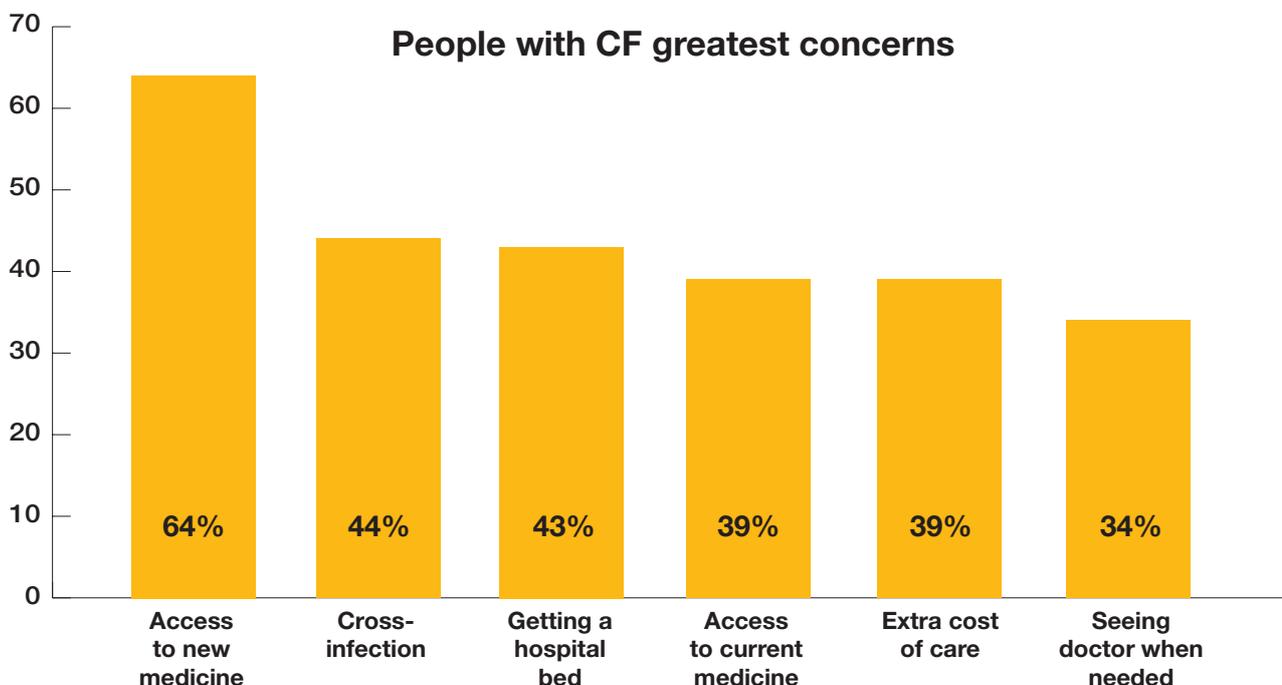
“Not being able to plan ahead means we still miss out on group activities, and often not being invited because people know you cannot commit.”

10. Care concerns

10.1. People with CF

Respondents were asked which of a group of potential issues made them feel very concerned when thinking of the next 12 months.

Ninety-five per cent of people with CF selected at least one as a concern, while 51% cited at least three. Men, on the whole, are concerned about more of the issues than women, and are specifically more concerned about access to beds and new medicine. Women with CF are relatively more concerned with cross-infection.



Thirty-nine per cent of people with CF describe the extra cost of care as a major concern. There is a huge cross-over, with 21% of those with CF who say financial support is the one thing that would help their life (described in Section 9).

10.2. Other members of the community

For partners, the focus is more prominently on access to meds, both current and new.

Parents of under-16s, while slightly less concerned with access to beds or seeing doctors than other groups, are much more concerned about access to new meds (81% are really concerned about this). They are also the most concerned community about both cross infection and access to current meds.

Parents of adults with CF, while still most concerned about access to new meds, are more concerned about getting a bed or seeing a doctor. They are also more concerned than other groups about the financial burden attached to having cystic fibrosis.

"Not being listened to. If I don't fit into the predetermined expectations of the disease and I feel undervalued."

"How general public health taxes such as sugar tax (or the eventual sugar tax they will bring in) will affect persons with cystic fibrosis."

11. Getting older

11.1. People with CF

The second survey asked if there is anything about getting older either people with CF or the Trust should be made more aware of. The answers varied, but from people with CF, certain themes, which to some extent are interwoven, emerged very strongly.

Words like anxiety and stress appeared frequently, often related to the lack of understanding or knowledge of people with CF living to advanced ages. There is no model of what middle-age with CF is like: it is a frightening journey into the unknown. Additionally, older respondents commented upon how they felt no need to prepare for the future, whether in financial planning or even investing in long-term relationships because they did not expect to be alive at the age they are now.

The quotes below illustrate these points:

"Although this attitude is shifting now I have, in the past, found that doctors are more concerned with simply prolonging life than they are with the quality of that life. Other than the medical implications, my concerns around growing older are financial — I have no pension plans as I can't earn a proper living and wasn't expecting to live long enough to need them!"

"Being prepared for a longer life in general. To put it bluntly I thought I'd be dead by now. I didn't invest in relationships fully as I didn't see the point of getting married. I didn't think about

getting a house (I've just got my first house at 32). I thought having a baby was impossible, and I didn't save money; the list goes on. I'm only now realising that I could be here for a long time yet."

"Planning for older age is probably a good thing to do in general but when you start to get there it can be overwhelming."

"I feel guilty that younger people with CF have passed away and I am still here; I'm 41!"

"I have found that things get harder as I get older, not just with the physical aspect of things but also with the emotional, ie the responsibility of looking after family, the worry of being able to provide financially and emotionally, the stress of

keeping up with treatments whilst looking after my daughter and wife, the constant worry of what will happen to them if I get a bad infection and deteriorate quickly, etc."

11.2. Parents of adults with CF

Parents of adults with CF brought two further dimensions to the conversation about ageing. First, while it is wonderful that their son or daughter will now live to a mature age, as parents, they will no longer be able to offer the care and support they have done for their child. If they can't, who will? The other dimension added by parents of adults with CF comes from their long-term perspective on service and support. Parents commented that as services diminish through shrunken resources, they worry their children will not be cared for as they once were.

"Their main carers not being able to look after them due to their old age and health problems, causing more cost for NHS."

"Support and care from the hospitals is rapidly decreasing, and I am very scared for what the future will bring."

12. Wellbeing / happiness and life with CF

12.1. Self-reported happiness

When asked to evaluate their level of happiness the previous day in the first survey, more than half (57%) described themselves as happy. This is three times the percentage describing themselves as unhappy (19%).

12.2. Comments about life from people with CF

When asked to describe life with CF in their words, 34% used positive, often defiant and/or philosophical language.

"It's all I have ever known."

"It has shaped my personality, and my approach to CF has strengthened me and my relationships."

"A challenge that shapes me, informs me, sometimes dictates to me but never controls me."

"I am someone who has CF; CF does not have me."

When asked to describe life with CF in their words, 66% used predominantly negative language. Key words include constant, tiring and frustrating.

"Painful. Bloody. Makes me feel pretty disgusting at times."

"There is a lot of, often unspoken, pressure from friends and family to 'be brave' when all you want to do is scream and shout about how unfair it is."

"It's like being on a treadmill that you can never get off; CF has no 'holiday' or rest days."

"Challenging, expensive, time consuming and a bit sh*t."

12.3. Comments on life with CF from parents

The following is a representative selection of comments from parents:

"It's heart breaking to hear our child who's three almost four, say that he doesn't want to have cystic fibrosis anymore because he doesn't like coughing."

"Causes arguments when she won't do physio/take tablets etc. Upsetting when the drugs make her sick and she misses her family/friends/school."

"We love our angel so much and only wish we could take this from him and for him."

"The day-to-day management is fine but the black shadow of fear for my child sits like a boulder on my chest at all times. It suffocates me."

13. Adherence to clinical advice

3.1. Exercise

Ninety-six per cent of adults with CF said they have had a discussion with their clinical care team about exercise. Only 20% stated that they always do as much exercise as recommended by the care team.

Doing exercise as often as he/she is recommended	Percentage
Always	20%
Usually	26%
Sometimes	31%
Rarely	18%
Never	4%

13.2. Medication and physio

The survey told us that across the sample, adults with CF were taking their medication 89% of the time they had been advised, nebulizer 77% and physio 69%.

Self-reported adherence rates are higher for men by 6% with medication, 5% with nebulizer and 7% with physio. The lowest level of adherence is with under-20s: typically around 6% below the mean.

14. One change

We asked participants what one thing they would ask for. Unsurprisingly, we received a range of responses, which we coded into eight categories to allow us to see which themes were often mentioned.

These codes or categories are:

1. Better access to medication
2. Help with CF-caused financial burden
3. To be treated face-to-face with greater empathy
4. CF to be better understood (by the general public/media etc.)
5. Better equipment and facilities
6. More investment into research
7. Better peer access
8. Provision of better information

Codes 3 and 4 are clearly connected, in that both relate to awareness and understanding in the broader community. Therefore, should we choose to aggregate these two, then a total of 26% of all comments were about this, with 32% among people with cystic fibrosis.

	People with CF	Parents <16	Parents >16	Partners	Overall
Access to medicine	21%	35%	21%	22%	27%
Help with financial burden	21%	16%	23%	17%	17%
To be treated with empathy	20%	10%	14%	9%	13%
CF to be better known/understood	12%	13%	10%	16%	13%
Better facilities/equipment	9%	10%	16%	17%	12%
Research	10%	7%	11%	9%	8%
Peer access	3%	6%	3%	4%	4%
Receiving better info	5%	5%	3%	7%	4%

14.1. People with CF

Three issues were almost equally prevalent for people with CF.

Access to medicine was the joint most popular topic. Predominantly, comments referred to access to Orkambi. We also saw many references to both wanting a commitment to making upcoming medicines available, and an end to the postcode lottery of drug availability.

At the top, with 21% of mentions, was help with the **financial burden**. In this, we saw many mentions of prescription and hospital parking charges.

At 20%, was the desire to be **treated with empathy**. This included employers understanding why he or she may need more time off, or people who should know better, such as health care professionals, showing greater understanding.

14.2. Other members of the community

The table (on page 21) shows that while all of the codes we use are obviously important, certain issues are more important to different groups. For example, 35% of parents of children under the age of 16 with CF rate access to medicines as the most important issue; parents of adults with CF have a greater focus on help with the financial burden directly attributable to CF (23%).

While access to medicine is also the most frequently mentioned priority for partners, they are the audience most concerned with CF being better understood, and for better facilities and equipment to be made available (this includes everything from more beds to availability of appropriate exercise opportunities).

While lagging behind other priorities, the research shows an appetite in a sizeable proportion of the community for improved access to peers. For example, amongst parents of under-16s this was most prevalent at two key points: beginning education (both for child and parent) and teenage years.

Accompanying quotes

“These drugs are available and even though the improvements are modest, it’s hard knowing they’re there and could make even a small impact on such an all-encompassing disease. Any help is something.”

“Burden of treatment is huge –especially nebulisers and physio which really eat into time, and is not something that is acknowledged (eg by employers who actually benefit if we stick to treatments and don’t skip, as we’ll need less time off work for sickness/IVs).”

“When new treatments become available, it is pointless informing us when cost puts them out of reach. This is very depressing, frustrating and annoying.”

“Having to spend so much time completing stupid forms to justify the severity of CF and the impact it has on the sufferer and immediate family/carers.”

“Seriously though, if the Trust funded personal training sessions at my gym, I would be hyper motivated.”

“Tailor-made care depending on the severity of or symptoms of each individual rather than one dose fits all.”

“Free WIFI in hospitals (sorry, sounds small, but for kids in hospital for weeks at a time, it would make things much better!)”

“More documented guidance about the little things in life: where is the real danger at home and how do I minimize it? In the garden?”



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