Cystic Fibrosis our focus

Working towards living a life unlimited by Cystic Fibrosis

A summary of the support in the UK for people with CF and their families/carers, in terms of 3 areas:

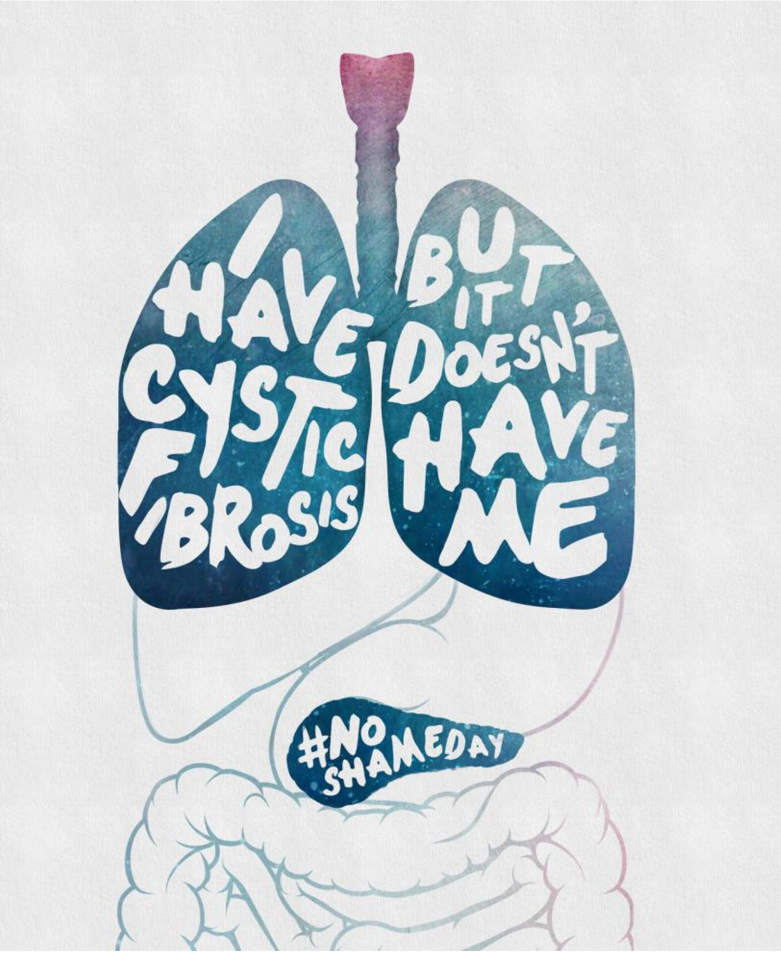
Social Security rights,
Help and support at school and
Employment and Disability Rights

Sangeeta Enright, Welfare and Rights Advisor

Fighting for a Life Unlimited

The Cystic Fibrosis Trust is fighting for a life unlimited for everyone affected by cystic fibrosis. Our mission is create a world where being born with CF no longer carries a death sentence, when everyone living with the condition will be able to look forward to a long, healthy life.

Cystic Fibrosis and disability



- Using the words ‘disabled’ and ‘disability’ – some find it useful, some think it’s just a negative label that doesn’t apply to them

- Important to think about disability when considering your legal rights in Social Security, Education and Employment

‘Disability’ – what is it anyway?

The Equality Act 2010 defines disability as:

‘A physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities.’

When we use the word ‘disability’ in relation to cystic fibrosis, we are often doing so because we are talking about someone’s legal rights and because we want to ensure that people with cystic fibrosis are protected from discrimination in their day-to-day activities.

Welfare and rights advice

This is part of the Support Service of the Cystic Fibrosis Trust. Our other services include our Helpline, peer support for parents (‘CF Connect’) and our Grants programme.

What does my work involve?

- Benefits support – advice on applications, and appeal support up to tribunal
- Supporting letters based on care needs form
- Advice and advocacy on issues such as employment and housing and signposting to further advice and support
- Training and support for CF teams, working with Social Workers and our policy team
- Access advice by calling our Helpline

At a glance: CF Insight Survey June 2018

1,095
people completed 100%
of the survey, while 400
more surveys were
‘substantially completed’

- 63% were in some kind of employment
- 82% of people with CF who claimed benefits in the last two years found the process difficult
- 77% of adults with CF experienced at least some concern about the financial burden of their condition.

Social Security rights

The UK benefits system has different types of benefits intended for different purposes:

- Compensatory benefits (created after WW1- ‘war disability pension’).
- Earning-replacement benefits- more recent, e.g Invalidity benefit 1972
- Means-tested benefits- Income Support, Jobseeker’s Allowance and now Universal Credit
- Extra costs benefits- **Disability Living Allowance** (under 16s), **Personal Independence Payment** (16-64)

Disability Living Allowance (DLA)

- DLA is designed to help with some of the extra costs incurred by parents/carers of disabled children.
- It is a non-means-tested, non-taxable, non-contributory benefit with two components.
  - The care component is paid at three rates according to assessed need for supervision and help with personal care, and can be claimed by anyone whose disability starts when they are under 16.
  - The mobility component is paid at two rates according to assessed need for help with getting around and can be claimed by anyone aged under 16, but over 3.

How much is DLA?

Care component
Weekly rate

Lowest: £22.65
Middle: £57.30
Highest: £85.60

Mobility component
Weekly rate

Lower: £22.65
Higher: £59.75

How does Personal Independence (PIP) help?

John, a student at University

- to afford the higher costs of high-calorie foods,
- to afford the higher than average rent to be in a dirt/mould free environment with lectures and facilities close by,
- to afford transport between home and back and to cover in general the income

“I cannot earn through part-time work due to the time and energy taken up by my treatments and university itself (most students can cope with part-time work to supplement their loans).”

How much is PIP?

Daily living part

The weekly rate for the daily living part of PIP is either £57.30 or £85.60.

Mobility part

The weekly rate for the mobility part of PIP is either £22.65 or £59.75.

Carer's Allowance

How can you qualify?

- The person you care for must already get one of the qualifying benefits
- You must earn no more than £120 a week after tax and expenses.
- All of the following must also apply:

- you're 16 or over
- **you spend at least 35 hours a week caring for someone**
- you've been in England, Scotland or Wales for at least 2 of the last 3 years
- you normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces
- you're not in full-time education
- you're not studying for 21 hours a week or more
- you're not subject to immigration control

The Vision

A social security system that:

- works for everyone, providing support in times of need, and compensating for the additional costs of impairments & caring *
- recognises, values & makes possible work in all its diverse forms *
- is non-stigmatising & a source of pride for its citizens *
- redistributes income, and reduces inequality, and is underpinned by the argument that a more equal society is beneficial to us all *

Also:

- Ensuring there is good/accessible **welfare rights advice available to all**

N.B nod to values & possibilities of embedding principles of dignity and respect within social security system (see Simpson et al, 2017)

Help and support at school-
The rights of children with cystic fibrosis at school

Equality Act 2010: https://www.gov.uk/government/publications/equality-act-2010-advice-for-schools

England: Supporting Pupils with Medical Needs in School (2015)

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/484418/supporting-pupils-at-school-with-medical-conditions.pdf

Health Conditions in Schools Alliance

http://medicalconditionsatschool.org.uk/

Supporting Pupils with Medical Needs in School* (2015) - England

How does this relate to children with cystic fibrosis?

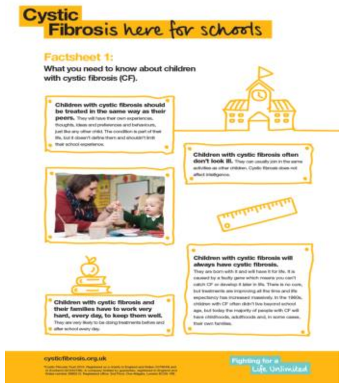
- Support to have full access to education, including trips and PE
- All schools should have a policy in place, and all pupils with medical needs should have an **individual healthcare plan**’
- School trips: risk assessments, reasonable adjustments ‘…fully participate…’
- ‘Not generally acceptable practice’ to :
  - Penalise children for their attendance record where absences relate to their medical condition
  - Prevent children eating, drinking or taking toilet breaks when linked to their condition
- ‘No parent should have to give up working because a school is failing to meet their child’s medical needs…’

*(Applies to maintained schools, academies and PRUs – not early years settings or independent schools)

Explaining cystic fibrosis to schools, teachers and pupils

www.youtube.com/user/CFTrust

<u>Factsheets for schools and teachers: primary and secondary school</u>



Cystic Fibrosis here for schools

Factsheet 1:

What you need to know about children with cystic fibrosis (CF).

Children with cystic fibrosis should be treated in the same way as their peers. They will have their own experiences, thoughts, ideas and preferences and behaviours, just like any other child. The condition is part of their life, but it doesn't define them and shouldn't limit their school experience.

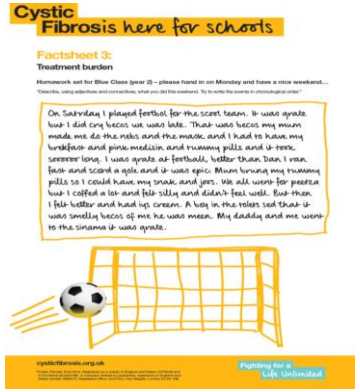
Children with cystic fibrosis often don't look ill. They can usually join in the same activities as other children. Cystic fibrosis does not affect intelligence.

Children with cystic fibrosis will always have cystic fibrosis. They are born with it and will have it for life. It is caused by a faulty gene which means you can't catch CF or develop it later in life. There is no cure, but treatments are improving all the time and life expectancy has increased massively. In the 1960s, children with CF often didn't live beyond school age, but today the majority of people with CF will have childhoods, adulthoods and, in some cases, their own families.

Children with cystic fibrosis and their families have to work very hard, every day, to keep them well. They are very likely to be doing treatments before and after school every day.

cysticfibrosis.org.uk

Fighting for a Life Unlimited



Cystic Fibrosis here for schools

Factsheet 3:

Treatment burden

Homework set for Blue Class (year 2) – please hand in on Monday and have a nice weekend…

"Describe, using adjectives and connectives, what you did this weekend. Try to write the events in chronological order."

On Satrday I played footbol for the scool team. It was grate but I did cry becos we was late. That was becos my mum made me do the nebs and the mask and I had to have my brekfast and pink medisin and tummy pills and it took sooooo long. I was grate at football, better than Dan I ran fast and scord a gole and it was epic. Mum brung my tummy pills so I could have my snak and jocs. We all went for peetza but I coffed a lot and felt silly and didn't feel well. But then I felt better and had iys creem. A boy in the toilets sed that it was smelly becos of me he was meen. My daddy and me went to the sinama it was grate.

cysticfibrosis.org.uk

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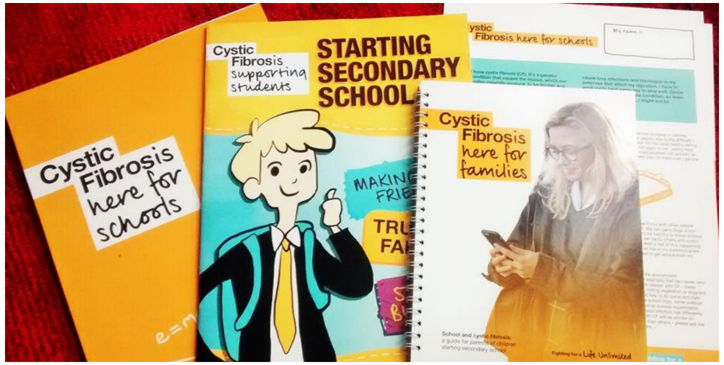
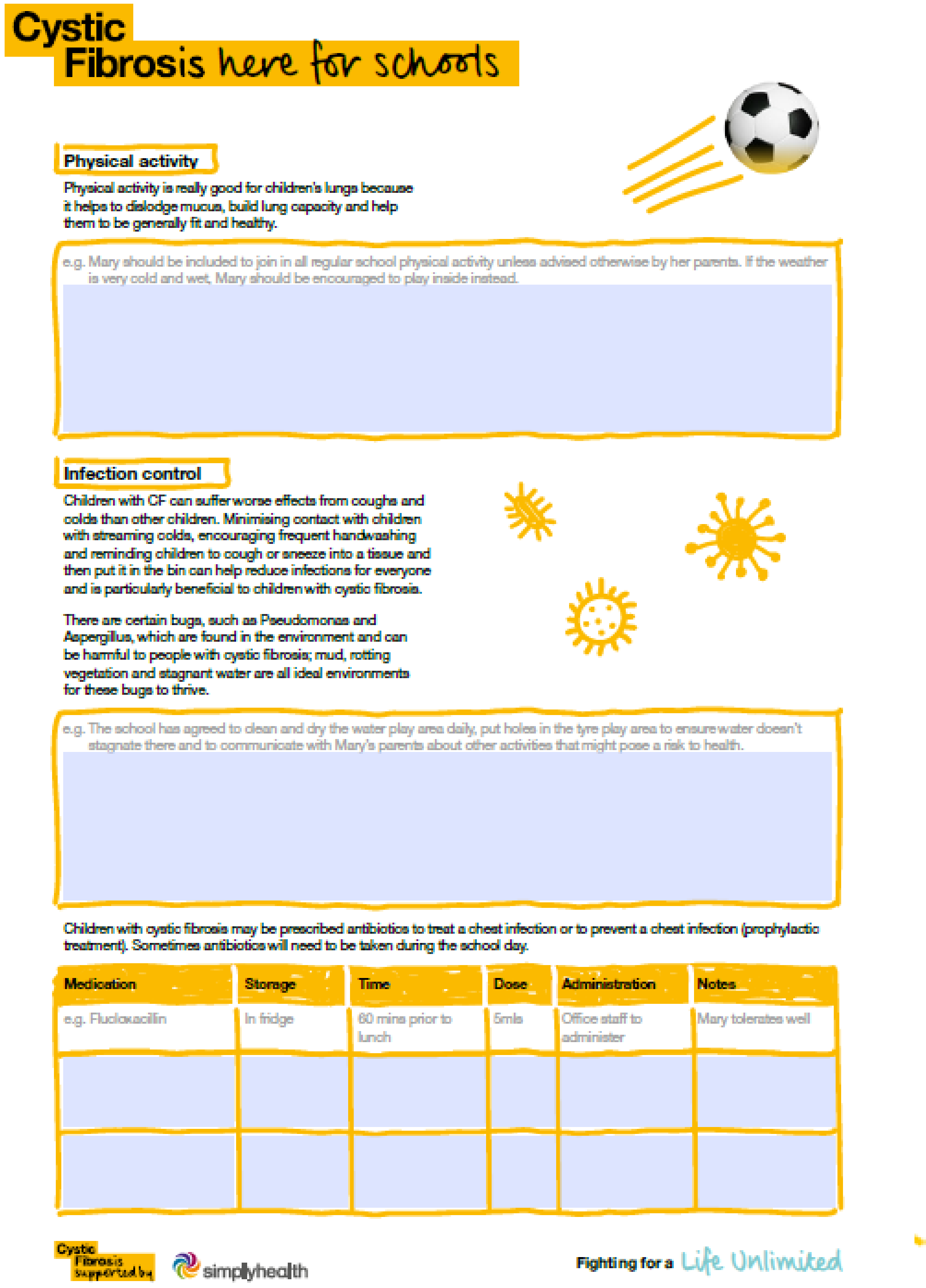


www.cysticfibrosis.org.uk/what-is-cystic-fibrosis/my-friend-has-cf

Individual healthcare plans

- Template: download a copy (https://www.cysticfibrosis.org.uk/life-with-cystic-fibrosis/pre-school-and-primary-school) or request a printed copy from our helpline
- Things to cover:
  - Medication: timings, doses, storage, who will administer?
  - Infection control
  - Physio and physical activity
  - Creon: doses, storage, is help needed?
  - Diet
  - Child's understanding of CF
  - Attendance



Cystic Fibrosis here for schools

Physical activity

Physical activity is really good for children's lungs because it helps to dislodge mucus, build lung capacity and help them to be generally fit and healthy.

e.g. Mary should be included to join in all regular school physical activity unless advised otherwise by her parents. If the weather is very cold and wet, Mary should be encouraged to play inside instead.

Infection control

Children with CF can suffer worse effects from coughs and colds than other children. Minimising contact with children with streaming colds, encouraging frequent handwashing and reminding children to cough or sneeze into a tissue and then put it in the bin can help reduce infections for everyone and is particularly beneficial to children with cystic fibrosis.

There are certain bugs, such as Pseudomonas and Aspergillus, which are found in the environment and can be harmful to people with cystic fibrosis; mud, rotting vegetation and stagnant water are all ideal environments for these bugs to thrive.

e.g. The school has agreed to clean and dry the water play area daily, put holes in the tyre play area to ensure water doesn't stagnate there and to communicate with Mary's parents about other activities that might pose a risk to health.

Children with cystic fibrosis may be prescribed antibiotics to treat a chest infection or to prevent a chest infection (prophylactic treatment). Sometimes antibiotics will need to be taken during the school day.

Medication	Storage	Time	Dose	Administration	Notes
e.g. Flucloxacillin	In fridge	60 mins prior to lunch	5mls	Office staff to administer	Mary tolerates well

Cystic Fibrosis supported by simplyhealth

Fighting for a Life Unlimited

Jess- However things can go wrong

"School accused of discrimination after cancelling student's trip because she has cystic fibrosis"

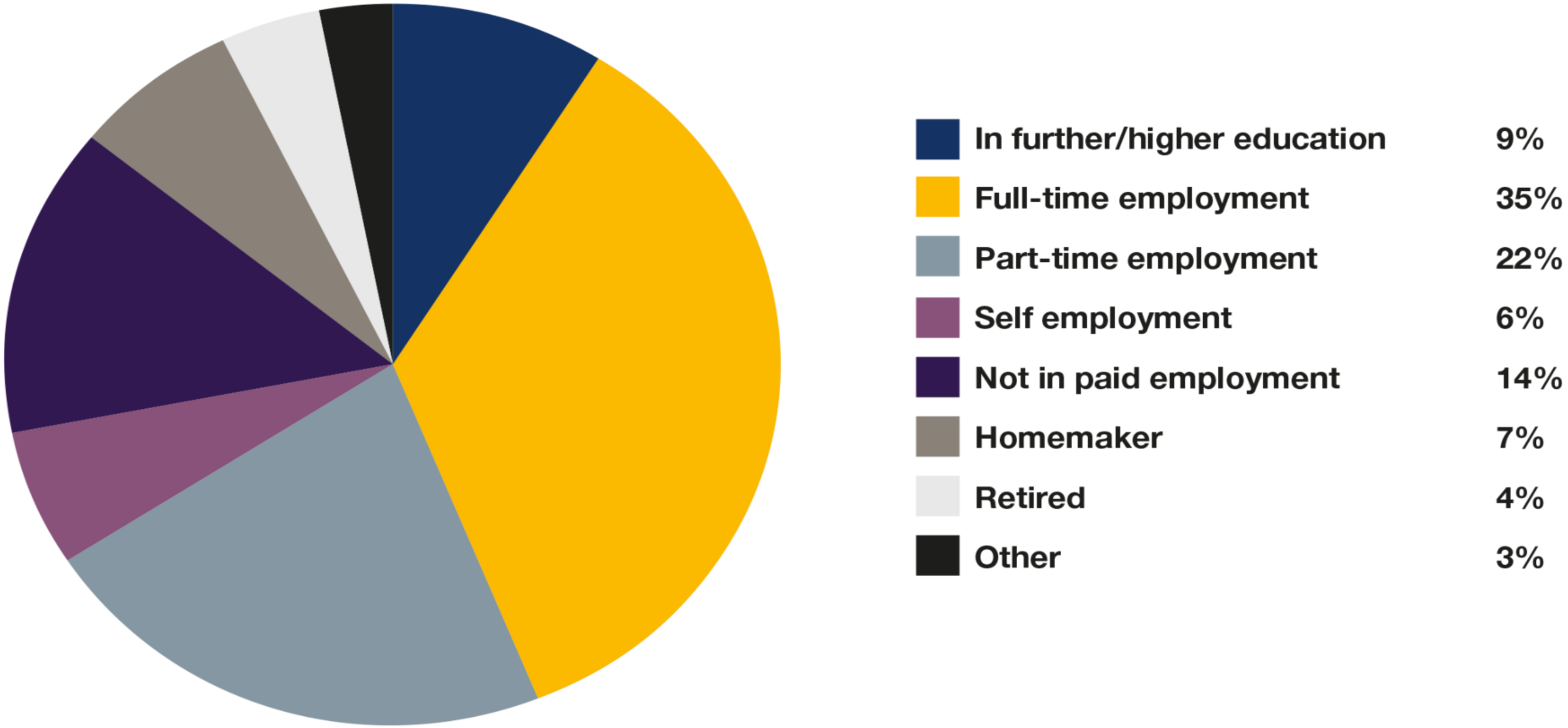
Jess' mum Helen who works as a diabetes nurse, said the school took the decision because Jess needs a nightly insulin injection for her CF-related diabetes. Jess' parents started paying for the trip in October last year, and told the school in May that Jess needs her nightly injection, adding that she was currently giving her this as her daughter is scared of needles, but was teaching her to self-administer.

Helen said she agreed with the school that Jess needed to be able to self-administer her insulin by at least one week before the trip, with a deadline set for Monday 25 June. Helen, emailed the school that Monday morning to say that Jess had started to administer her injections herself, but one day later, the family were told Jess could not go. Helen has now made an official complaint to the school on the grounds of **discrimination**.

Employment and Disability rights

- In our Spring edition of our magazine ‘CF life’, we spoke to four people about their experiences of working with cystic fibrosis. While some were able to turn setbacks into new opportunities, others faced discrimination and difficulties along the way. Here you can read their full stories and find some useful advice.
- As far as possible, CF should not be allowed to limit your choices. For many jobs, reasonable adjustments could be made to enable you to undertake the role.
- We support people with the resources they need to negotiate with their Employer through our Employment factsheet, written by a Specialist barrister in 2017. Many people want to resolve the issue, and therefore we signpost them to ACAS (Advice and Reconciliation Service).

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).

Michelle-

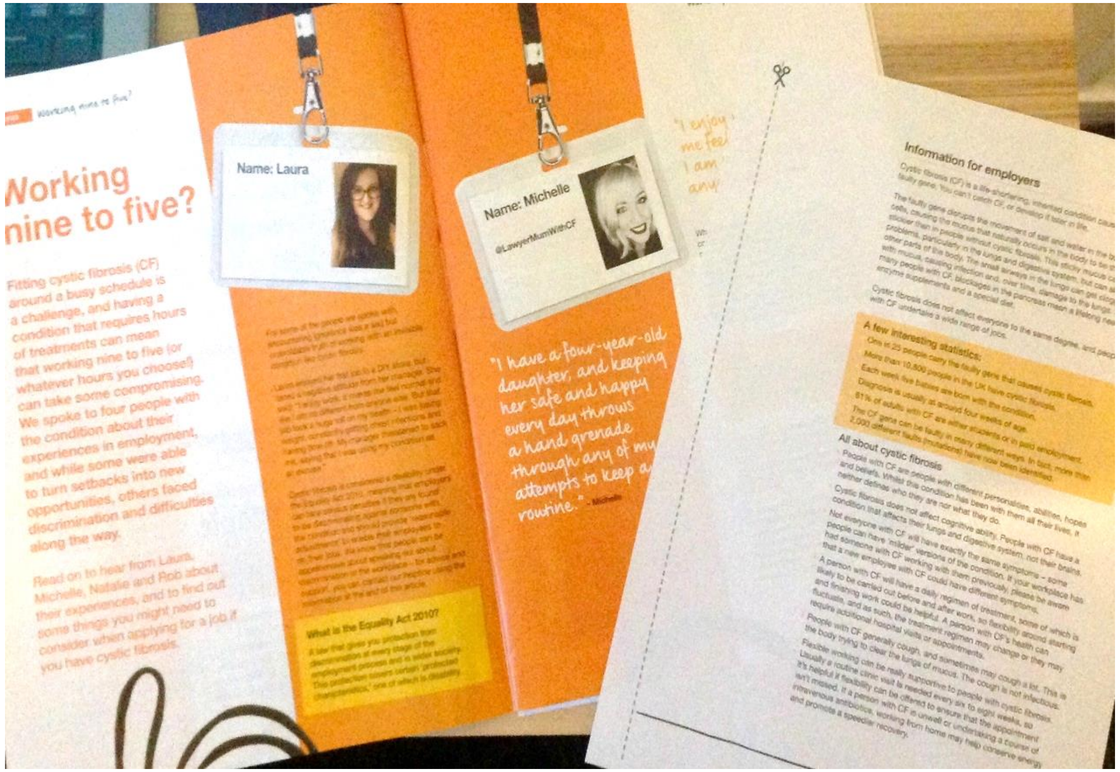
has a 4 year old daughter and owns her own law firm

“According to the Equality Act 2010, employers are required to make reasonable adjustments for any employee who has a disability, and there can be serious repercussions if they don’t. Employers therefore often play lip service to the idea of reasonable adjustments to avoid liability, but anyone with a condition like CF will know that you can only really flourish at work when you feel genuinely accepted.

I’m very lucky to own my own business, with an understanding director and shareholder and wonderful, caring, hardworking secretaries. If I am out of breath they meet me at the door and carry my bags. If I am absorbed in a piece of work, they remind me to eat. Client meetings can become a problem when I have a chest infection, and I am not able to work during IV treatment anymore, as they make me too ill. These days when I have hospital admissions I generally arrive at the hospital and flop onto the bed.”

Advice for Employers

Supporting an employee with cystic fibrosis



Working nine to five?

Working nine to five?

Fitting cystic fibrosis (CF) around a busy schedule is a challenge, and having a condition that requires hours of treatments can mean that working nine to five (or whatever hours you choose!) can take some compromising. We spoke to four people with the condition about their experiences in employment, and while some were able to turn setbacks into new opportunities, others faced discrimination and difficulties along the way.

Read on to hear from Laura, Michelle, Natalie and Rob about their experiences, and to find out some things you might need to consider when applying for a job if you have cystic fibrosis.

Name: Laura

Name: Michelle

@LawyerMumWithCF

"I have a four-year-old daughter, and keeping her safe and happy every day throws a hand grenade through any of my attempts to keep a routine." - Michelle

What is the Equality Act 2010?

Information for employers

A few interesting statistics

All about cystic fibrosis

- Talk to the individual about how CF could affect their work. As mentioned earlier, people with CF differ in how the condition affects them, and it is important to be clear from the outset how your employee is affected.
- Establish a contingency plan about how any absences could be managed. For example, is it possible for the individual to bank their time to allow for absences?
- Provide in-house training, if your employee wishes, to other employees to help them understand the impact of cystic fibrosis.

Any questions?

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Thank you

cysticfibrosis.org.uk